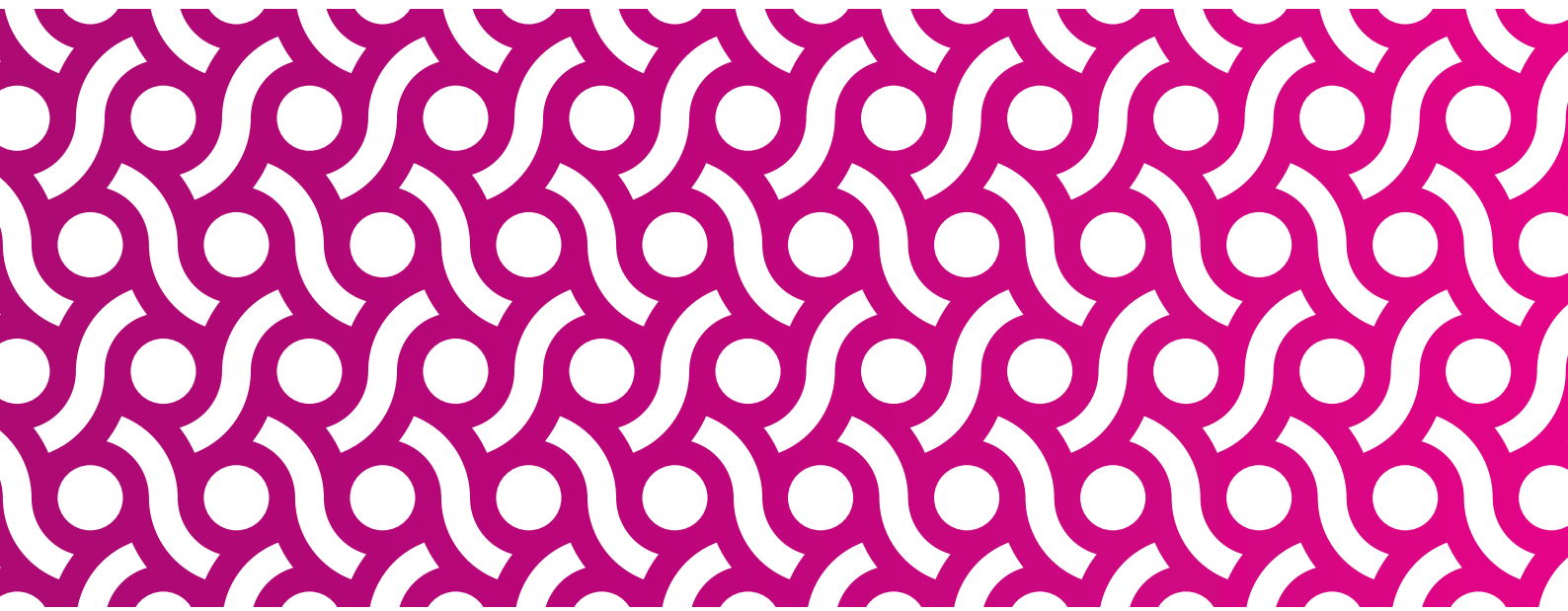


National Study of Family Experiences of Organ and Tissue Donation

Wave 5

Experiences in 2018 and 2019 – Research Report



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

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Executive summary

The Organ and Tissue Authority gathers feedback on the experiences of donor families in the National Study of Family Experiences of Organ and Tissue Donation (Donor Family Study). This report details the findings of Wave 5 of the study and represents the views and experiences of families who made a decision about donation in 2018 and 2019. The research includes families who consented to and those who declined donation. The research seeks to understand families' experiences before, during and after the decision about donation, to understand and monitor how the needs of families can best be met.

This wave's findings demonstrate that almost all families (96%) felt comfortable with the decision they made about donation.

Amongst the family members who consented to donation in 2018 and 2019, 491 family members opted to participate in the Wave 5 study, resulting in a 20.7% response rate. Families who declined donation were also approached, with 34 family members choosing to participate. This equates to a 7.2% response rate.

Of the 525 family members who participated in Wave 5 of the Donor Family Study, 197 volunteered to take part in an in-depth interview. This included 187 family members who consented to donation and 10 family members who declined donation. From this group, 31 family members were randomly selected to take part in an in-depth interview, including 25 who had consented to donation and six who had declined donation.

We wish to acknowledge and thank all family members who gave their time so generously to talk about their experiences. Feedback from families is integral to the study, providing insight and evidence that leads to improvements in the way donor families are cared for and supported.

Impact of prior knowledge

Findings from the Donor Family Study continue to highlight the importance of prior knowledge of a family member's donation wishes when it comes time to making a decision about donation in hospital.

Families who know what their family member wanted find it easier to make a decision about donation (88% of family members who discussed and knew their family member's wishes found the decision easier). When decisions align with a family member's wishes, families feel comfortable with their decision.

Conversely, the study shows that when the wishes of a family member are unknown, the decision about donation tends to be a more difficult one, with 16% of those who had not had a conversation with their family member being more uncertain of their decision. When wishes are unknown, family members can struggle to come to a unified decision, and this can result in conflict, discomfort, and sometimes regret over their decision.

Prior knowledge of a family member's donation wishes is important for families when making a decision about donation.

Motivations and barriers to donation

Consistent with previous waves, most donor families (78%) saw organ and tissue donation as a chance for something positive to come out of a personal tragedy. Seven in 10 (72%) family members were motivated to say yes to donation as they felt their loved one would have wanted to help others.

When looking at barriers to donation, the main reason most families declined donation was because they knew or felt that their family member would not want to donate (30%). The next highest reported reason for declining donation, at 27%, was the belief that their family member had been through enough. This is consistent with Wave 4 findings.

Interaction with hospital staff

The experience of those who are asked to consider donation usually begins in the Intensive Care Unit or Emergency Department of hospitals across Australia. The majority of families, irrespective of their decision about donation, felt hospital staff treated them with consideration and sensitivity (91% of families who consented to donation felt this occurred to a great extent, and 82% of families who declined donation felt this occurred to a great extent).

Families who made a decision about donation in 2018 and 2019 mostly experienced great kindness, compassion, empathy and sensitivity from hospital staff. Families were also especially appreciative of the respect shown to their family member by hospital staff. Families who stated they were treated with consideration only to some extent were more likely to have experienced inconsistencies in the level of care shown to them by hospital staff.

The majority of families approached about donation felt that hospital staff made it clear that their family member's condition was critical and that they would not survive (97% of families who consented and 94% of those who declined donation). These findings have been consistent since Wave 1.

Helping families to understand that their family member will not recover requires clear, concise and consistent communication and information from hospital staff, delivered with authenticity, compassion and empathy.

Brain death testing

During 2018 and 2019, 25% of family members surveyed, who experienced the neurological determination of death pathway, were asked if they would like to be present during the brain death testing of their family member. This is a significant decrease since Wave 4, where 36% of family members were given this opportunity.

Of the families who chose to be present, the majority (86%) of consenting families and all declining families, said that it helped them to understand that their family member had died. Some families will need the clarity that comes from brain death testing before they can take in new information about donation.

Witnessing brain death testing often helps families to understand that their family member has died. All family members should be given the opportunity to witness the brain death testing of their family member, as it can help to provide clarity of their family member's death. Family members who choose to attend should be supported by hospital staff during the testing.

The donation conversation

Consistent with previous waves, health professionals continue to be the primary initiator of the donation conversation. This occurred with 60% of families who consented to donation and 71% of families who declined donation. Families who raised donation themselves represent 27% of families who consented to donation and 9% of families who declined.

In 2018 and 2019, 46% of consenting family members were asked about donation by a health professional before (10%) or at the same time (36%) as being told of their family member's neurological death or expected death. Amongst families who declined donation, 80% were asked to consider donation at the same time or before being told of their family member's prognosis.

Wave 5 findings indicate that families are much more receptive to the donation conversation after they have had time to accept that their family member is not going to survive. Approximately three quarters (76%) of family members who consented to donation, and 65% of families who declined donation, felt that the timing of the approach by health professionals was appropriate. While timing is one factor; the way donation is approached must also be considered.

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

The way families are approached about organ donation can influence not only their decision, but their view of donation. The overwhelming majority of family members in Wave 5 who consented to donation felt that discussions about donation were handled sensitively and with compassion (92% of family members strongly agreed). This is significantly less so amongst families who declined donation (56% strongly agreed that the conversation was handled sensitively).

With regards to making an informed decision about donation, 98% of family members who consented to donation agreed (88% strongly agreed) that they were given sufficient information to allow them to make an informed decision. Families who declined donation were significantly less likely to feel that they were given enough information to allow them to make an informed decision about donation (64% strongly agreed that they were).

Almost all family members (98%) who consented to donation in 2018 and 2019 agreed that their family was provided with enough opportunities to ask questions about donation (89% strongly agreed). Families who declined donation were significantly less likely to feel this way (60% strongly agreed).

Most families (97%) who consented to donation felt they were given enough time to discuss donation and to make their decision (88% strongly agreed). Families who declined donation were much less likely to feel they were given sufficient decision-making time (50% strongly agreed).

When asked how the way in which donation was discussed with them at the hospital could have been improved, 61% of family members felt that no improvements were necessary as the discussions were handled well and staff were compassionate and supportive. However, there is still scope for improvement, as 18% of families suggested better communication to keep families informed of the process and timelines. Families who declined donation suggested improvements in the timing, approach, and the tone of the donation conversation, as well as who is present in the room.

Families need clear and consistent communication, compassion, time, and privacy.

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 donation process and timelines.

Donation process

Nine in ten (92%) donor families participating in Wave 5, recalled meeting or having a discussion with a DonateLife staff member. After this meeting 83% of donor family members felt well informed, whilst 15% still had unanswered questions, and 3% left the discussion with no clear understanding of the donation process. Significantly fewer families (48%) who went on to decline donation recalled meeting with a DonateLife staff member. Of the 15 families who did meet with a DonateLife staff member and subsequently declined donation, 80% felt they were well informed after this meeting.

In 2018 and 2019, 52% of consenting donor family members recalled being provided with written information explaining organ and tissue donation whilst in hospital. Of families who declined donation, just 6% recalled receiving 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 detailed when requested. Donation Specialist have specific skills and training and it is important for a Donation Specialist to be involved in the conversation and process to aid in supporting and informing families when they are making a decision about donation. Written information, given to families whilst in hospital, is supplementary detail that may provide support and assist families to consolidate their understanding of donation.

Three quarters (76%) of donor family members in Wave 5 were offered the support of a social worker or chaplain at some time during their family member’s stay in hospital. Of families who declined donation, 70% report they were offered this type of support. Families noted that the support received helped them during this time.

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

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 family member**
- **Health professionals continuing to care for their family member with respect**
- **Being shielded from witnessing procedures that directly relate to donation surgery**

Donation surgery

Almost all families (96%) who consented to donation during 2018 and 2019 felt they were given enough time with their family member prior to donation surgery. The majority of donor families had positive experiences with ICU staff; 93% of donor family members felt that their family member was treated with respect by ICU staff in the lead up to the donation surgery.

A recurring theme present in the Donor Family Study is the support provided when a family member’s loved one is taken for donation surgery. This is a difficult time for families because of the finality of the situation and families often feel lost and alone at this point. There is an opportunity to strengthen the provision of support for family members at the time when their family member is leaving for donation surgery.

It is often 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 leaves for the donation surgery.

Follow-up service and DonateLife resources

During 2018 and 2019, 95% of family members who consented to donation state they were offered support from either a hospital and/or DonateLife staff member. Of those families who were offered support from DonateLife, 90% accepted it. The support from a DonateLife staff member was reported to be helpful by the majority (97%) of family members. Of the families surveyed, 21% who declined donation said that a follow-up phone call from a DonateLife staff member would have been helpful.

Families can initially under-estimate the value of follow-up contact and resources from DonateLife. However, over time the support offered by DonateLife can provide families with reassurance and comfort. Some family members surveyed (18%) advised that ongoing contact with DonateLife helps them because it makes them feel less alone, and that they are valued and not forgotten.

In terms of DonateLife resources, donor families found the initial phone call informing them of the outcome of the donation to be helpful (99% of family members who received it). The content of the DonateLife letter and some basic information about the transplant recipients are also considered helpful by 99% and 100% respectively of donor families who received these.

Most donor family members (85%) felt the contact they have had with DonateLife has been at the right level. Conversely, 13% of donor family members felt they have not had enough contact with DonateLife since their family member died, a significant decrease since Wave 4 (20%).

Contact from DonateLife provides families with support. 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 was to know the progress of recipients.

Correspondence with recipients

More than half (56%) of donor families who participated in Wave 5 have received a letter from at least one transplant recipient, via DonateLife. All those who received correspondence from recipients were comforted by this (77% found the correspondence to be of great comfort; 22% of some comfort). For most donor families, hearing from recipients not only reaffirmed their decision to donate, but made them feel that their family member's death wasn't in vain. This correspondence from recipients often also filled donor families with pride for their family member, and most importantly, helped them to heal.

In Wave 5, 30% of donor families who had opted-in to receive correspondence from recipients, had not received any. These families reported feelings of disappointment and sadness by the lack of contact.

DonateLife will continue to work with transplant teams to convey the significance for many donor families of receiving correspondence from the recipient.

On reflection

For 96% of families who consented to donation, the decision about donation made in 2018 and 2019 still sits well with them today, 86% very much so. When reflecting, families not comfortable with their decision cite not knowing their family member's donation wishes and difficulty coming to terms with their death as the two predominant reasons.

One quarter (24%) of families who declined donation are not very comfortable with their decision about donation today; 6% are very uncomfortable with their 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 family member would have wanted, the family opted to decline. On reflection, some feel that they may have made a different decision if they had more time.

The majority of donor family members (96%) found comfort from their family member being able to donate. For these family members, donation provided comfort through knowing that their loved one has helped somebody (90%) and that they have honoured their loved one's wishes (53%).

Consistent with previous waves, 88% of family members surveyed who consented to donation would donate their own organs and/or tissues after death. Among families who declined donation in 2018 and 2019, 83% would make the same decision again, while 7% would make a different decision about donation, and 10% are undecided.

We are heartened to note the vast majority of families reported being treated with compassion and respect during their experience. It is important to recognise families who consented to donation reported finding something positive out of this very difficult time.

We thank all families who gave their time to contribute to this report by providing feedback. The sharing of your experiences will help guide further improvements in the way donor families are cared for and supported throughout the donation process in Australia.

Part A – Research overview

1 Research background

The Organ and Tissue Authority (OTA) contracts Proof Research to independently conduct the National Donor Family Study to obtain information on family experiences of deceased organ and tissue donation. 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 families provide valuable evidence for the ongoing review and enhancement of the care and support provided to families before, during and after the decision about donation is made. The Donor Family Study gives the opportunity for families to be heard. The findings are used to determine how the needs of families can best be met.

This report details findings of Wave 5 of the Donor Family Study. Wave 5 represents families who made a decision about donation in 2018 and 2019 and compares findings with the previous waves of the Donor Family Study.

“ This is why I was very keen to respond to this questionnaire, because I felt like, ‘okay, I’ve got a voice now, I can be heard.’”

2019 – Consented to donation

“ I think it was a very good survey.... It is such a delicate process, in my case it was losing a son who I had cared and loved for 40 years. Thank you for giving me the opportunity to be in your research.”

2018 – Consented to donation

“ I just want to help. It’s great that you’re doing this research.”

2018 – Declined donation

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 decision to consent to or decline donation.
- Identify the nature and quality of services provided to families at all stages of families' experiences.
- Identify the way in which information is provided to families to help them with their decision about donation.
- Determine perceptions of care and support provided before, during and after the decision about donation 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 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

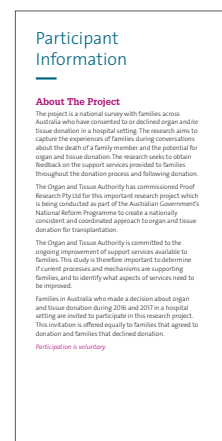
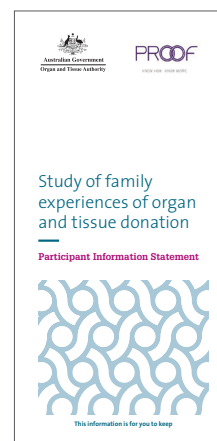
Stage 4 Analysis and reporting

3.1 Stage 1: Review of research instruments and documents

Wave 5 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 HREC approved study documents is shown below.

- 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)
- Participant Information Sheet
 - Consent form for families who declined donation in Victoria
- Site-specific Participant Information Sheet
 - Consent form (PICF) for families who declined donation in Victoria
- 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 5 of the Donor Family Study was granted by the Human Research Ethics Committees (HRECs) shown in Table 1.

Table 1 List of HRECs for consenting strand of research

State/territory	Human Research Ethics Committee	Wave 5 Approval Date
ACT	ACT Health HREC	19 September 2020
NSW	South Eastern Sydney Local Health District HREC	9 February 2021
VIC	Austin Health HREC	22 December 2020
	Australian Red Cross Blood Service Ethics Committee	17 September 2020
NT	Menzies School of Health Research	6 August 2020
	Central Australian HREC	11 August 2020
WA	Sir Charles Gairdner Osborne Park Health Care Group HREC	8 March 2021
	St John of God Health Care HREC	12 August 2020
QLD	Townsville Hospital and Health Service HREC	6 August 2020
SA	SA Department for Health and Wellbeing HREC	6 August 2020
		7 December 2022
TAS	UTAS HREC	13 August 2020
		10 March 2023

Site specific applications were required to include feedback from families who declined donation, as family contact details are held by the Hospital and Health Service/ hospital, not by DonateLife. Approval to conduct Wave 5 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	Wave 5 Approval Date
ACT	ACT Health HREC (for Canberra Hospital and Calvary Hospital)	19 September 2020
NSW	Northern NSW Local Health District	16 February 2021
	The Sydney Children's Hospitals Network	10 May 2021
	Illawarra Shoalhaven Local Health District	23 March 2021
	Northern Sydney Local Health District	8 July 2021
	Hunter New England Local Health District	9 April 2021
	Western Sydney Local Health District	18 March 2021

State/territory	Research Governance Office	Wave 5 Approval Date
VIC	Peninsula Health	3 June 2021
	Ballarat Health Services	11 June 2021
	Northern Health	30 June 2021
	Austin Health	22 April 2021
	Eastern Health	10 June 2021
	Western Health	7 July 2021
	The Royal Children's Hospital Melbourne	16 June 2021
	St Vincent's Health	9 April 2021
	Melbourne Health	11 June 2021
	Monash Health	8 June 2021
NT	Top End Health Service (TEHS)	18 February 2021
WA	North Metropolitan Health Service	29 June 2021
	Child and Adolescent Health Service	7 September 2021
	South Metropolitan Health Service	15 June 2021
	East Metropolitan Health Service	18 June 2021
QLD	Gold Coast Hospital and Health Service	25 September 2020
	Metro South Hospital and Health Service	10 February 2021
	Townsville Hospital and Health Service	29 October 2020
	Metro North Hospital and Health Service	21 September 2020
	Sunshine Coast Hospital and Health Service	28 January 2021
SA	Central Adelaide Local Health Network	3 September 2020
TAS	Department of Health Tasmania	13 July 2023

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.

“ We really appreciate this opportunity to be able to put some of our feelings, thoughts and reflections down on paper, so thank you.”

2018 – Consented to donation

3.3.1 Quantitative fieldwork

Databases containing contact details of family members were received from authorised DonateLife Agencies and hospital staff throughout Australia. Survey packs were then 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 to maximise 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 from DonateLife agencies (for the consenting strand) and hospitals (for the declining strand). Survey packs were distributed to families who **consented to donation** between 24 August 2020 and 20 April 2021. Reminder cards were distributed between 29 January 2021 and 8 June 2021.

For families who **declined donation**, survey packs were distributed between 17 November 2020 and 13 January 2022.

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

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 in Queensland, and via Zoom with families in other states and territories, due to COVID-19 travel restrictions. Rhonda McLaren, Director of Proof Research, conducted all interviews, with the interview length averaging 60 minutes.

Interviews were conducted between 16 March 2021 and 14 March 2022. All family members interviewed gave permission for their interview to be audio recorded for transcription and analysis purposes.

During the interviews, the offer of further support via 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 family member. Whilst the topic of death and donation is an emotive one, participants spoke openly and honestly about their experience.

“It was quite cathartic to meet with you yesterday and relive those 3 days in April 2019 when my husband died.”

2019 – Consented to donation

“I didn't want contact from DonateLife, but I can see that this research is a genuine effort to improve the system. It's important for us to be providing feedback.”

2018 – Consented to donation

3.4 Stage 4: Analysis and reporting

Quantitative fieldwork for families who **consented** to donation was completed in July 2021 while the fieldwork period for families who declined **donation** was completed in January 2022. Data from the questionnaires and online survey were then merged into one central file for statistical analysis. Quantitative analysis was carried out using SPSS software. A phase of data cleansing and validation was carried out to address anomalies, missing responses and to confirm the final response rate. Recordings of 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 5 are compared and contrasted against findings from earlier waves.
- Throughout this report, statistically significant differences are noted for sub-groups of the sample with these symbols: significantly lower significantly higher

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 rate).

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

Note, throughout this report where sub-totals add to $\pm 1\%$ of the parts, this is due to rounding errors to zero decimal places.

4 Sampling – families who consented to donation

4.1 Sample frame

Families who consented to organ and/or tissue donation in a hospital setting during 2018 and 2019 were invited to participate in Wave 5 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=2,553 family members who consented to organ and tissue donation. Of these, 176 were returned to sender due to a change of address or the family member had died. This brought the total survey population to N=2,377. Of these, n=491 family members who consented to donation in 2018 or 2019 took part in Wave 5 of the Donor Family Study. This equates to an overall response rate of 20.7%. The maximum margin of error associated with this sample size is $\pm 3.9\%$ at the 95% level of confidence.

In terms of the qualitative research strand, 187 consenting donor family members agreed to participate in an in-depth personal interview. Of these, 25 in-depth interviews were conducted, 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 across all states and territories, between 0.1% (WA) and 2.6% (NSW).

As shown in Table 3, 491 individual family members took part in Wave 5 of the Donor Family Study. These individuals represent 421 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.

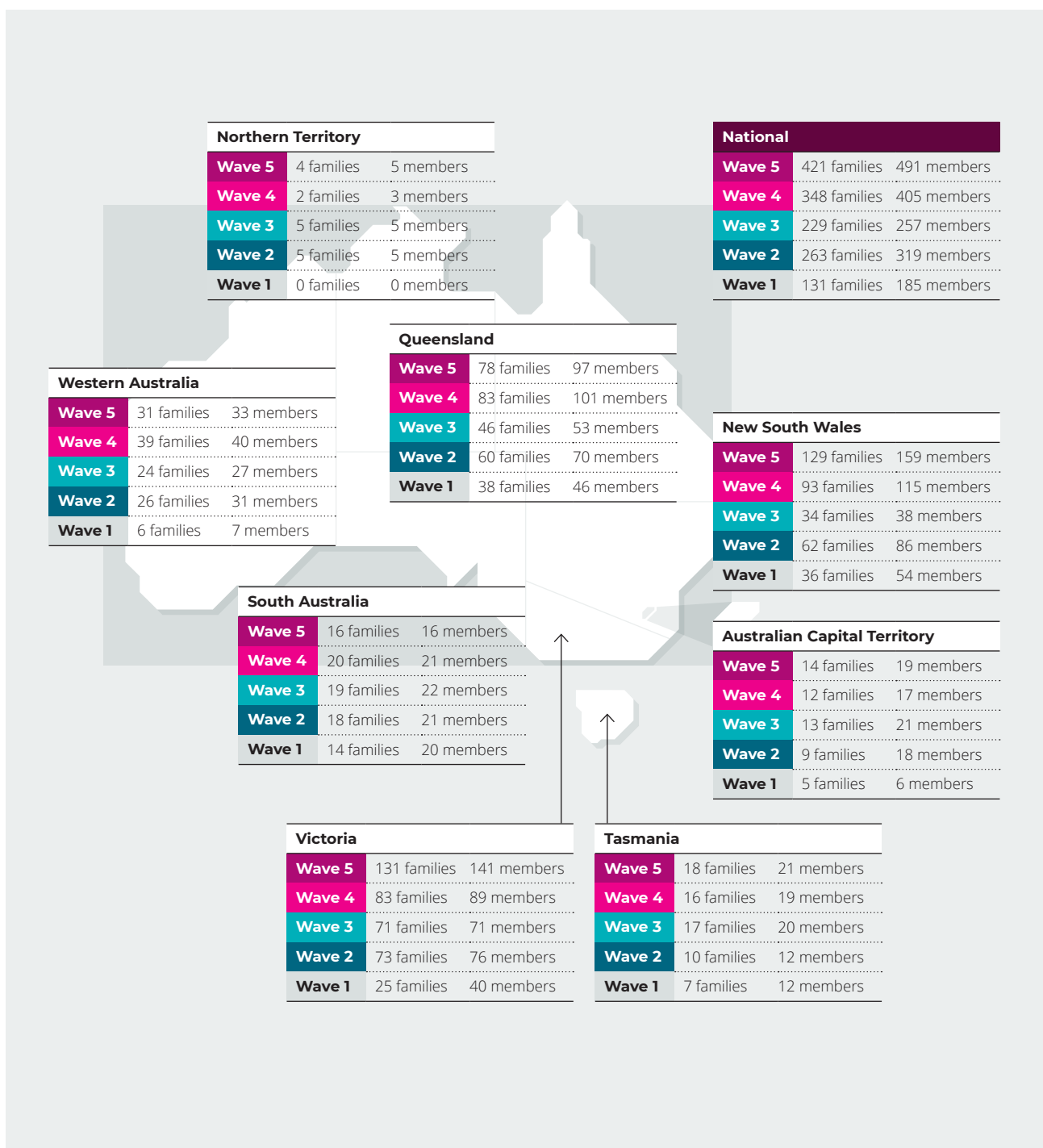
Table 3 Wave 5 – Quantitative sample distribution by state/territory (consenting strand)

State/ Territory	Target Population		Participating Sample		
	Consenting Donor Family Members*	% of National Total	No. Family Members Participated	% of National Sample	Response Rate
QLD	457	19.2%	97	19.8%	21.2%
NSW	832	35.0%	159	32.4%	19.1%
VIC	654	27.5%	141	28.7%	21.6%
WA	156	6.6%	33	6.7%	21.2%
ACT	114	4.8%	19	3.9%	16.7%
NT	18	0.8%	5	1.0%	27.8%
SA	64	2.7%	16	3.3%	25.0%
TAS	82	3.4%	21	4.3%	25.6%
Total	2,377	100.0%	491	100.0%	20.7%

* Excluding survey packs that were returned to sender

A comparison of the Wave 5 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



4.3.2 Year of donation

In terms of the year-of-donation breakdown, 49% of donor families included in the Wave 5 sample consented to donation in 2018; the remaining 51% in 2019 (Table 4).

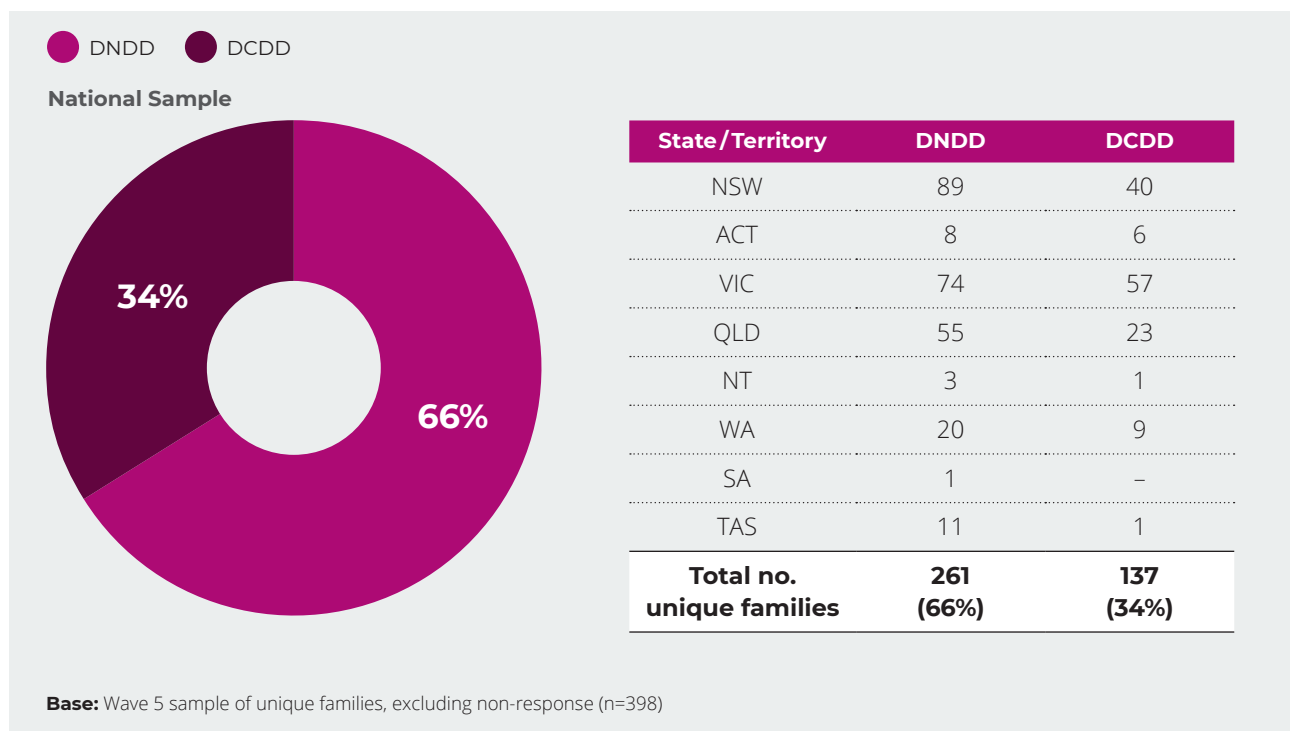
Table 4 Total number of unique donor families by state/territory and year of donation across all waves

State/ Territory	Wave 1		Wave 2		Wave 3		Wave 4		Wave 5	
	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
NSW	13	23	33	29	14	20	32	61	61	68
QLD	14	24	23	37	21	25	41	42	38	40
VIC	9	16	34	39	30	41	36	47	73	58
WA	4	2	13	13	8	16	19	20	11	20
ACT	2	3	6	3	7	6	7	5	8	6
TAS	4	3	5	5	10	7	6	10	5	13
SA	8	6	7	11	8	11	10	10	8	8
NT	0	0	2	3	4	1	2	–	3	1
Total	54 (41%)	77 (59%)	123 (47%)	140 (53%)	102 (45%)	127 (55%)	153 (44%)	195 (56%)	207 (49%)	214 (51%)

4.3.3 Donation pathway

There are two pathways to deceased donation: donation after neurological determination of brain death¹ (DNDD) and donation after circulatory determination of death¹ (DCDD). Families who consented to donation after their family member was determined dead via either neurological or circulatory determination of death, were included in the Donor Family Study. Figure 2 shows that DNDD comprises 66% of the Wave 5 sample, while DCDD comprises 34%.

Figure 2 Donation pathway of study sample – Provided by DonatLife agencies

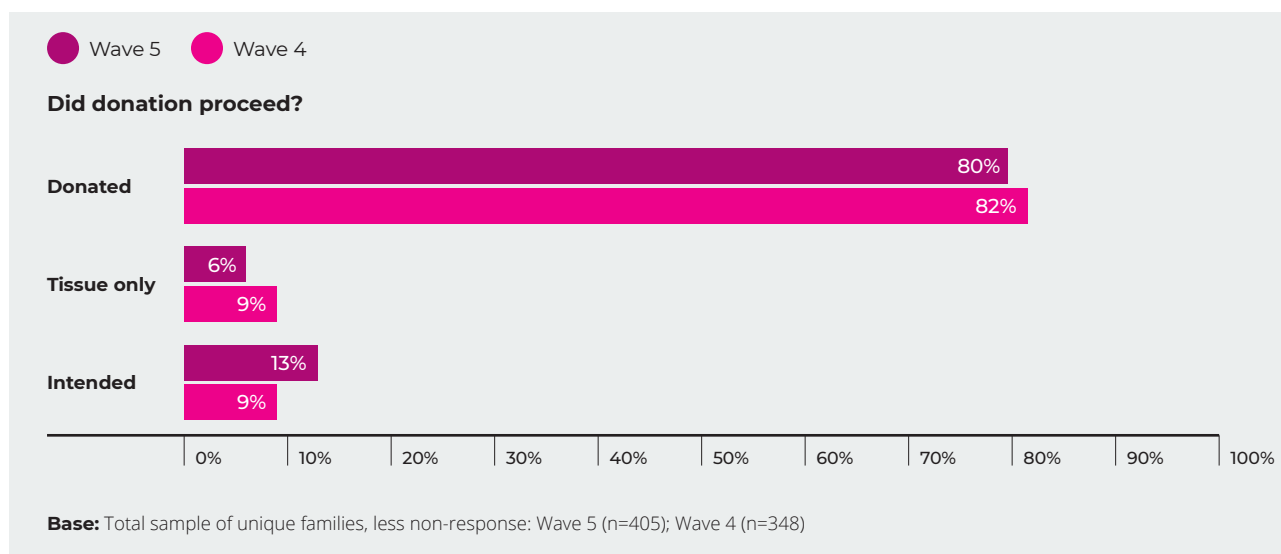


¹ The Australian New Zealand Intensive Care Society (ANZICS) Statement on Death and Organ Donation Edition 4.1 defines the standards for determining death after circulatory determination of death and neurological determination of death (formerly referred to as brain death determination). For the purpose 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 Donation outcome

Thirteen percent (13%) of families who took part in Wave 5 intended to donate, but donation did not proceed due to medical reasons.

Figure 3 Study Sample profile – Outcome (unique donor families)



4.3.5 Relationship and age

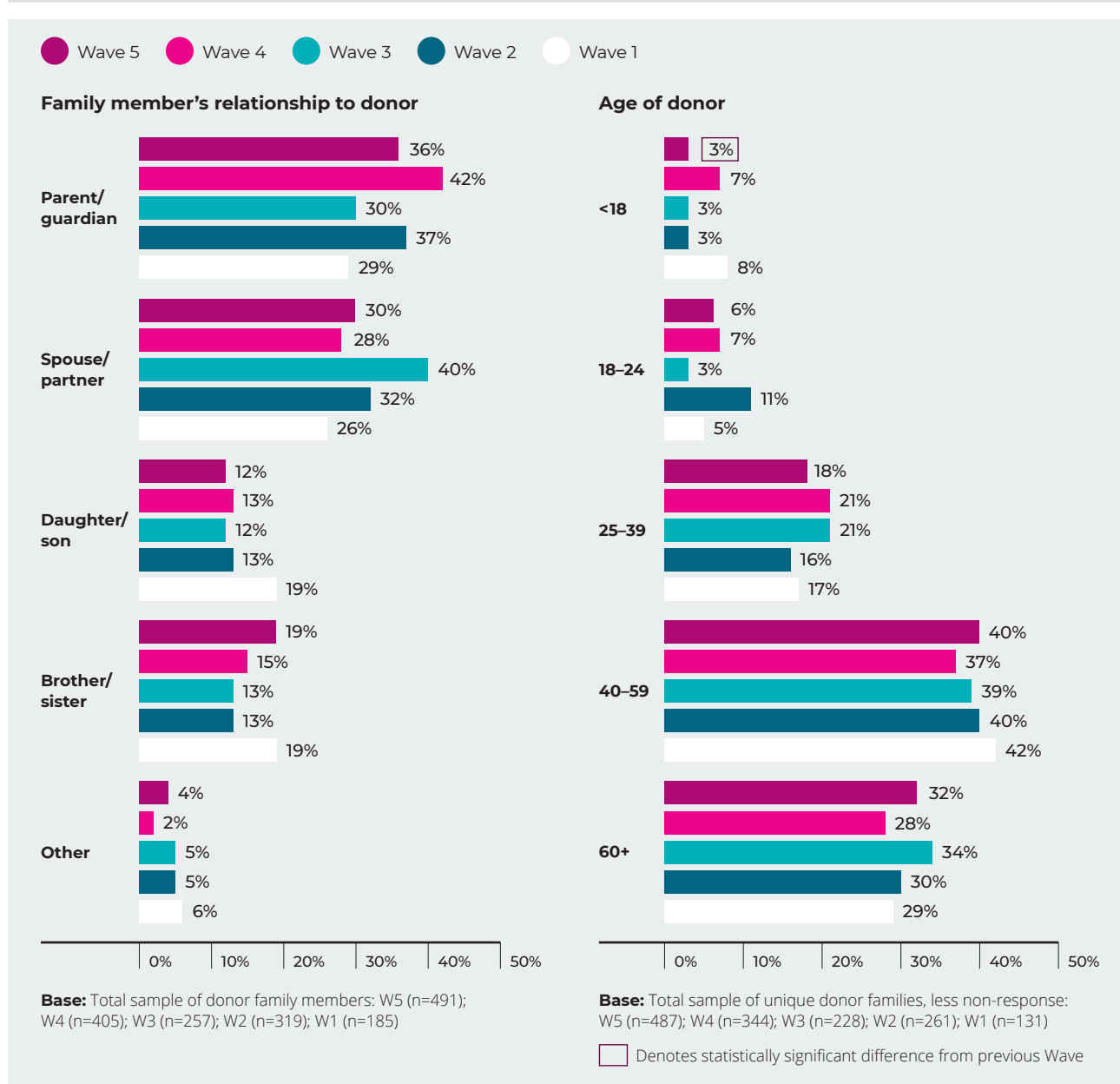
Table 5 shows the relationship of the family member to the donor, together with the average age and age range of donors.

Table 5 Relationship of respondent to donor and age of donor

Relationship of Respondent to Donor "I am his/ her/ their"	Average Age of Donor	Age Range of Donor
Parent/ guardian	34 years	10 months to 61 years
Spouse/ partner	58 years	33 to 80 years
Daughter/ son	67 years	52 to 84 years
Brother/ sister	54 years	20 to 71 years
Other (sister-in-law, niece, grandparent, uncle, friend)	55 years	10 to 80 years

As shown in Figure 4, a wide range of family members are included in the study, with donors ranging in age from 10 months to 84 years.

Figure 4 Relationship to donor and age of donor



4.3.6 Ethnicity

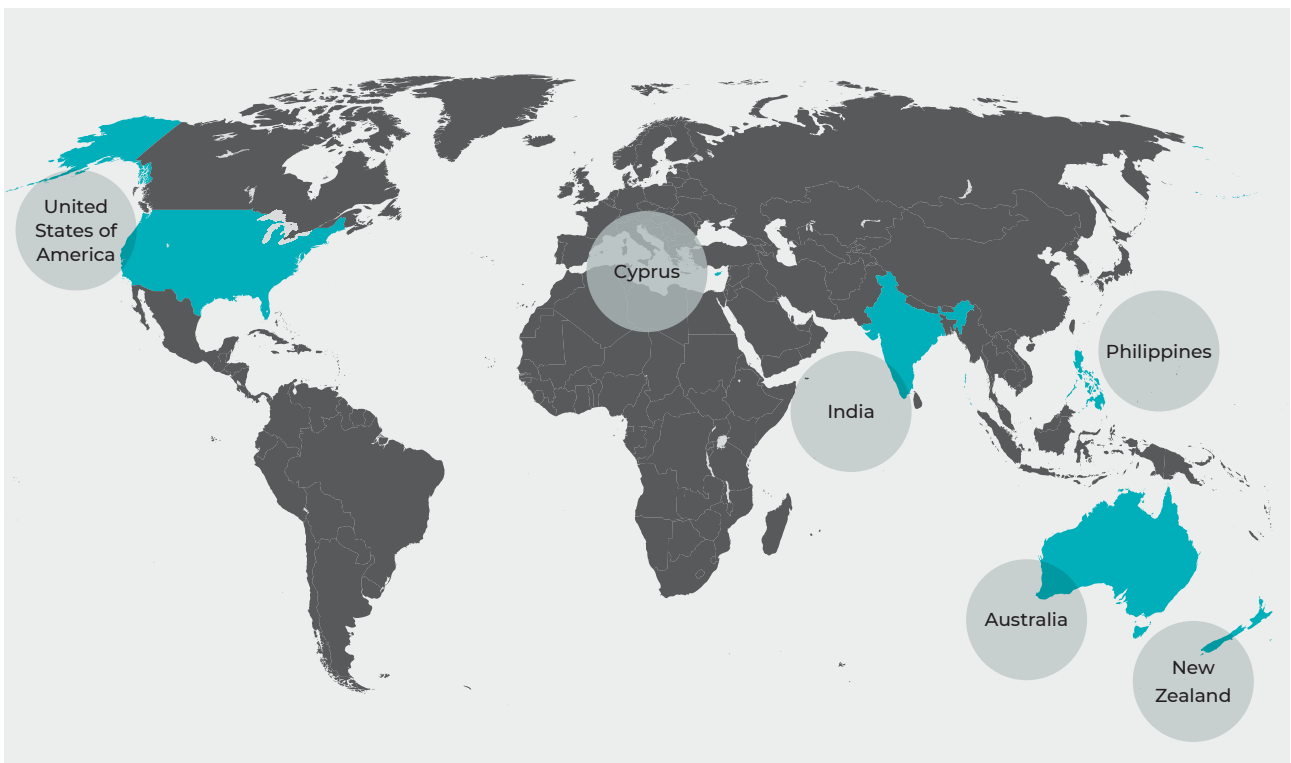
Six percent (6%) of the Wave 5 sample of donor families stated that their family member spoke a language other than English at home, consistent with Wave 4 (6%). The languages spoken include:

- Auslan
- Bengali
- Chinese
- Croatian
- Czech
- Danish
- Dutch
- Estonian
- Filipino
- French
- German
- Greek
- Hungarian
- Italian
- Kannada
- Macedonian
- Maltese
- Mandarin
- Norwegian
- Serbian
- Slovene
- Tagalog
- Tamil
- Vietnamese

Consistent with earlier waves, 2.4% of the Wave 5 donor sample are of Aboriginal or Torres Strait Islander (ATSI) descent. According to the latest available Census data (Australian Bureau of Statistics, 2021), Aboriginal and Torres Strait Islander peoples represent 3.8% of Australia's population.

The Donor Family Study also reached families living outside of Australia. Figure 5 shows that families in New Zealand, India, the United States of America, the Philippines, and Cyprus took part in the online version of the survey.

Figure 5 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 In-depth Interviews Conducted				Year of Donation		Total In-depth Interviews conducted for each State/ Territory – Consented to Donation
		DNDD	DCDD	Tissue only	Intended	2018	2019	
NSW	62	7	1	–	–	4	4	8
QLD	34	2	1	–	1	1	3	4
VIC	56	4	–	–	–	2	2	4
WA	13	2	1	–	–	2	1	3
ACT	6	3	–	–	–	2	1	3
NT	2	1	–	–	–	1	–	1
SA	9	–	–	–	–	–	–	–
TAS	5	1	–	1	–	–	2	2
National	187	20	3	1	1	12	13	25

As shown above, 187 family members who consented to donation volunteered to take part in an in-depth interview with a Proof Research researcher. Of these, interviews were conducted with 25 families, including a family who consented but the donation did not proceed (intended).

5 Sampling – families who declined donation

5.1 Sample frame

Families who declined organ and/or tissue donation in a hospital setting during 2018 and 2019, at a participating hospital, were invited to take part in Wave 5 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 DonatLife. Thirty hospitals in Victoria, New South Wales, Western Australia, Queensland, and the Australian Capital Territory took part in the declined strand of the Donor Family Study, Wave 5, providing families who declined donation an opportunity to share their experiences.

5.2 Response rates

Survey packs were sent to N=526 family members who declined organ and tissue donation. Of these, n=52 were returned to sender due to a change of address or the person being deceased, bringing the total survey population to N=474. Of these, n=34 family members took part in Wave 5 of the Donor Family Study. This equates to an overall response rate of 7.2%, higher than that achieved in Wave 4 (5%). Table 7 shows the breakdown by state/territory.

Table 7 Wave 5 – Quantitative sample overview by state/territory (declined strand)

State/ territory	Target Population		Participating Sample	
		Family members who declined donation*	No. Family Members Participated	Response rate
NSW	Wave 5	143	12	8.4%
	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 5	87	7	8.0%
	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 5	165	6	3.6%
	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 5	55	7	12.7%
	Wave 4	80	2	2.5%
	Wave 3	52	2	3.8%
	Wave 2	61	2	3.3%
	Wave 1	Did not participate		

State/ territory	Target Population		Participating Sample	
		Family members who declined donation*	No. Family Members Participated	Response rate
ACT	Wave 5	24	2	8.3%
	Wave 4	9	2	22.2%
	Wave 3	4	0	0.0%
	Wave 2	Did not participate		
	Wave 1	9	0	0.0%
TAS	Wave 5	Did not participate		
	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 5	Did not participate		
	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 5	Did not participate		
	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 5 (families in 2018/2019)	474	34	7.2%
	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

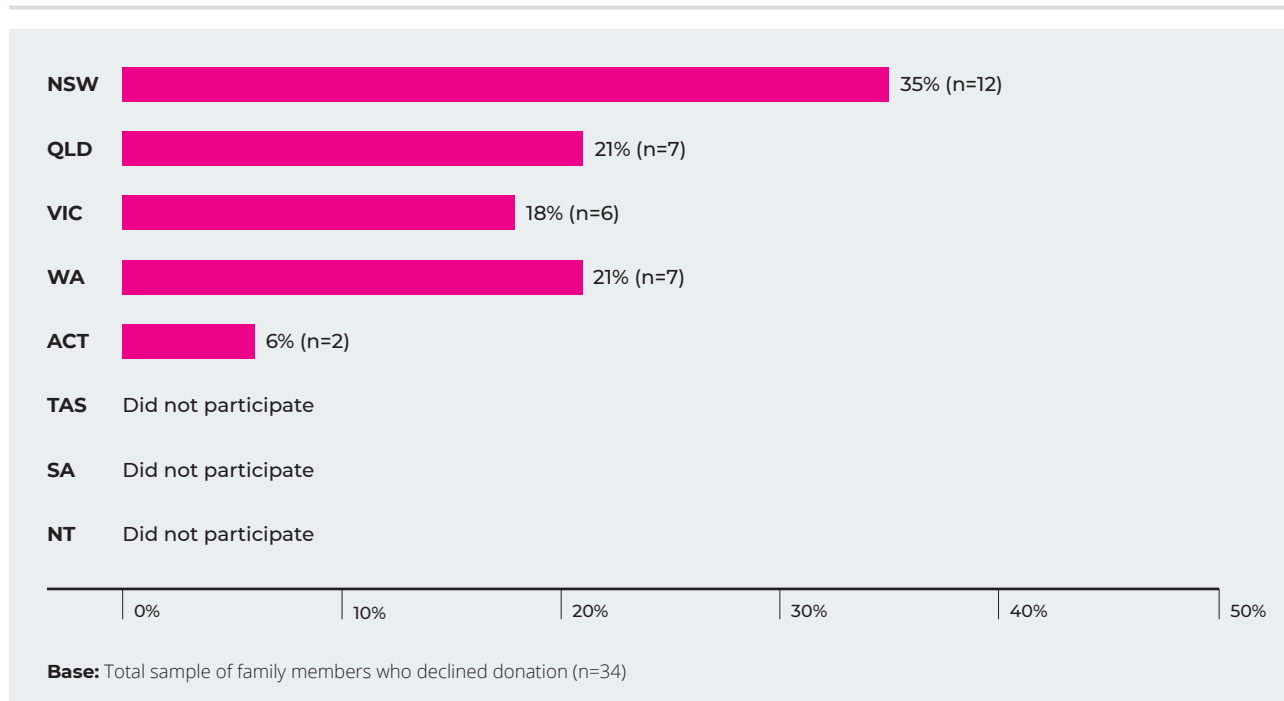
In terms of the qualitative research strand, 10 families who declined donation agreed to participate in a personal interview. These families were from Victoria, Queensland and New South Wales. In-depth interviews, each lasting approximately 60 minutes, were conducted with six family members.

5.3 Sample composition – quantitative

5.3.1 Geographic coverage

The geographic distribution of the 34 family members who declined donation who took part in the research, is shown in Figure 6.

Figure 6 Response distribution – Families who declined donation (Wave 5)



5.3.2 Year of decision about donation

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

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

State/territory	Wave 2 (no. of families)		Wave 3 (no. of families)		Wave 4 (no. of families)		Wave 5 (no. of families)	
	2012	2013	2014	2015	2016	2017	2018	2019
NSW	0	1	3	5	3	1	6	5
QLD	3	2	3	2	2	4	6	1
VIC	0	2	5	7	6	3	3	3
WA	0	2	2	0	1	1	1	5
ACT	N/A	N/A	0	0	0	2	1	1
TAS	0	2	2	2	1	0	N/A	N/A
SA	0	0	1	0	N/A	N/A	N/A	N/A
NT	0	0	0	0	0	0	N/A	N/A
Total	3	9	16	16	13	11	17	15

5.3.3 Relationship and age

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

Table 9 Relationship of respondent to potential donor and age of potential donor

Relationship of Respondent to Potential Donor "I am his/ her /their..."	Average Age of Potential Donor	Age Range of Potential Donor
Spouse/ partner (n=18)	62 years	47 to 77
Parent/ guardian (n=4)	31 years	19 to 45
Daughter/ son (n=10)	74 years	59 to 89
Brother/ sister (n=2)	63 years	53 to 72

5.3.4 Ethnicity

Among families who declined donation who took part in the research, 81% spoke only English at home; 19% spoke another language (Burmese, Italian, Filipino, Thai, German, Hindi). 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. Ten family members (from 10 individual families) agreed to an in-depth interview and six family members were interviewed.

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

State/ Territory	No. of Family Members Agreed to In-depth Interview	Year of Death		Total In-depth Interviews Conducted Declined Donation
		2018	2019	
NSW	4	3	1	2
ACT	0	0	0	0
VIC	3	2	1	1
QLD	3	2	1	3
NT	Did not participate	-	-	-
WA	0	0	0	0
SA	Did not participate	-	-	-
TAS	Did not participate	-	-	-
National	10	7	3	6

Part B – Research findings

6 The decision to consent to or decline donation

Unlike most other important and enduring decisions, the decision about donation is made at a time when families are under enormous emotional stress and significant time pressures. Whilst every family is different, the Donor Family Study has identified similarities in the paths leading to a decision about donation. These paths, shown in Figure 7, have remained consistent over time.

Figure 7 Pathways to decision about donation

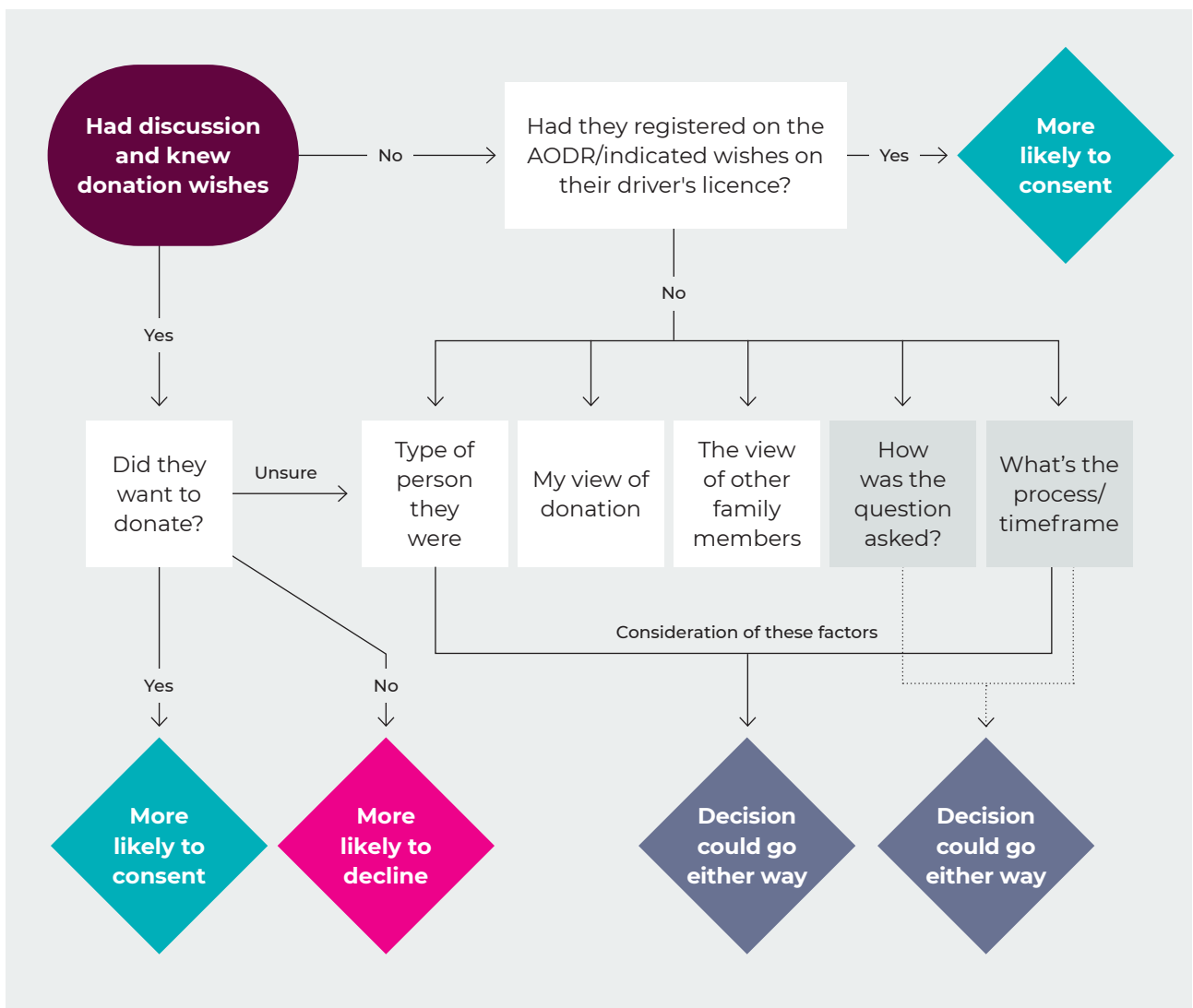


Figure 7 shows that when a family member's donation wishes are known, either in the form of prior knowledge through a discussion, via the Australian Organ Donor Register (AODR), or as indicated on a family member's driver's licence, making a decision about donation is easier for families. Family members often feel the final decision about donation is not actually theirs to make; they are simply carrying out the wishes of their loved one. The impact of prior knowledge is discussed in greater detail in Section 6.

“ No one was stressed about the decision to agree to donation because it was known that this was his wish.”

2019 – Intended to donate

“ I recall him saying something about ticking that box on his license renewal, so in that way I felt we needed to respect that. It was just a sense of respect for what his wishes were.”

2018 – Intended to donate

In the absence of knowledge of their family member's donation wishes, families typically consider several things, including:

- How they themselves feel about donation
- How the rest of their family feels about donation
- The type of person their family member was and what they would want to do

“ We weren't sure how he would feel about donating. However, knowing how much he loved to help people, we felt fairly sure he would have agreed.”

2019 – Consented to donation

Whilst these three areas considered by families can be discussed and explored by donation specialists and medical practitioners, greater influence could possibly be achieved through focused community awareness and understanding of donation to provide some clarity to the conversations that families have.

The last two areas that families consider, as shown in Figure 7, are well within the control of hospital staff. They are:

- How families are approached about donation
- The donation process/ timeframe

How donation is approached with families and the impact of this on the decision about donation, is detailed in Section 8.0.

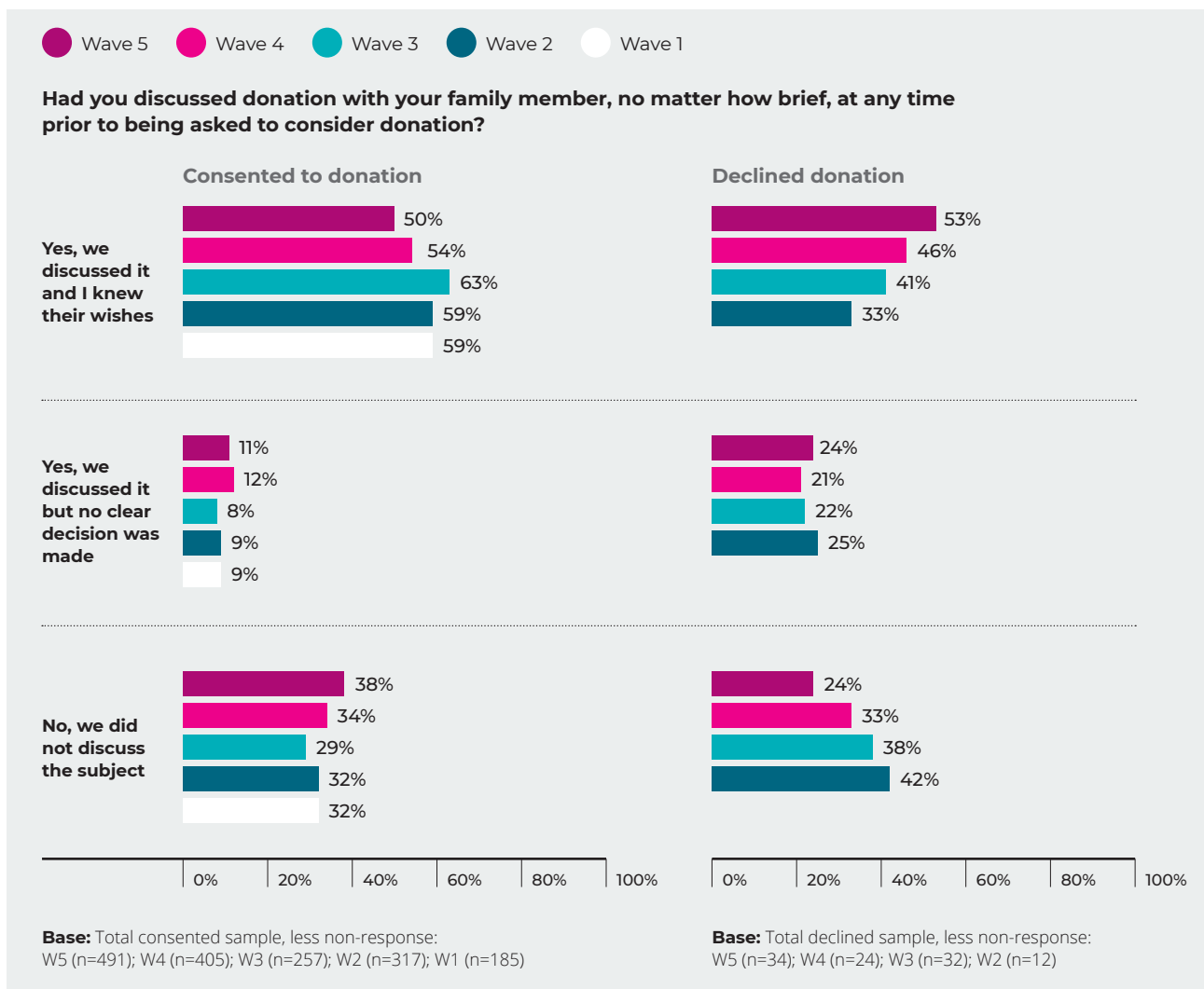
In terms of the process and timeframe, findings indicate that family members are looking for clear, concise and easy-to-understand information. What are the broad steps in the process and how long will it take? How will potential donation impact on their family member's stay in hospital? Findings show that providing timely information and keeping families up-to-date during their hospital stay is essential to their experience.

6.1 Impact of prior knowledge

Findings from the Donor Family Study continue to highlight the importance of prior knowledge of a family member's donation wishes when it comes time to making a decision about donation in hospital. These findings have been consistent since Wave 1 of the Donor Family Study.

However, it's not just about having the discussion. It's about having the discussion and ensuring that a family member's wishes are clearly known. Figure 8 shows that half (50%) of family members who took part in the study had discussed organ and tissue donation with their family member and knew their wishes. This is consistent with Wave 4 findings (50%). As shown, 11% of family members who consented to donation and 24% of those who declined donation had discussed the topic, but no clear decision about donation was articulated by their family member.

Figure 8 Prior discussion of organ donation



“ Not knowing if it was what he really wanted made our decision difficult.”
2019 – Declined donation

Figure 8 also shows that approximately 2 in 5 family members (38%), including those who consented to donation and those who declined donation, had not discussed organ and tissue donation with their family member prior to being asked to make a decision about donation in the hospital. Not knowing the wishes of a family member makes the decision about donation more difficult.

In addition to making the decision about donation more difficult, when a family member's wishes are unknown, because either a conversation had not occurred or because their wishes had not been recorded on the AODR, over time, some family members can grow to doubt the decision they made in hospital, irrespective of whether that decision was to consent to or decline donation.

“That’s another reason why it is just so important that people have these conversations, because if there is one thing that haunts me, it’s that. Did we get this right? We will never know.”

2018 – Consented to donation

As shown in Table 11, those who had discussed donation with their family member and knew their wishes found it much easier to make a decision about donation in a hospital setting. Of those who had discussed donation and knew their family member's wishes, 88% said it made their decision easier, compared with 23% of those who had not had this conversation with their family member.

“We had all spoken about it as a family and knew that if we were ever in that position, that’s what we would do. So it was easy to say yes on that day because she would have been so furious if we would have said no.”

2018 – Consented to donation

“We had talked about it and we were both really clear about what we would do in this situation. Even though it was a really hard decision, it was a simple one because I knew.”

2019 – Consented to donation

Consistent with findings from previous waves of the Donor Family Study, 78% of families who had discussed donation and knew their family member's wishes found the decision to consent to donation *a lot easier*, compared with just 16% of those who had not discussed donation (Table 11).

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

Impact of Degree of Discussion	Discussed and knew wishes (n=245)	Discussed but no clear decision made (n=55)	Total Discussed donation (n=300)	Did not discuss donation (n=188)
Made our decision a lot easier	78%	22%	67%	16%
Made our decision a bit easier	11%	24%	13%	7%
Made decision easier – net	88%	45%	80%	23%
Did not impact on our decision	11%	42%	17%	61%
Made our decision a bit more difficult	–	9%	2%	11%
Made our decision a lot more difficult	–	4%	1%	5%
Made decision more difficult – net	0%	13%	3%	16%

□ Significantly lower likelihood to feel this way □ Significantly higher likelihood to feel this way

This was also the case for families who declined donation. As shown in Table 12, 59% of families who knew their family member's wishes found it a lot easier to decline donation (in line with those wishes), compared to just 13% of those who had not had the discussion.

“It was comforting to know I was following his wishes.”

2018 – Declined donation

“I knew exactly what he wanted. He strongly did not want to donate.”

2018 – Declined donation

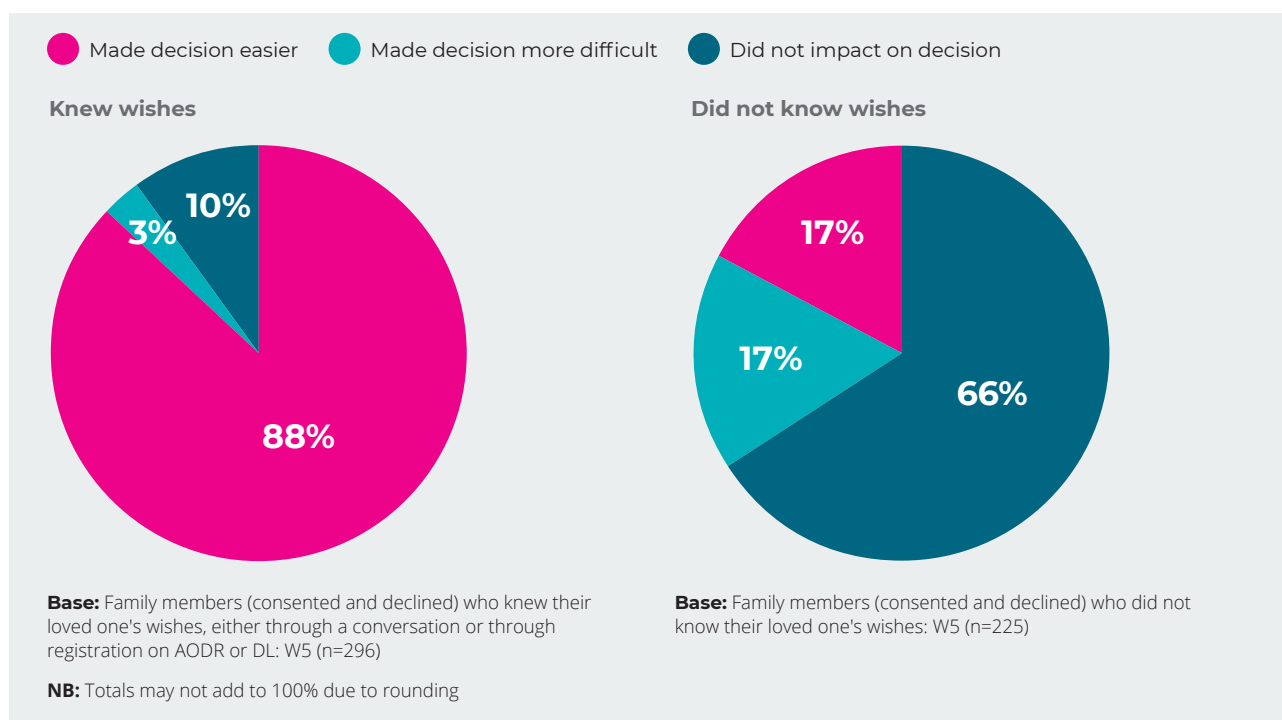
Table 12 Impact of prior discussion on the decision about donation – Families who declined donation

Impact of Degree of Discussion	Discussed and knew wishes (n=17)	Discussed but no clear decision made (n=8)	Total Discussed donation (n=25)	Did not discuss donation (n=8)
Made our decision a lot easier	59%	–	40%	13%
Made our decision a bit easier	–	13%	4%	–
Made decision easier – net	59%	13%	44%	13%
Did not impact on our decision	12%	50%	24%	88%
Made our decision a bit more difficult	12%	25%	16%	–
Made our decision a lot more difficult	18%	13%	16%	–
Made decision more difficult – net	29%	38%	32%	–

Significantly higher likelihood to feel this way

Figure 9 shows the difference between families who knew the donation wishes of their family member (through a conversation or because they were registered on the AODR or via their driver’s licence) and those who did not. As shown, 88% of those who knew their family member’s wishes say this made the decision about donation easier, compared with 17% of those who were unaware of their family member’s wishes. This is a significant difference.

Figure 9 Impact of knowing/ not knowing donation wishes



Family members were asked in what way knowing or not knowing the wishes of their family member made their decision easier or more difficult. Responses have been grouped and coded, and are shown in Table 13. These findings indicate that those who knew their family member’s wishes found the decision easier knowing that they were honouring those wishes (76%). Further, 12% stated that knowing those wishes helped to facilitate conversations with their family and helped all family members to agree.

“Of course we are very happy that we were able to honour our sister's wish to donate her organs.”

2018 – Consented to donation

“He was registered as an organ donor, and I know I wanted to donate but I hadn't spoken to him about it. Knowing he was registered made it easier to justify to family members who were against it.”

2018 – Consented to donation

As evidenced in Figure 7, in the absence of prior knowledge of a family member's donation wishes, family members who found the decision easy relied on the type of person their family member was (50%) and the fact that their donation would greatly help others (38%).

Almost three quarters (73%) of those who did not know their family member's wishes and found the decision difficult said it was difficult because they could not be guided by their family member – they didn't know what he/she would have wanted.

“The decision was difficult as I didn't know his wishes and I wanted to do what he would have wanted.”

2018 – Consented to donation

Table 13 Reasons for decision being easier or more difficult – Consented to donation

Wave 5 – Consented to donation Please explain how knowing/ not knowing made your decision easier or more difficult	Decision made easier		Decision made more difficult	
	Knew wishes (n=213)	Did not know wishes (n=24)	Knew wishes (n=2)*	Did not know wishes (n=26)
Wanted to honour the wishes of our family member	76%	–	50%	–
Knowing his/her wishes made the decision easier at a difficult time (no further information)	14%	–	–	–
Not knowing means we will always wonder if we made the right decision / decision difficult because we didn't know family member's wishes	–	–	–	73%
It made it easier for all family members to agree due to wishes being known	12%	–	–	–
Not knowing made it difficult for family to agree	–	–	–	19%
Relied on type of person donor was (generous and giving)	6%	50%	50%	15%
Knowing that the donation would help other people	7%	38%	–	–
Decision made easier because we believe in donation	9%	8%	–	–
We had no doubts about what to do / we were certain	5%	4%	–	–
Just seemed like the right thing to do	2%	8%	–	8%
We felt comfortable with our decision	1%	8%	–	4%
Know someone who has received / is waiting for transplant	3%	17%	–	–
Work in medical field and understand the importance of donation	2%	–	–	–

* Caution: small sample size

Significantly higher when comparing knowing and not knowing a family members wishes

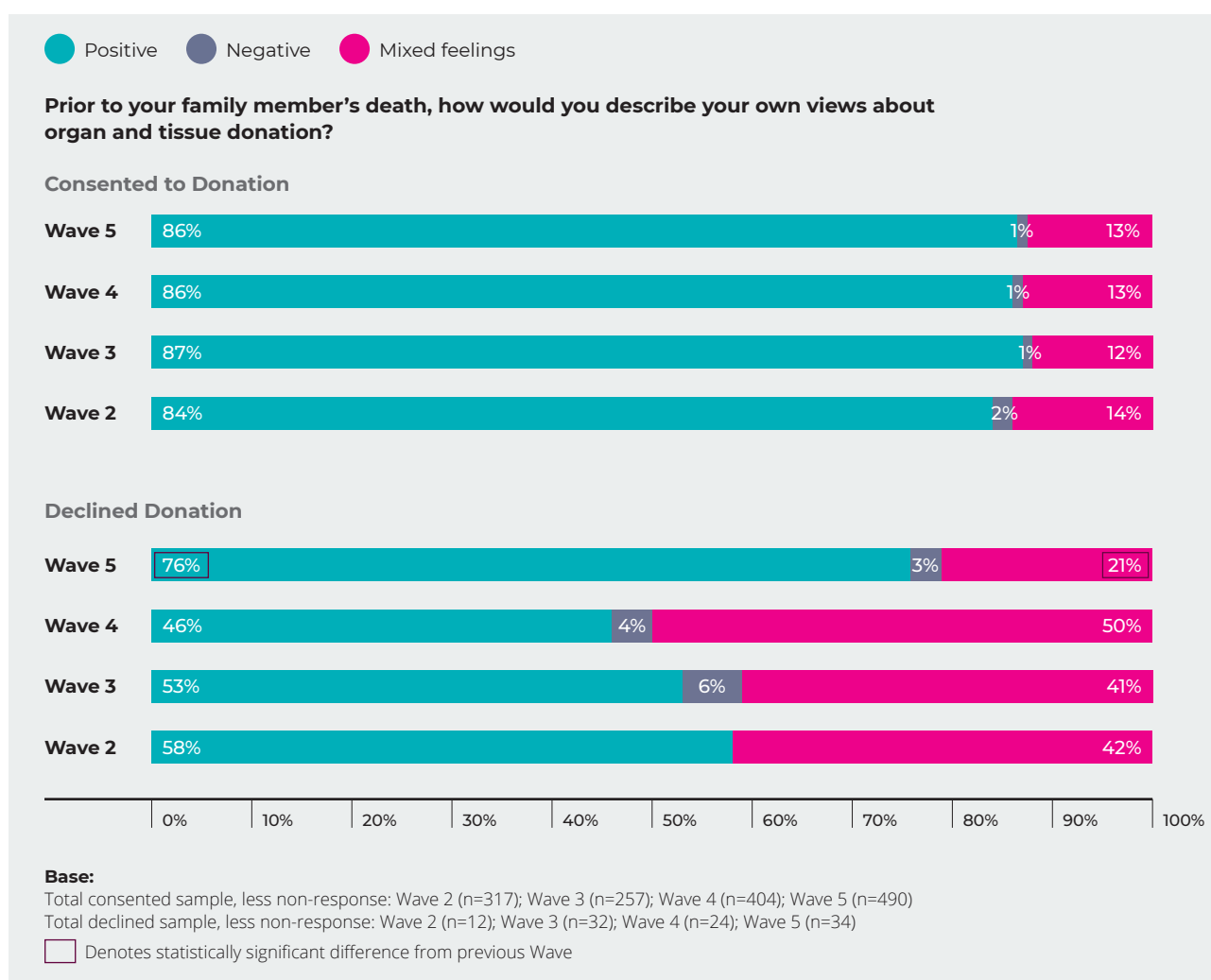
Looking specifically at families who declined donation, of those who said their decision was a relatively easy one, all (100%) were following the wishes of their family member not to donate.

“The deceased had made her wishes very clear and I simply complied with those wishes.”
2018 – Declined donation

6.2 Personal views of donation

Figure 10 shows that 86% of family members who consented to donation were supportive of organ donation prior to their family member’s death, compared with 76% of family members who declined donation (this difference is not statistically significant). Pleasingly, a significantly higher proportion of family members who declined donation during 2018 and 2019 held positive views of donation (76%), compared with families in 2016 and 2017 who declined donation (46%).

Figure 10 Personal views of donation prior to family member’s death



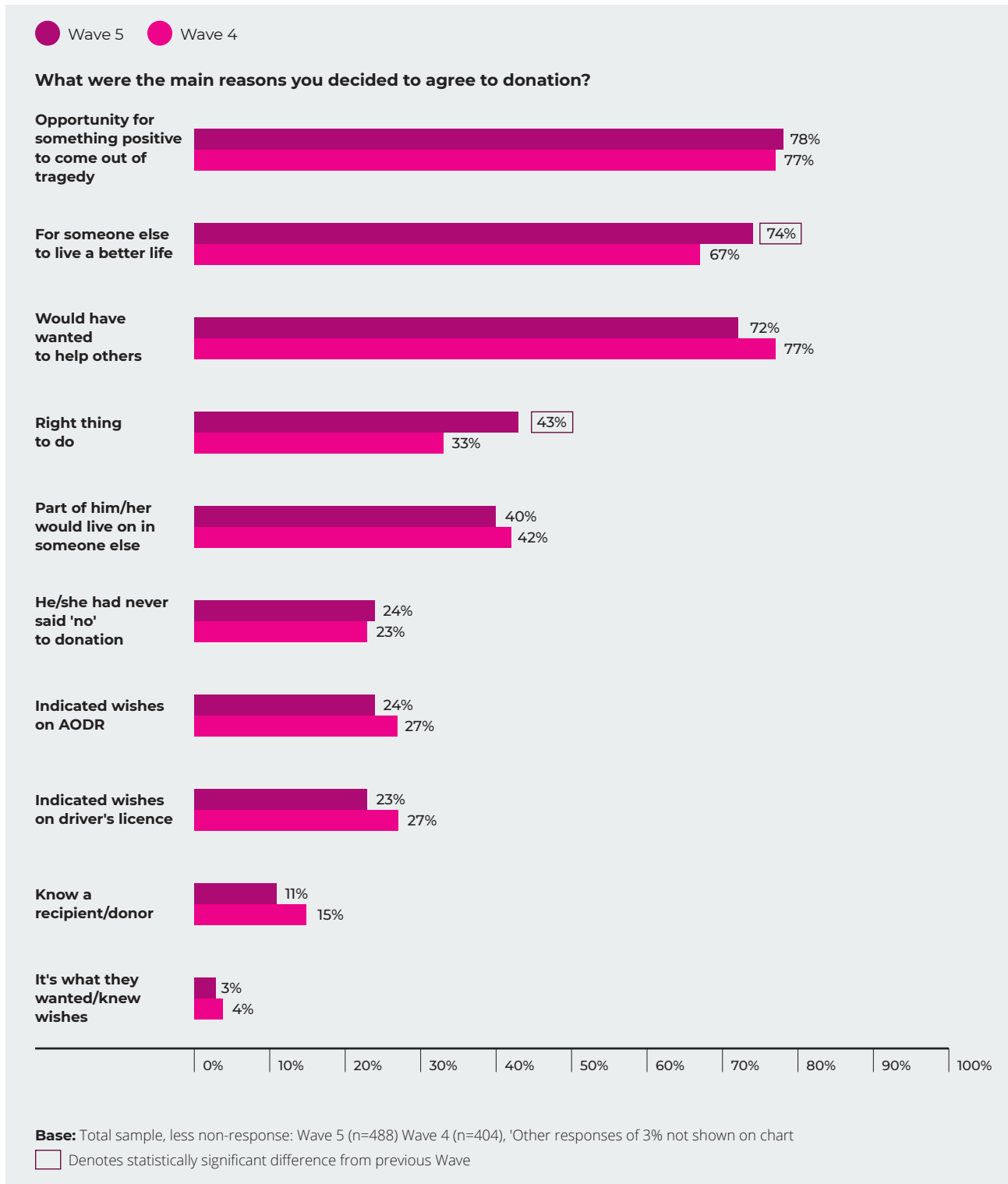
Looking specifically at family members who declined donation and took part in an in-depth interview with the researcher, there were instances where a family member wanted to donate their loved one’s organs, yet other family members felt differently.

“I know that Dad wanted to donate and if I had the choice, I would have said yes to it, but unfortunately Mum decided not to.”
2018 – Declined donation

6.3 Motivations for donation

Consistent with previous research waves, a large proportion of donor families (78%) in 2018 and 2019, saw organ and tissue donation as a chance for something positive to come out of a personal tragedy (Figure 11).

Figure 11 Motivations for donation



“ I felt donation was the only positive that could come out of this horrible tragedy. There is nothing else. If we don't do this, we walk out of here with nothing; nothing to hold on to. There is no legacy, there is nothing.”

2018 – Consented to donation

Seven in 10 (72%) donor family members were motivated to donate because they felt that their family member would have wanted to help others. In these instances, family members used substituted judgement – they put themselves in the place of their family member and tried to choose as they would.

Altruism continues to be evident as a motivating factor. Seven in ten (74%) donor family members agreed to donation so that someone else can live or have a healthier life, whilst two in five (43%) felt like donation was the right thing to do (an increase since the previous wave).

“ To increase the quality of life for someone else by donating; the value of that is significant.”

2018 – Consented to donation

6.4 Barriers to Donation

As many family members consent to organ and tissue donation because they know or believe that this is what their family member would want, so too do some families decline donation – because they know or believe that their family member would not wish to donate. Carrying out the wishes of a family member not to donate is a reason for declining donation for 30% of families. However, in 29% of cases (n=10), families selected not to donate, despite knowing their loved would have wanted to. This is due to a cultural or religious belief, or because they feel uncomfortable with the idea of donating their family member's organs.

“ It made it difficult because I felt we were going against his wishes, but my mother's cultural belief that he go to heaven whole also made it difficult to go against her wish to decline donation.”

2018 – Declined donation

“ My mother had expressed that she was happy to donate but my father wouldn't allow it.”

2018 – Declined donation

Amongst family members surveyed who declined donation during 2018 and 2019, 27% declined because they felt that their family member had been through enough and/or they didn't want him/her to have the donation surgery. This 'best interests' approach to decision making is when the family decide what they think is best for their family member. Findings are consistent with Wave 4 (39%).

Process related concerns are cited by 24% of families surveyed who declined donation. These concerns include the extra time needed in hospital to accommodate the donation process, and the timing between extubation and donation.

“ I wanted to spend every minute with him. Taking him away after passing was too soon.”

2018 – Declined donation

A full list of reasons for declining donation, tracked over time, is shown in Table 14. Please note that this question prompted family members with a list of pre-coded responses, whereas the in-depth interviews encouraged family members to speak freely and allowed further exploration of reasons for declining.

Table 14 Reasons for declining donation across Waves 2–5

What were the main reasons you decided to decline donation?	Wave 2 (n=12)	Wave 3 (n=30)	Wave 4 (n=23)	Wave 5 (n=33)
He/she didn't want to donate	17% (n=2)	20% (n=6)	35% (n=8)	30% (n=10)
He/she had been through enough	33% (n=4)	33% (n=10)	26% (n=6)	27% (n=9)
Donation was going to take too long and I couldn't wait	8% (n=1)	17% (n=5)	9% (n=2)	15% (n=5)
He/she was not registered on the AODR*	N/A	N/A	N/A	15% (n=5)
Other family members declined	17% (n=2)	–	4% (n=1)	15% (n=5)
Family member would be taken away too quickly after dying	–	–	–	12% (n=4)
I didn't have enough information about what was involved with donation	17% (n=2)	7% (n=2)	–	9% (n=3)
I didn't accept death and couldn't agree to donation	17% (n=2)	17% (n=5)	4% (n=1)	6% (n=2)
I don't like the idea of donation	8% (n=1)	7% (n=2)	4% (n=1)	6% (n=2)
I didn't want him/her to have surgery for donation	25% (n=3)	17% (n=5)	30% (n=7)	3% (n=1)
I didn't know what he/she would have wanted	25% (n=3)	23% (n=7)	22% (n=5)	3% (n=1)
Donation is against my religious beliefs	–	13% (n=4)	4% (n=1)	–
I wanted the donated organs to go to specific people	–	–	4% (n=1)	–
I wasn't happy with the care	–	7% (n=2)	–	–
Other	17% (n=2)	23% (n=7)	22% (n=5)	21% (n=7)

* New statement in Wave 5

□ Significantly lower than Wave 4

In-depth interviews were conducted with six families who declined donation. Analysis of their experiences revealed four common themes regarding reasons for declining donation, some of which are present in the above table. They are:

- 1 Honouring wishes of family member not to donate
- 2 Poor approach to family
- 3 Family disagreement
- 4 Donation process

These themes are supported by the following comments from family members:

“ I felt pressured that we had to make a decision in a couple of minutes. I had to ask to have some private time to talk about it.”

“ His daughter, ex-wife and friends came back and said that we weren't going to donate, and that was basically it. I felt I was outnumbered, even though I was his next of kin. No one really consulted me. I feel bad about it because he wanted to donate.”

“ One of the main concerns was we would have to be in the hospital longer.”

“ We didn't want her to be alone when she passed.”

The approach to family is further discussed in Section 8.

6.5 Families' thoughts about their decision to donate

Families were asked the open ended question during the survey, "Is there anything else you would like to add about your decision to donate?" Findings from the 187 family members who responded to this question are detailed in Table 15.

Table 15 Thoughts about decision to donate

Is there anything else you would like to add about your decision to donate?	Donation proceeded (n=153)	Intended to donate (n=16)*	Declined donation (n=18)*
Happy with decision to donate / was right decision	27%	6%	6%
Donation provided comfort/ meaning / helped the grieving process	27%	19%	-
We believe in organ donation	14%	19%	-
We wanted to help others	12%	12%	-
Followed family member's wishes	11%	-	17%
Received excellent support from hospital staff and DonateLife team	8%	12%	-
Family member would have wanted to help	7%	6%	-
Very difficult decision	7%	-	-
Would make same decision again	5%	-	-
Positive experience	4%	6%	-
Donation process is difficult/stressful/arduous	4%	-	-
Would like more information and updates about recipients / would like to hear from recipients	3%	-	-
Process should be faster once decision about donation has been made / timeframes should be better communicated to families	3%	6%	6%
Updates about/from recipients provides comfort / recipient updates make us feel appreciated	3%	-	-
Hospital and DonateLife staff require further training / poor treatment from staff	3%	-	6%
Felt pressured / not given enough time to make decision	3%	6%	6%
Sad and disappointed that some organs were not able to be used	3%	6%	-
Dispute about next of kin / staff not including certain family members in discussions	2%	-	-
Felt family member had been too sick in past to now be a donor	-	-	22%
Wanted to be with family member at time of death	-	-	22%
Not happy about donation approach (including timing and tone)	-	-	17%
Other (1 response each)	8%	12%	28%

*Caution: small sample size

□ Significantly lower when comparing between columns □ Significantly higher when comparing between columns

7 At the hospital

7.1 Interaction with hospital staff

As shown in Figure 12, all donor families feel that hospital staff treated them with consideration and sensitivity prior to any discussions about donation (91% feel this occurred to a great extent; 8% to some extent). These findings are consistent with previous research waves.

“Myself, my husband and daughter were given compassion, empathy and understanding. We, as a family, were so very grateful. We couldn't praise the doctor, nurses and specialist enough. Forever thankful.”

2018 – Intended to donate

The majority of families in the study who declined donation also feel that they were treated with consideration and sensitivity prior to making their decision about donation (82% feel this occurred to a great extent; 18% to some extent). These findings are consistent with Wave 4.

“The staff in ICU were amazing, caring, compassionate, incredible. We can't thank them enough for everything they did for our daughter, for us and our family.”

2018 – Declined donation

Figure 12 Interaction with hospital staff prior to decision about donation

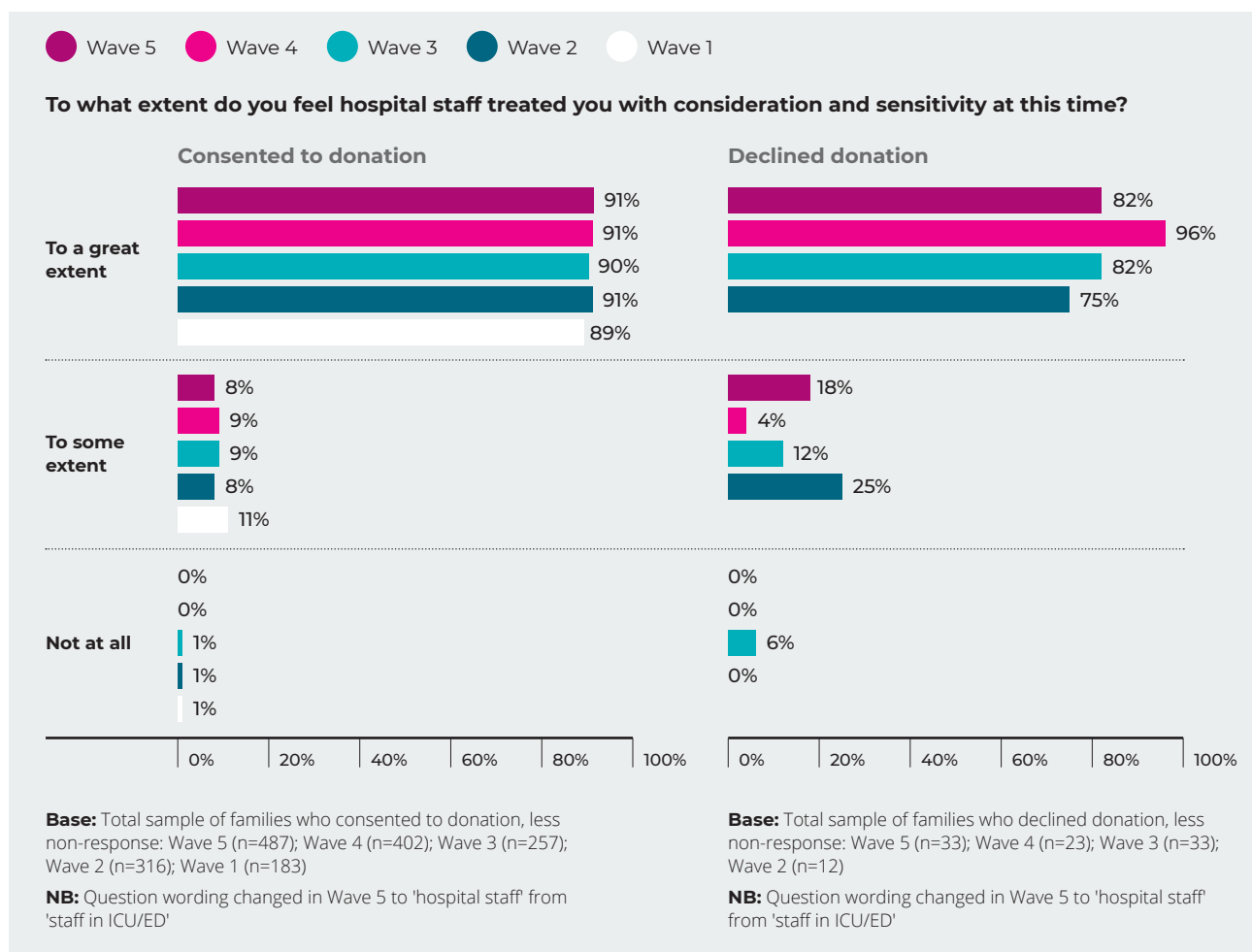


Figure 12 shows families mostly experienced great kindness, compassion, empathy and sensitivity from hospital staff, and they are especially appreciative of the respect shown to their family member.

“ All staff members were so compassionate. They showed not just our family, but also treated our son with such amazing respect and as a human being. They are a credit to the profession.”

2019 – Consented to donation

Family members who felt that hospital staff treated them with consideration only to some extent generally experienced inconsistencies in the level of care shown to them by hospital staff, as demonstrated in the following comments:

“ Unfortunately we had a doctor in the beginning who was very blunt and showed no real compassion but all the nurses and the doctors after him were very good. If the original doctor had not been so uncaring, the decision to donate his organs could have been a group decision, not by just me.”

2019 – Consented to donation

“ Most staff were empathetic and informative. Only a few were a little callous. Some staff were very compassionate and helpful. Some treated us like lepers.”

2018 – Consented to donation

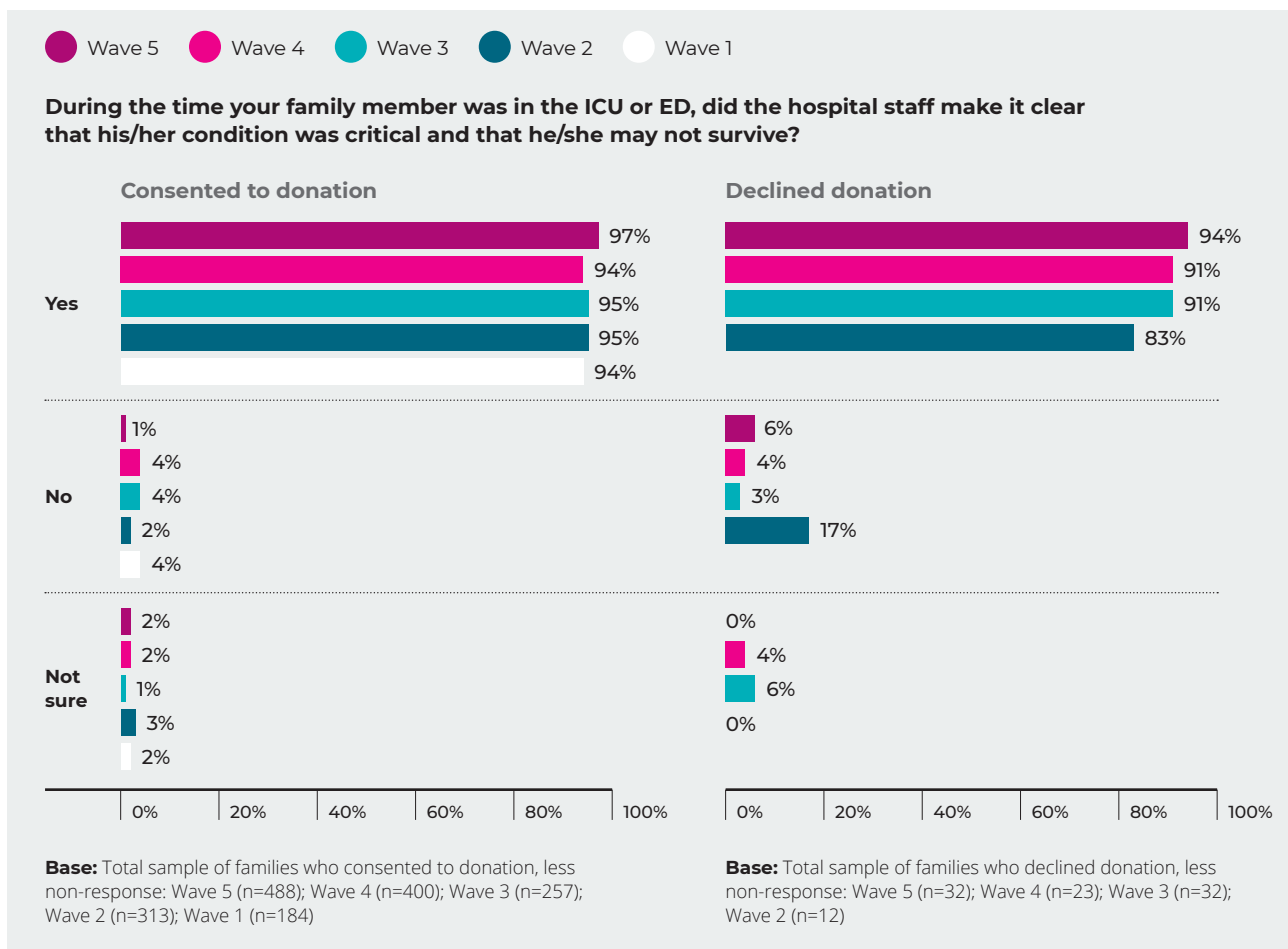
Findings indicate that families understand that the first priority of hospitals is caring for patients. The study shows the importance of hospital staff treating family members with kindness and sensitivity, especially considering the often fragile emotional state of families.

7.2 Delivering news of death or impending death

7.2.1 Clarity of communication

The majority (97%) of family members who consented to donation felt that hospital staff made it clear that their family member's condition was critical and that they may not survive. These findings have been consistent since Wave 1 (Figure 13). Similarly, the majority (94%) of families who declined donation felt that the prognosis of their family member was clearly communicated to them.

Figure 13 Clarity of communication – Prognosis



Families need to have a realistic view of their family member’s prognosis so that they can move to a place of acceptance (this is further explored in Section 8.0). Witnessing brain death testing, and being shown scans and medical evidence of their family member’s condition helps families to understand the prognosis (further information in Section 7.3). Findings show that acceptance is necessary before being asked about donation and that bad news should always be delivered privately and sensitively.

“ I didn’t understand their subtle terms and my partner had to communicate it to me.”

2019 – Consented to donation

“ The only negative part was that I was waiting down in ED and was told that my father was not going to survive over the phone. It would have been better to be told in person.”

2019 – Declined donation

As well as ensuring that families understand the likely prognosis for their family member, findings support a need for hospital staff to be mindful of *how* this news is delivered, ensuring that it is communicated in a direct way, but with kindness and empathy.

“ The specialists and doctors were very prompt to see us. The news was broken to our family in an honest and kind way, and we appreciated this.”

2019 – Consented to donation

Mostly this does happen, but unfortunately there are some occasions when the bad news is delivered without compassion. When this happens, it can impact negatively on families for years to come.

“ The female doctor came in and she was very frank. Too frank for me. She was the doctor that I was really happy that I didn't see again after that night. Her words were 'there is no hope'. 'There is no hope. This is it'. Like, you can say those words in a different way. She may as well have told me that there was no water in the kettle. There was no emotion or empathy, or anything attached to the way she spoke.”

2018 – Consented to donation

Wave 5 of the Donor Family Study highlights the importance for clarity of information and consistency of information between hospital staff and the family.

“ The staff were generally informative but we received the incredibly confusing message on 3 or so occasions that my brother might 'go to a nursing home'. This was at odds with the main message we were receiving. It led to confusion for family members as it suggested the possibility he might improve if given more time and/or treatment.”

2018 – Declined donation

“ I don't really think that I realised that our daughter would die until day 2. I know that organ donation was talked about by the doctor in charge and by counsellors but it didn't sink in. We still thought and hoped that she would wake up and be ok. It was only by day 2 when we spoke to one of the nurses that the truth hit us.”

2018 – Declined donation

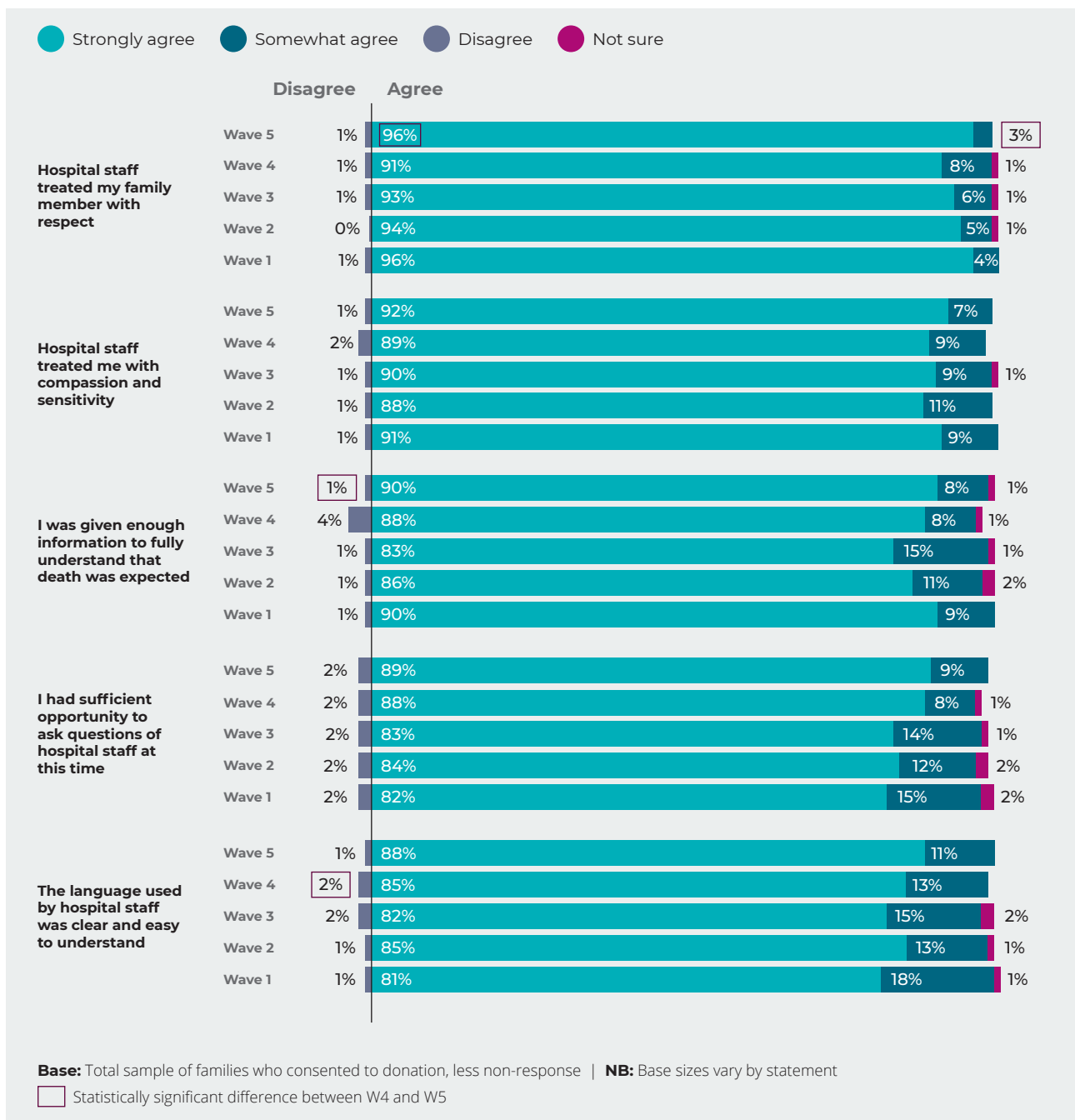
The findings show that helping families understand that their family member will not recover requires clear, concise, and consistent communication and information from hospital staff, delivered with authenticity, compassion and empathy.

7.2.2 Treatment of families

Depending on the circumstances of each patient, hospital staff may have discussed with family members either testing for brain death or turning off the ventilator. When family members reflected on that specific time in hospital, the majority who consented to donation (98%) felt they were given sufficient information to understand that death was expected.

While most of the five constructs measured have remained consistent over time (Figure 14), more families in 2018 and 2019 felt that hospital staff treated their family member with respect (up significantly from 91% to 96% strongly agreed).

Figure 14 Treatment of consenting families by hospital staff



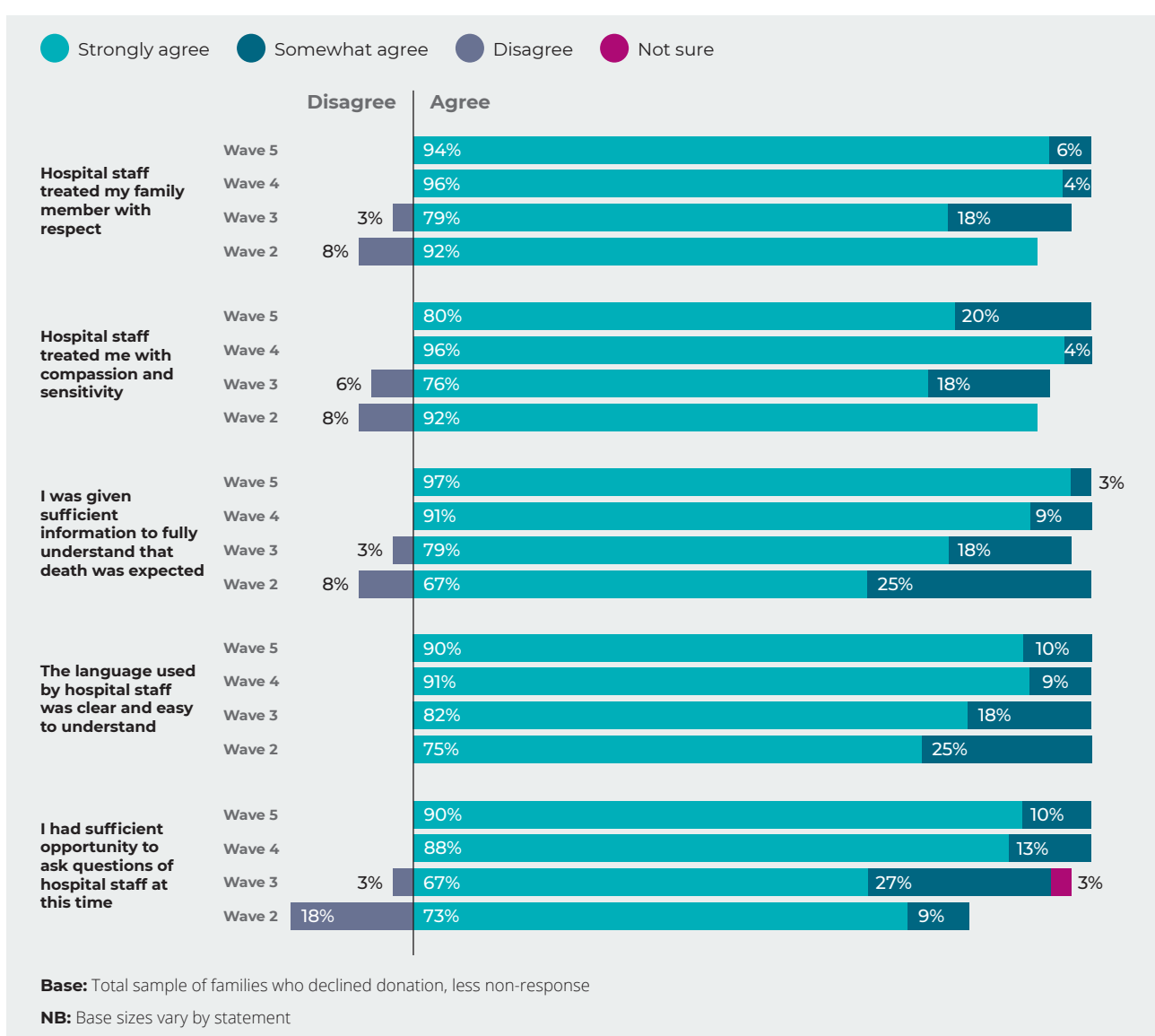
Looking at families participating in the study who declined donation (Figure 15), 94% felt that hospital staff treated their family member with respect, consistent with Wave 4 findings. Eight in 10 (80%) family members who declined donation strongly agreed that they themselves were treated with compassion and sensitivity. There is some room to improve in this area, and again, we see inconsistencies in how families are treated.

“ The ICU nurses were amazing, compassionate and caring. The Neurologist was heartless.”

2019 – Declined donation

In terms of the language used by hospital staff, findings are consistent with Wave 4 in that 90% of families who declined donation strongly agreed that the language used was clear and easy to understand; 10% somewhat agreed. The study continues to show the importance of utilising language that is clear and easy to understand for families.

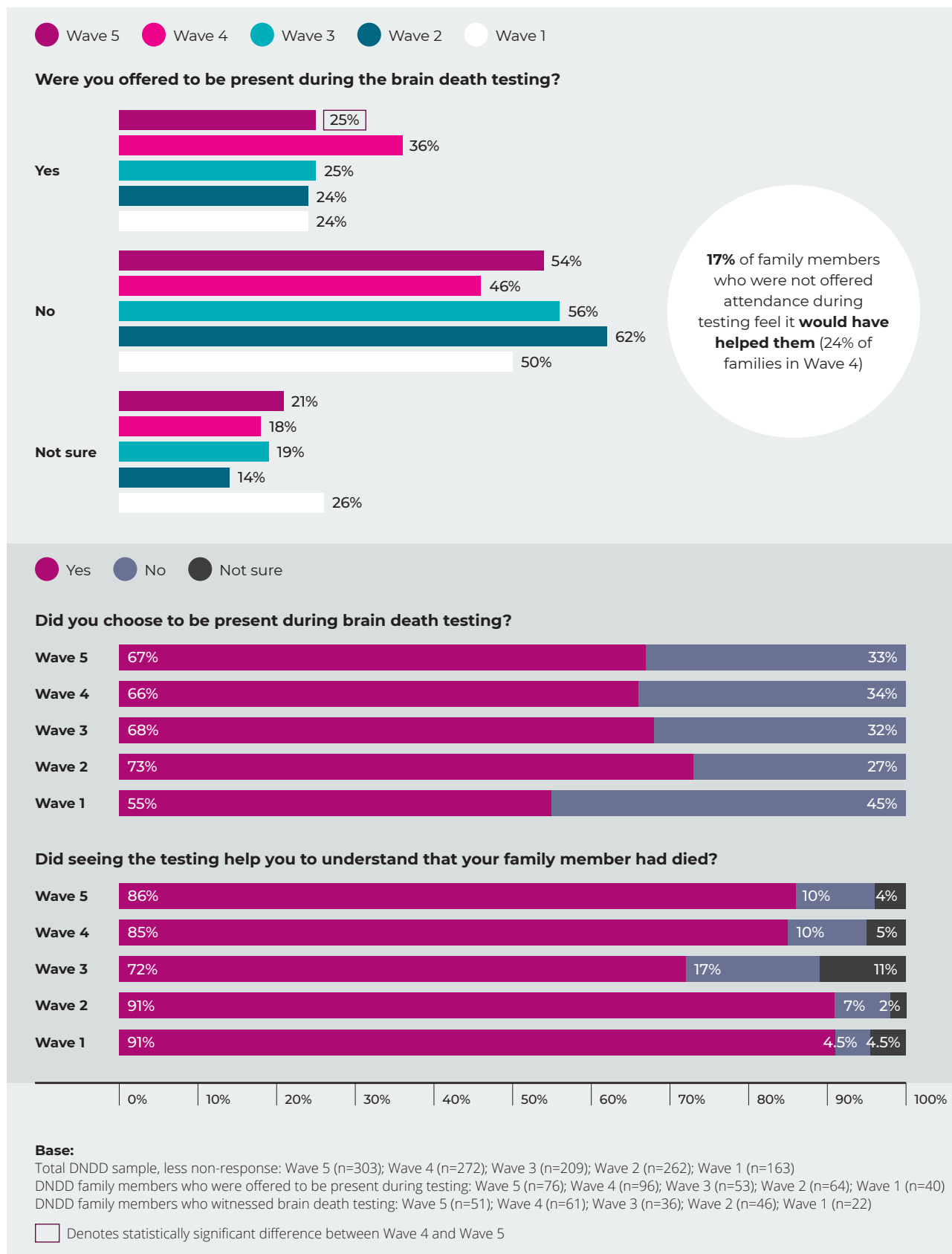
Figure 15 Treatment of families who declined donation by hospital staff



7.3 Brain death testing

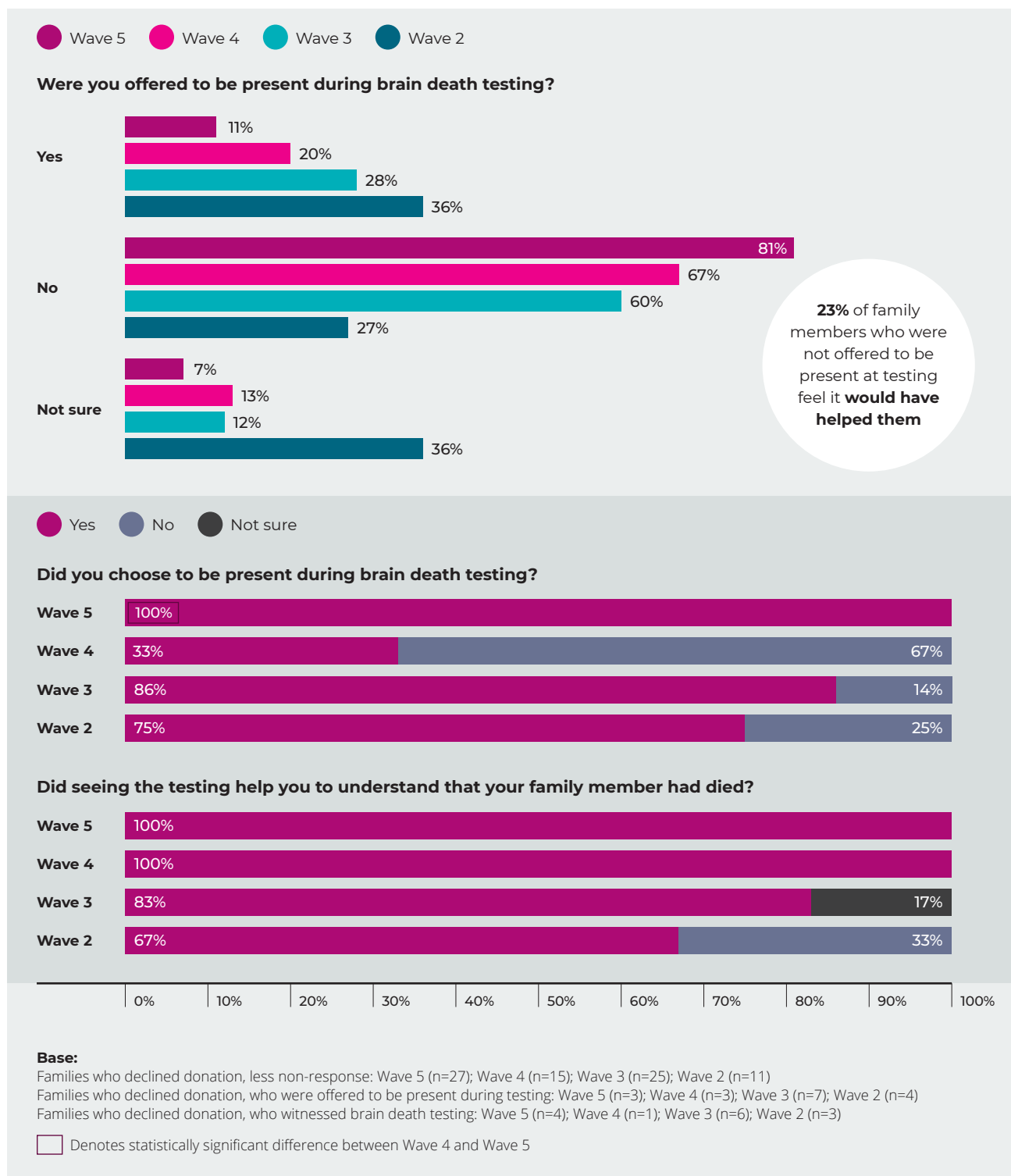
During 2018 and 2019, 25% of family members who experienced the brain death pathway, were asked if they would like to be present during the brain death testing of their family member. This is a significant decrease since Wave 4, when 36% of family members were given this opportunity (Figure 16).

Figure 16 Brain death testing – Consenting families



Among families who declined donation, only 3 families (11%) were asked if they would like to be present during brain death testing (Figure 17).

Figure 17 Brain death testing – Declining families



7.3.1 Impact of witnessing brain death testing

Of families who consented to donation who were invited to attend the testing, 67% opted to be present, consistent with previous research waves. Of those families who chose to be present, 86% felt that it provided clarity by helping them to understand that their family member had died.

“ The ‘proof of life’ from the brain death test was an extremely important experience for me.”
2019 – Consented to donation

“ Because I am a layperson, I always thought that while the heart pumps, the person is alive, but they’re not. I mean I didn’t realise that, and that’s what was hard for me and my kids.”
2019 – Consented to donation

Although base sizes are small, all declining family members in the study who were asked if they would like to be present, plus one family member who was not asked but requested to attend testing, chose to be present (Figure 17). All of these family members report that witnessing the testing helped them to understand that their family member had died. This understanding and acceptance of death is a necessary precursor to considering donation.

“ My daughters sat in on the test. I didn’t want to. They wanted to be absolutely positively sure before we take that responsibility and turn the machine off.”
2019 – Consented to donation

Feedback from families indicates that witnessing brain death testing on a family member is incredibly difficult and can cause stress. Fully informing family members about the testing procedure and purpose of the tests before they make the decision to be present was reported by participants as vital to their ability to understand and cope during the testing. Findings also show that family members present should be emotionally supported during the procedure.

“ The nursing and medical staff explained everything and so we understood each element of the testing. It was emotionally difficult.”
2019 – Intended to donate

7.3.2 Impact of not witnessing brain death testing

Of families who experienced the brain death pathway, approximately half (54%) of family members who consented to donation and 81% of family members who declined donation, were not given an opportunity to attend the brain death testing of their family member (Figures 16 and 17 respectively). On reflection, many of these families are okay with this, but some families (17% of those who consented and 23% of families who declined donation) felt it would have been beneficial for them to witness the tests.

“ I think if I had been present at the testing it would have placed me in no doubt over the 11 days he was on life support that his death was imminent.”
2018 – Consented to donation

“ I was not offered the opportunity to be present during the brain death testing and was not aware that it was an option until this survey. I would have appreciated having the choice regardless of if I agreed or not. I do think that if I had been allowed to be present, it would have offered another level of closure and acceptance of the situation.”
2019 – Consented to donation

7.3.3 The process of brain death testing

Family members were asked if they would like to make any comments about the process of brain death testing. Comments have been coded into like themes and are detailed in Table 16.

In total, 108 family members who experienced the DNDD pathway commented about brain death testing. Eighteen percent (18%) stated that the process was clearly explained to them, while a similar proportion (15%) had a different experience and feel that greater explanation was needed at the time.

“ I found it would have been easier to have the tests explained in more detail. I found them so ‘basic’ that it made me mad knowing there is so much technology around that more technology should have been used, but now I understand a bit better.”

2019 – Consented to donation

Table 16 Family comments about brain death testing

Would you like to add anything else about the process of brain death testing?	Wave 5 DNDD (n=108)
Brain death testing process was clearly explained / staff were informative	18%
More information and explanation was needed / still have unanswered questions	15%
Was not given the option to attend / had to request to see evidence of brain death	11%
Witnessing testing provided certainty and closure / helped us to make decisions	10%
No need to be present because we already understood family member was brain dead	10%
Staff were considerate/compassionate/professional	9%
Had full trust in the hospital staff / trusted Doctors	7%
Family members should be given the choice to be present / it's necessary to be there / would have liked to be there to help accept death	6%
Was shown brain scan / told results of brain scan	6%
Witnessing testing was traumatic/overwhelming/emotionally difficult	6%
Am medically trained and understood process	5%
Still have doubts about testing and prognosis	5%
Other family members attended the testing	4%
Did not wish to be present / could not face reality of testing and family member's death	4%
Doctor lacked empathy / doctor was blunt / doctor did not treat family member with respect	3%
Don't know if brain death testing took place / not aware of the testing/ process	3%
Testing was basic and 'primitive' which caused concern	2%
Hospital staff suggested we do not attend brain death testing due to it being confronting	2%

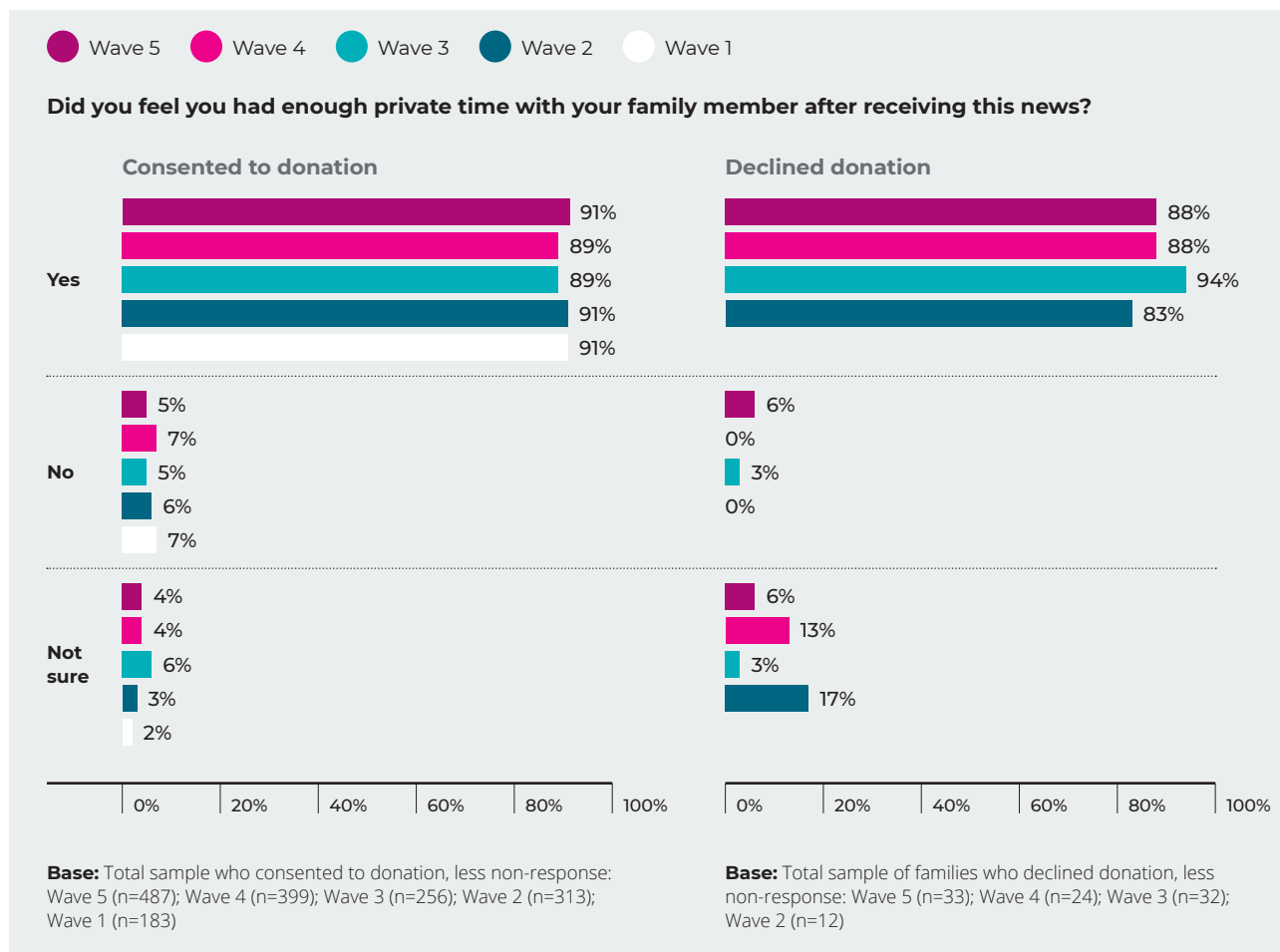
The study found that not every family member feels the need to witness brain death testing. However, so that families can make an informed decision, an explanation of the tests (written or verbal) should be provided, and all families should be given an opportunity to attend.

Findings suggest family members who choose to attend should be emotionally supported by hospital staff during testing.

7.4 Time with family member post-prognosis

In 9 out of 10 instances, family members 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. This is consistent amongst families who consented to donation (91%) and those who declined donation (88%), as shown in Figure 18.

Figure 18 Amount of private time with family member post prognosis



Five percent (5%) of family members who consented to donation and 6% of those who declined donation, felt that they did not have enough private time with their family member after receiving news that they would not survive.

“ I asked numerous times to see my sister and each time was told ‘in about 15 minutes’. I waited nearly 2 hours at the end of the day to see her to say goodbye before I went home for the night.”

2019 – Consented to donation

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

“ The hospital and the ICU boss were great. They set aside a separate private room so we could spend as long as we wanted with our brother.”

2019 – Consented to donation

7.5 Improving the hospital experience

Family members who took part in the survey 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 17. As shown, 43% of families who consented to donation and 30% of those who declined donation felt that nothing more could have been done to ease the hospital experience. Further, 53% of families who consented to donation and 26% of declining family members talk positively about hospital and DonateLife staff, a significant increase among consenting family members since Wave 4.

“ We have nothing but high praise for our team. They were amazing with our family and treated our son with the utmost respect and care. The team were very attentive of our feelings and sadness. Absolutely wonderful!”

2018 – Consented to donation

“ I was not at the hospital as I live in New Zealand, but was included in phone conversations with family and hospital. Hospital staff were very supportive and sensitive.”

2018 – Consented to donation

Table 17 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?	Consented to Donation		Declined Donation	
	Wave 4 (n=298)	Wave 5 (n=328)	Wave 4 (n=15)	Wave 5 (n=23)
Nothing more could have been done / handled well	40%	43%	47% (n=7)	30% (n=7)
NET: Positive comments about hospital and DonateLife staff	36%	53%	13%	26%
• Positive comment about ICU / hospital staff (amazing, caring, respectful, kind, supportive, compassionate, informative)	36%	34%	13% (n=2)	13% (n=3)
• Positive comment about DonateLife staff (caring, kind, respectful, compassionate, informative)	–	3%	–	–
• Positive comment about social worker/ chaplain (supportive, helpful, compassionate)	–	2%	–	4% (n=1)
• Positive comment about staff (staff member unspecified) (supportive, helpful, kind, amazing)	–	18%	–	9% (n=2)
More empathy and kindness from hospital staff towards us and our family member	7%	7%	7% (n=1)	4% (n=1)
More privacy (private room) for – being with family member / receiving information / family discussions	6%	3%	20% (n=3)	9% (n=2)
Family comfort – more seating / somewhere to sleep / somewhere to shower / better provisions in the family/waiting room	5%	2%	–	4% (n=1)
More time with family member / felt rushed / felt pressured	4%	5%	–	22% (n=5)
More accurate time frame estimations – prolonged experience or not as much time as expected	3%	5%	–	–
More support provided – counsellor / social worker	2%	2%	–	–
Less paperwork / fewer meetings / fewer unnecessary and confronting questions and repetition	2%	2%	–	–

Overall, how could your experience at the hospital at this time have been made easier for you and your family?	Consented to Donation		Declined Donation	
	Wave 4 (n=298)	Wave 5 (n=328)	Wave 4 (n=15)	Wave 5 (n=23)
Improve the approach to organ donation (timing of discussion, how donation is first mentioned, who is present in the room, sensitivity regarding children)	–	2%	–	–
Too expensive – hospital parking / accommodation / meals	2%	–	–	–
NET: Better and clearer communication	6%	9%	7%	17%
• Better communication amongst staff / doctors gave conflicting information / information not passed on during change of shift	2%	1%	–	13% (n=3)
• Regular updates / clearer information / more opportunities to ask questions / explain things in layman's terms	4%	8%	7% (n=1)	4% (n=1)
Allow more family members into the ICU at the same time	1%	1%	7% (n=1)	–
Wish to have been allowed to be present during tests / during passing	1%	1%	7% (n=1)	4% (n=1)
More time given for family discussions	0.3%	1%	–	–
Negative comment about staff, including being pressured into donation / lack of communication from DL staff / not involving certain next of kin in discussions / unaware of boundaries	–	3%	–	22% (n=5)
Other	6%	6%	13% (n=2)	13% (n=3)

□ Significantly lower than Wave 4 □ Significantly higher than Wave 4

The Donor Family Study highlighted key areas that could improve the hospital experience, including:

a Greater empathy and kindness from hospital staff:

“Nurses expressing their personal views on our decision to stop treatment due to their faith, is not something that should have happened.”

2019 – Intended to donate

b More privacy (for family discussions, with family members and to receive updates):

“The ICU by its very nature is a traumatic place. I wish I could have had time in a quiet room just with my daughter and not feel like I was in a hospital. It made the pain a bit worse.”

2019 – Consented to donation

c Improved environment for the family's comfort:

“A comfortable mourning room instead of a corridor.”

2019 – Consented to donation

d Regular updates and clearer communication:

“I feel that clear and easy to understand language needs to be used so that teenagers of the family member can fully understand and realise the outcomes.”

2019 – Consented to donation

“I appreciate it's very hard to keep to scheduled meetings in an ICU setting, but long wait times and not knowing when the doctor would be free to talk was hard.”

2018 – Consented to donation

e Not feeling rushed or pressured into making a decision about donation:

“ For Mum to have been allowed to spend time with Dad without continuously being approached by the doctor about whether she would agree to donation or not.”

2018 – Declined donation

The key things highlighted from the study that families need from hospital staff are:

- **Clarity** of information
- **Consistency** of information
- **Compassion** and understanding from all hospital staff
- **Time** to absorb the information
- **Privacy** with family member and family and a private room for family meetings

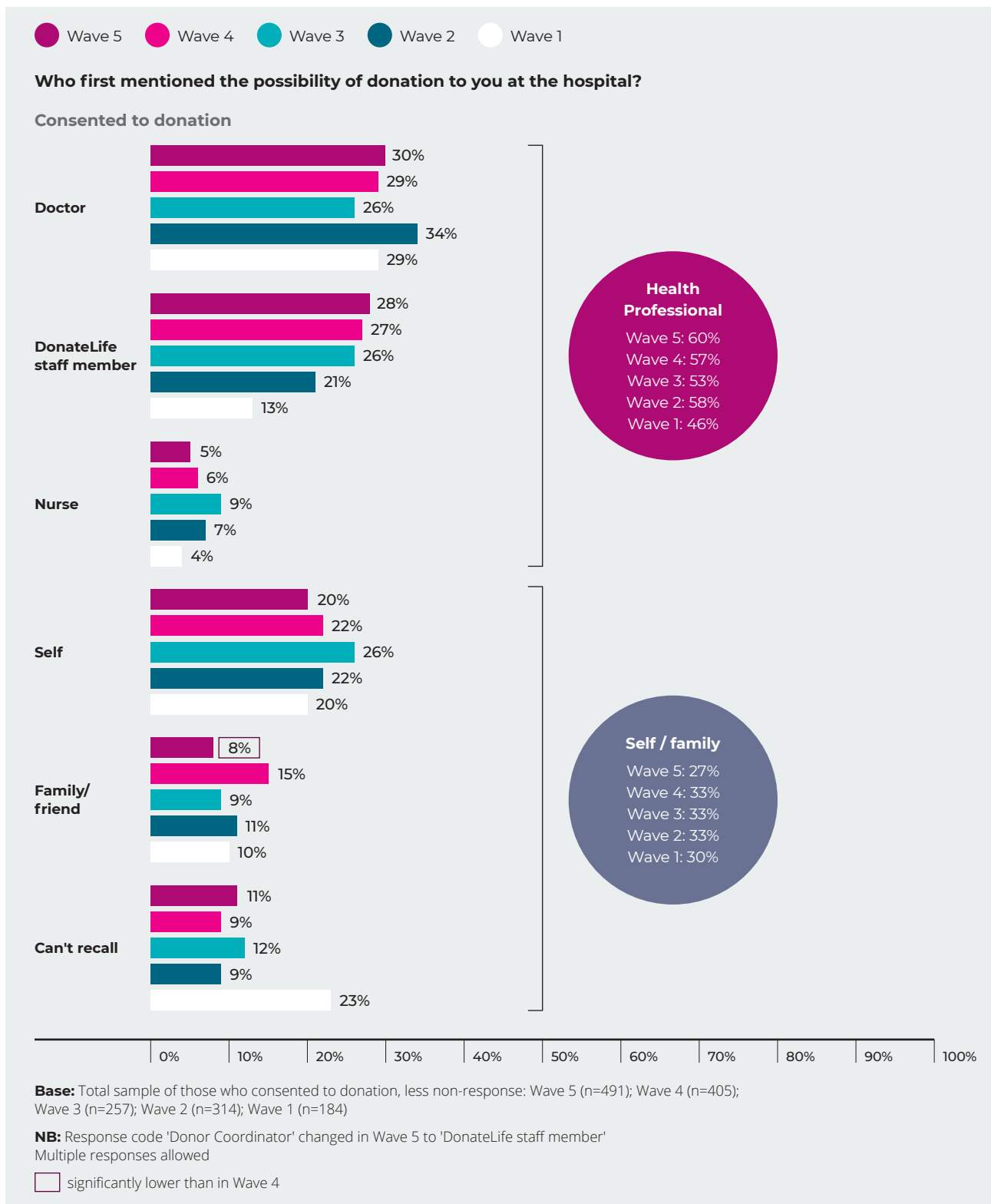
In addition, that consideration should always be given to the emotional wellbeing and physical comfort of family members during their loved one's stay in hospital.

8 The donation conversation

8.1 Instigating the donation conversation

The findings show that the possibility of donation continues to be primarily raised by health professionals (60% amongst consenting families; consistent with Wave 4). Figure 19 shows in 2018 and 2019, the donation conversation was instigated by a doctor in 30% of cases, a DonateLife staff member in 28%, and by a nurse in 5% of cases.

Figure 19 Who instigated the donation conversation – Consented to donation



For the 60% of consenting family members who were asked about donation by health professionals, including doctors, nurses and DonateLife staff members, families were sensitive to:

- Who raised the subject of donation (i.e. a doctor or DonateLife staff member) and who was in the room
- The timing of the conversation
- The approach and tone of staff

Once family members knew that their family member had died or would soon die, some thought about donation, raised it with their family, and then raised the subject with health professionals.

“ I knew she wouldn't survive her injury so I made sure the staff knew of our wishes to donate.”

2018 – Intended to donate

As shown in Figure 19, these families represent 27% of consenting donor family members. This is consistent with previous waves. Typically, family members in the study, who raised donation themselves had discussed donation with their family member (69%), and/or were searching for something positive to come out of the tragedy (83%). Donation gave them this.

“ Receiving such horrible news, we also saw the positive he could do donating; he would live on and help someone else.”

2019 – Consented to donation

Table 18 shows who instigated the donation conversation across waves and by donation pathway, for families who consented to donation. There are no significant differences between pathways in the proportion of conversations raised by a health professional (61% in DNDD cases; 57% in DCDD cases). In the case of DNDD, fewer family members instigated the donation conversation during 2018 and 2019 than in previous years (27% vs. 35% in Wave 4).

Table 18 Donation conversation instigator by donation pathway (over time) – Consented to donation

Who first mentioned the possibility of donation to you at the hospital?	W1 DNDD (n=164)	W1 DCDD (n=20)	W2 DNDD (n=276)	W2 DCDD (n=38)	W3 DNDD (n=219)	W3 DCDD (n=38)	W4 DNDD (n=278)	W4 DCDD (n=127)	W5 DNDD (n=311)	W5 DCDD (n=157)
Doctor	31%	10%	34%	37%	25%	29%	31%	26%	31%	28%
Nurse	4%	5%	6%	13%	8%	16%	5%	6%	5%	6%
DonateLife staff	12%	20%	21%	18%	26%	24%	24%	31%	28%	28%
Total health professional	47%	35%	57%	61%	52%	61%	56%	57%	61%	57%
Family / friend	10%	10%	12%	8%	10%	3%	16%	12%	10% ▼	4% ▼
Self	19%	30%	22%	24%	26%	29%	23%	20%	17%	26%
Total family/self	30%	40%	33%	32%	35%	26%	35%	29%	27% ▼	30%
Can't recall	23%	25%	9%	8%	12%	8%	8%	13%	11%	13%

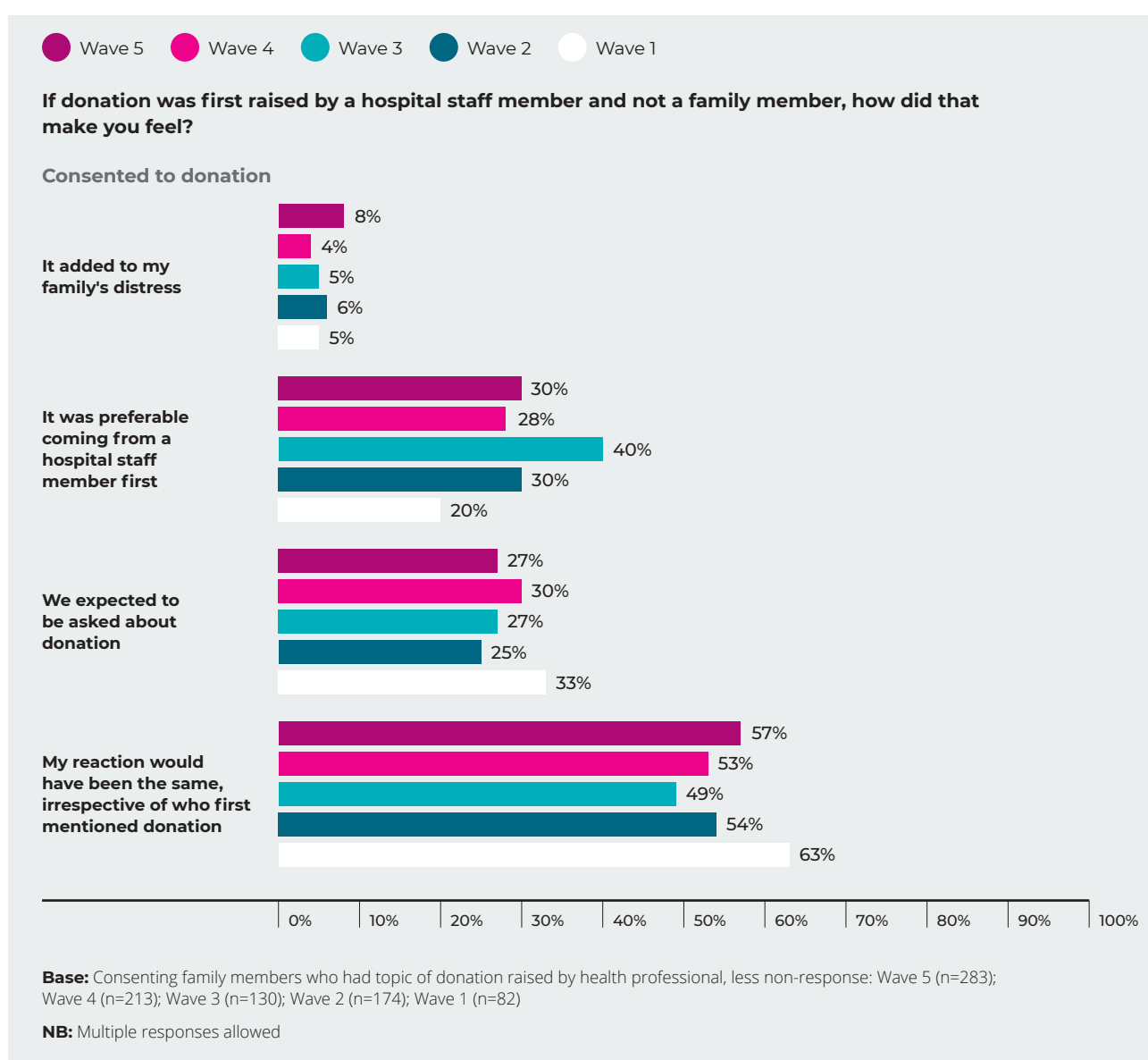
NB: Data in table represents the views of all family members who consented to donation, rather than family units (to be consistent with the way the question was measured in 2004 and 2008).

□ Denotes statistically significant difference between pathway within Wave 5

▲▼ Denotes a significant increase or decrease since Wave 4 within each pathway

Amongst families where donation was initially raised by a health professional, 27% say that they expected to be asked about donation, consistent with Wave 4 findings (Figure 20).

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



Just 8% of donor family members felt that being asked about donation by a health professional added to their family's distress (Figure 20). Looking specifically at these families, the distress was brought on not so much by the fact that the conversation was raised by a health professional in the first place, but by a combination of *when* it was raised, *how* it was raised and *by whom*.

“ I wanted a bit more time to come to terms with the situation.”

2019 – Consented to donation

“ At the time it made me angry. I was told nothing could be done and that he would be taken off life support. Asking if he was a donor could have waited. It was hard to comprehend the information.”

2018 – Consented to donation

Looking now at families who declined donation, 71% of donation conversations were initiated by a health professional, consistent with Wave 4 findings (Figure 21). Although this figure is higher than reported amongst families who consented to donation, the difference is not statistically significant.

Figure 21 Who instigated the donation conversation – Declined donation

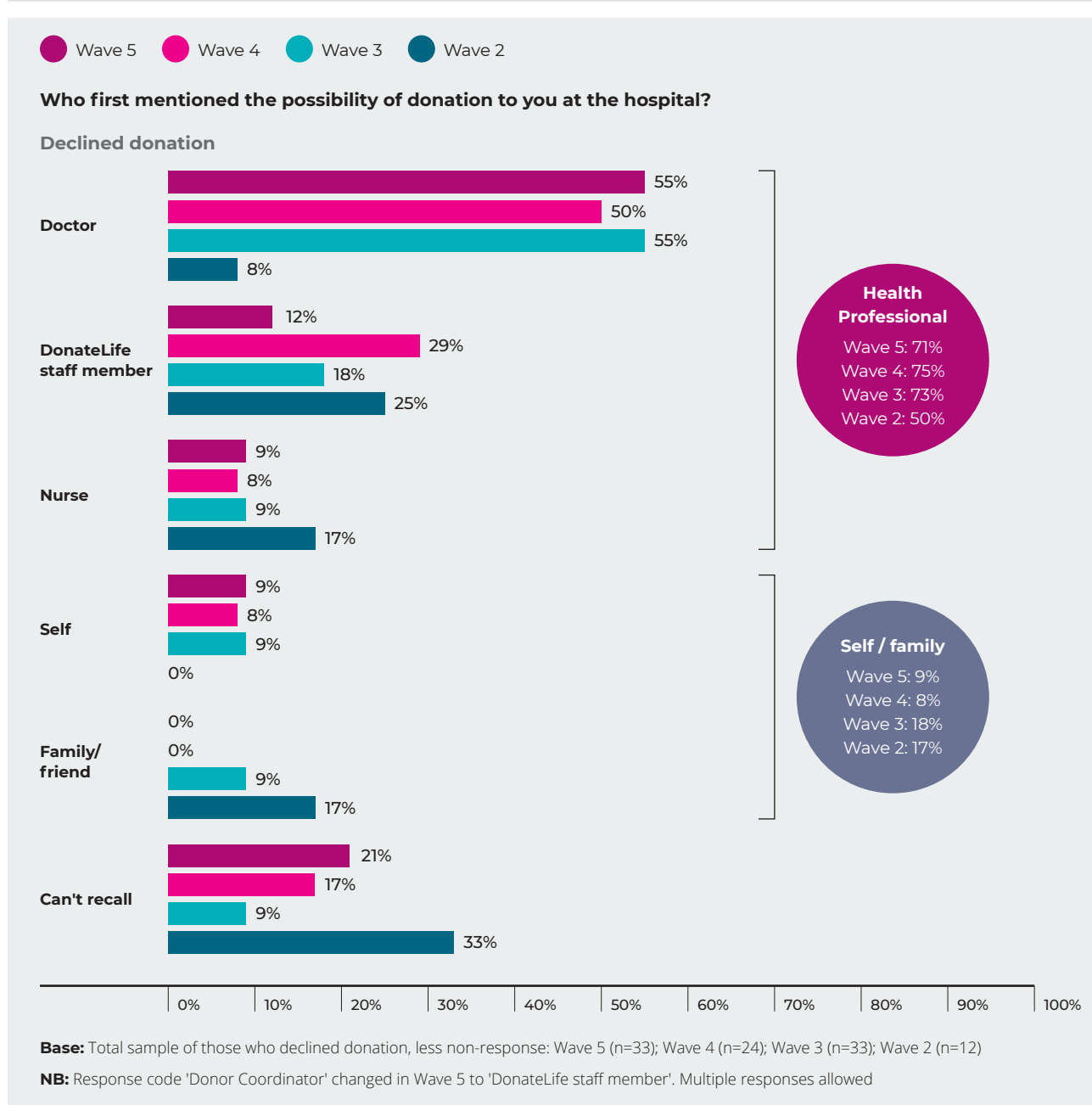
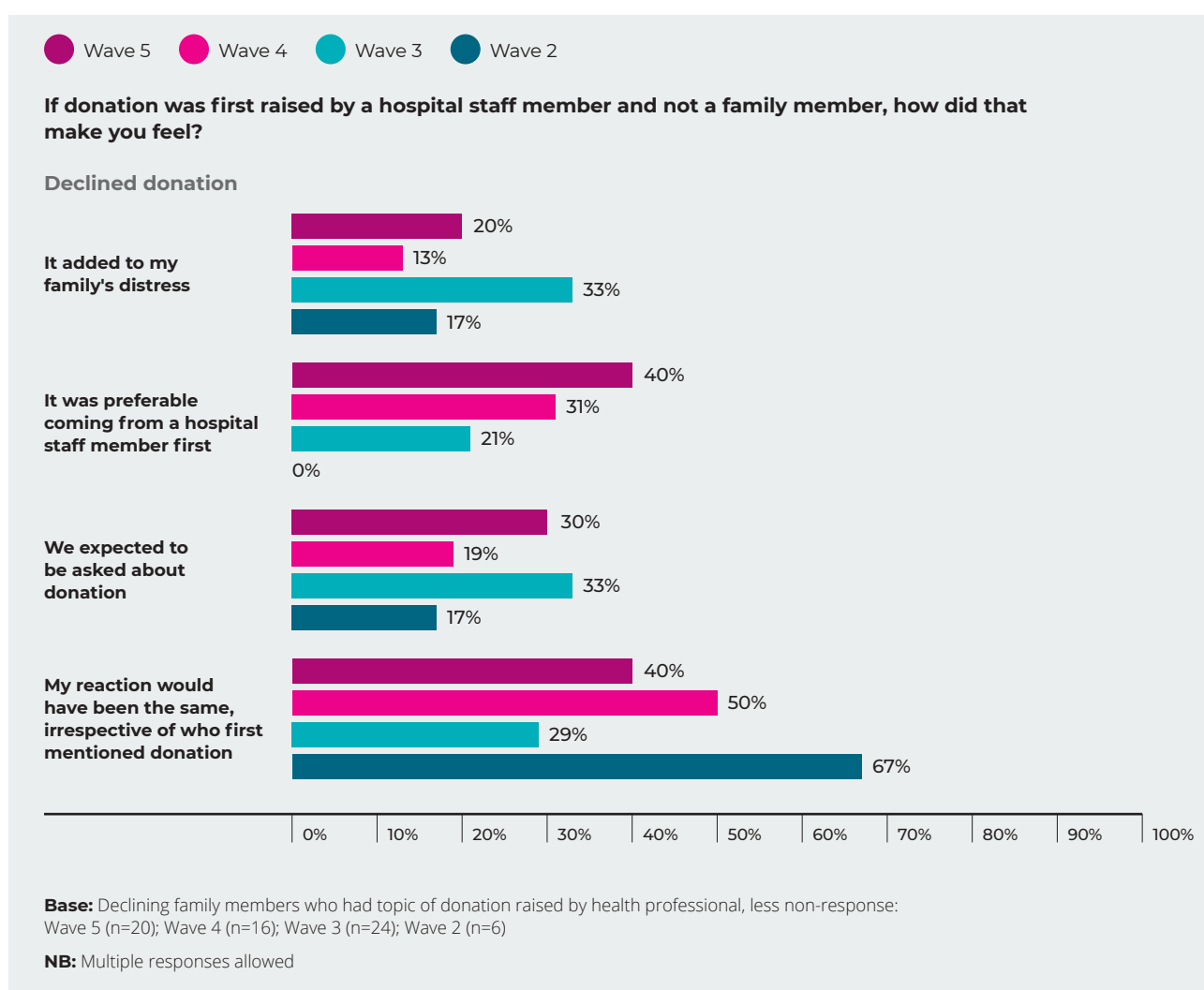


Figure 22 shows that 20% of families who declined donation felt that the donation conversation being instigated by a health professional added to their distress, while 30% expected to be asked about donation.

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



Consistent with families who consented to donation, those who declined donation who were initially approached by a health professional were also sensitive to the way in which the conversation was instigated. This includes the timing, the approach, and who is in the room at that time.

“ Over the day I was approached 4 times by 4 different staff members.”
2018 – Declined donation

8.1.1 Who is in the room

Findings from the Donor Family Study suggest that families are more receptive to the donation conversation when the following steps are taken:

- 1 The donation conversation is raised *after* news of the patient's prognosis has been clearly communicated to families and families are given time to absorb the information (further demonstrated in Section 8.2).
- 2 If donation is something the family will consider, they are asked if they would like to talk about this end-of-life option further.
- 3 Only then should the family be approached to discuss the process.

In essence, the conversation should be de-coupled – one family meeting to advise of the prognosis, and a subsequent family meeting to discuss end-of-life options, which include organ donation.

The following comments from family members who consented to and declined donation demonstrate the effectiveness of this approach.

“ We got over the initial shock and then we started to deal with it and realised that she wasn't going to come back. And then the doctor came and saw us and asked us if we were prepared to speak to the DonateLife people. They said they'll make arrangements for somebody from DonateLife to come and speak to us and go through what it was all about.”

2019 – Consented to donation

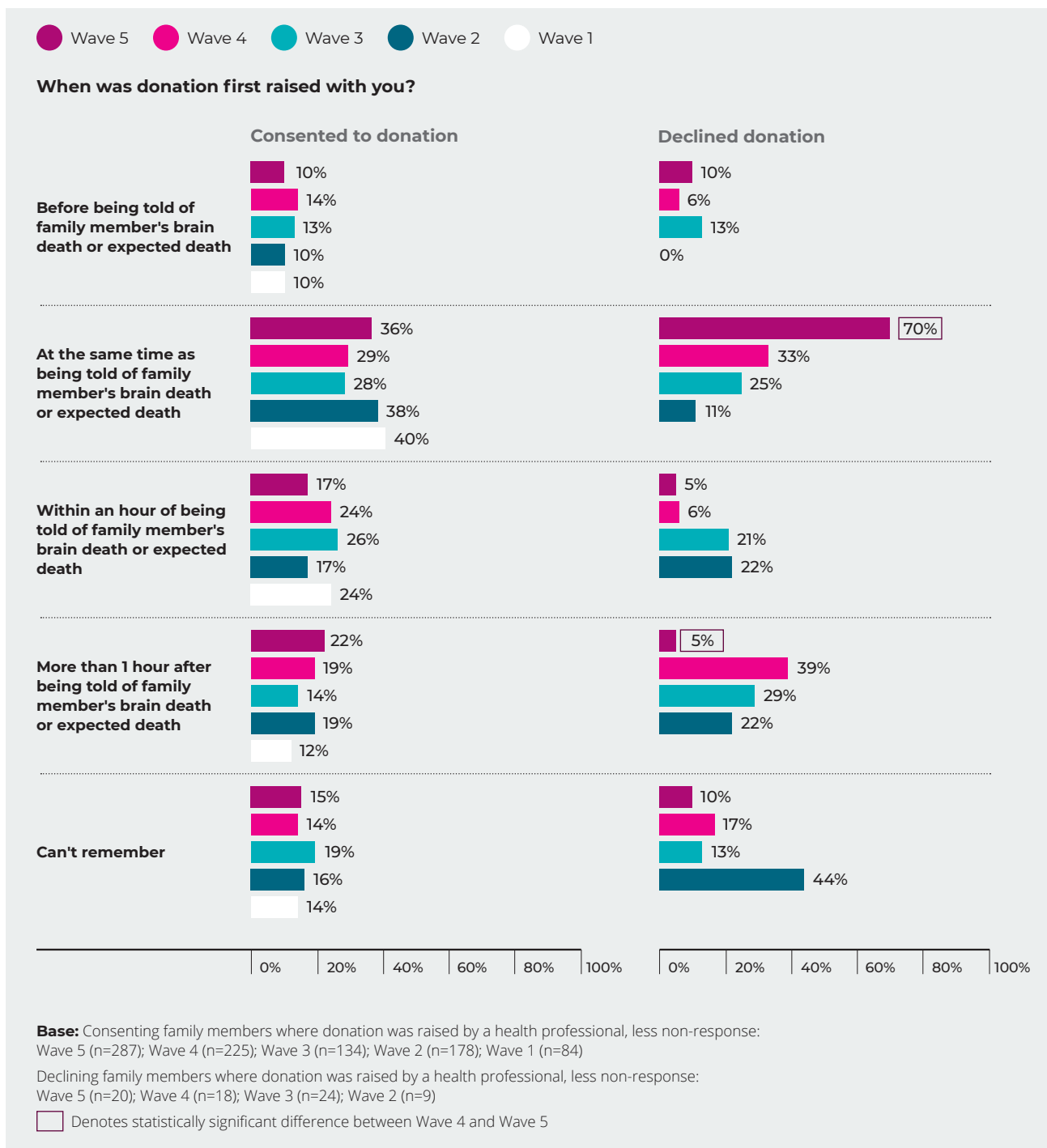
“ At the time I assumed I was finding out what the outcome of the brain test was. Instead, we were introduced to the donation people before even been told the results. During the conversation I was told I had 3 hours to make a decision. On day 1 I saw 3 different staff members from organ donation”

2019 – Declined donation

8.2 Timing of the donation conversation

In 2018 and 2019, 46% of consenting family members surveyed, were asked about donation by a health professional *before* (10%) or *at the same time* (36%) as being told of their family member's brain death or expected death. This is consistent with previous years, yet is a practice that families over time have been disappointed with. Amongst the families surveyed who declined donation, 80% were asked to consider donation at the same time or before being told of their family member's prognosis (Figure 23).

Figure 23 Timing of the donation conversation



As previously stated, findings indicate that families are much more receptive to being asked to consider donation after they have had time to accept that their family member is not going to recover.

“After being told there was nothing they could do for him and then a minute later being asked if he was a donor. That could have waited until my brain had processed the initial information.”

2018 – Consented to donation

“The doctor and the DonateLife staff member came in together to discuss the situation. It was totally inappropriate discussing turning off life support and donation in same meeting.”

2018 – Consented to donation

Table 19 details the findings regarding the timing of the donation conversation when instigated by a health professional, across states/territories. Although figures vary, any differences between states/territories are not significant. This means that throughout Australia, during 2018 and 2019, the donation conversation was instigated *before* or at the *same time* as the news of death/ impending death in 46% of cases and after the bad news was delivered in 39% of cases.

“They only spoke to us about donation at same time as discussion about extubation.”

2018 – Declined donation

“It was a discussion that was had after it was very clear that Dad was not going to survive.”

2018 – Consented to donation

Table 19 Timing of the donation conversation (consented to donation), by state/territory

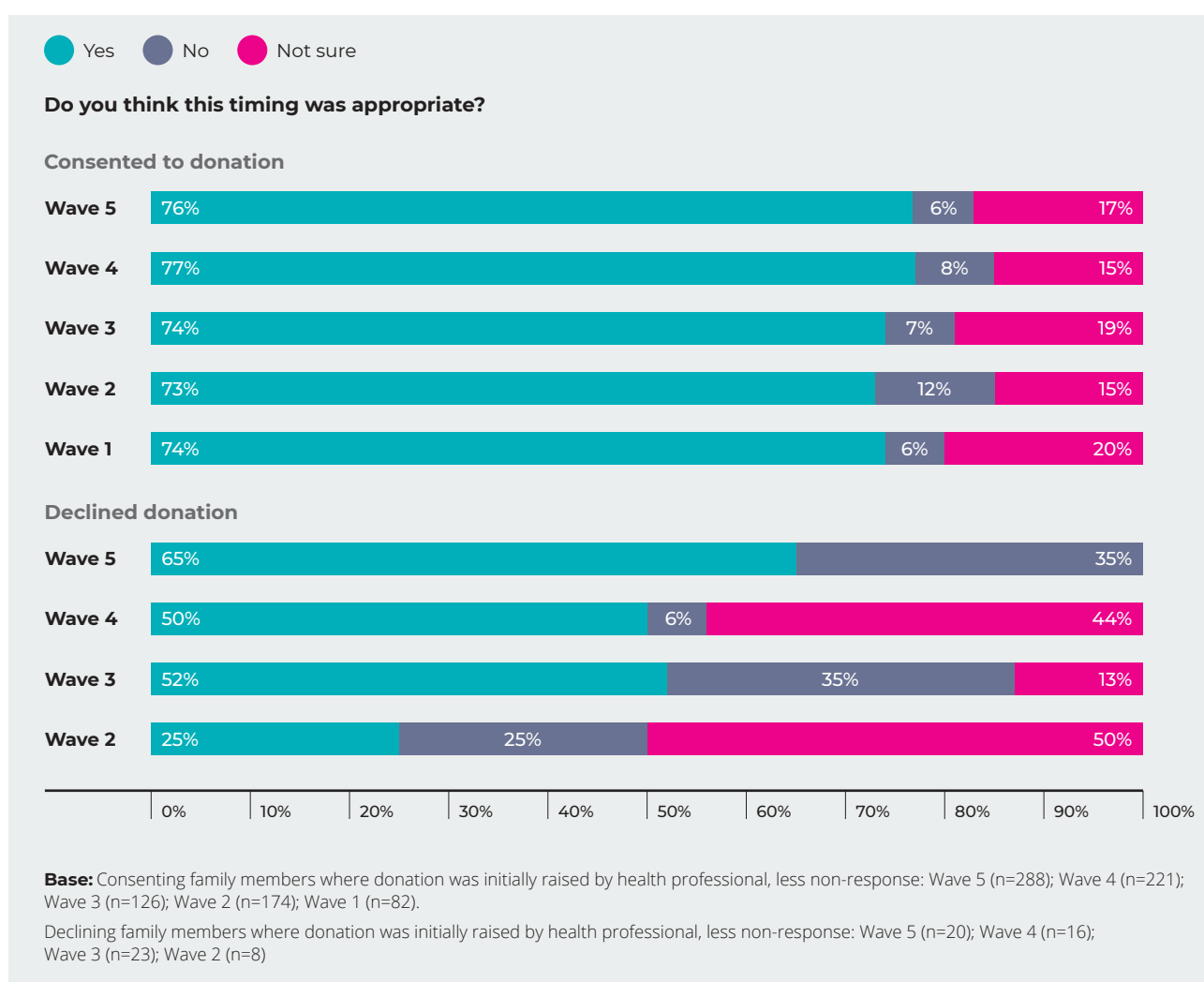
When raised by a health professional	Total (n=287)	QLD (n=60)	ACT (n=4)*	NSW (n=97)	VIC (n=77)	NT (n=3)*	WA (n=18)*	SA (n=12)*	TAS (n=16)*
Before	10%	13%	–	11%	4%	–	11%	17%	19%
At same time	36%	27%	50%	33%	42%	67%	50%	42%	38%
Before/same time as bad news delivered	46%	40%	50%	44%	45%	67%	61%	58%	56%
Within an hour	17%	20%	–	16%	18%	–	6%	25%	13%
More than an hour	22%	27%	25%	22%	19%	33%	28%	8%	25%
After bad news delivered	39%	47%	25%	38%	38%	33%	34%	33%	38%
Can't recall	15%	13%	25%	18%	17%	–	6%	8%	6%

* Caution: small base

NB: Sub-totals may not add to totals due to rounding

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 surveyed felt that the timing of the approach by health professionals was appropriate; 17% were not sure and 6% felt the timing was inappropriate (Figure 24). These findings are consistent with previous waves.

Figure 24 Appropriateness of donation conversation timing



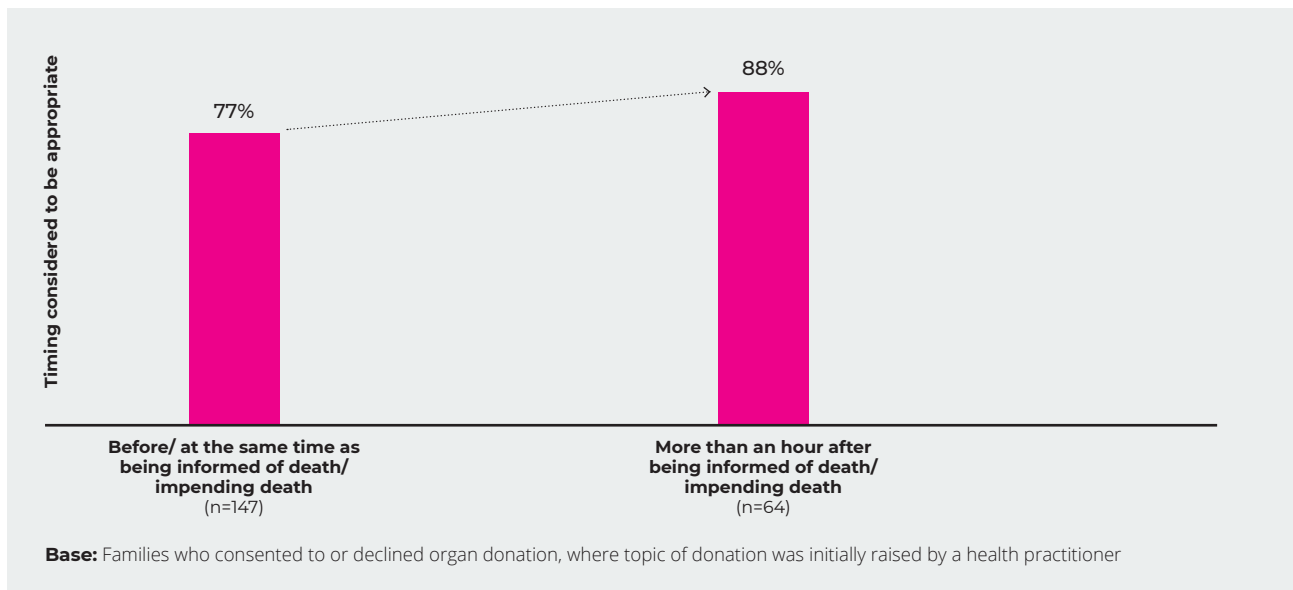
Families who declined donation were significantly more likely to feel that the timing of the donation request was inappropriate (35% compared to 6% of families who consented to donation). Mostly these families felt they needed more time to process the prognosis before they could absorb any other information.

“ We were not prepared that this would be asked at the meeting. They were quite insistent. After saying no, they still asked again.”

2018 – Declined donation

Figure 25 shows that when donation is raised by a health professional, the perceived appropriateness of the timing increases when families are given time to process the news of impending death or brain death of their family member. This has been a key finding of the Donor Family Study since Wave 1.

Figure 25 Appropriateness of timing when donation raised by health professional



“After the doctors tell you that your loved one is brain dead, they should let you process it. Then you should be given the choice if you would like to speak with the organ donation people.”

2019 – Declined donation

Consistent with previous waves, Wave 5 findings indicate that there is no golden rule for the best time to raise the topic of donation after the ‘bad news’ family meeting is held; rather medical staff are advised to use their judgement, allow some time for families to process the information and be guided by how family members are responding to news.

“It was important for me to understand and accept that there was zero medical chance that my husband could recover given more time and care in ICU. Once that fact was accepted, I then needed time to grieve with my child and we didn't get that time.”

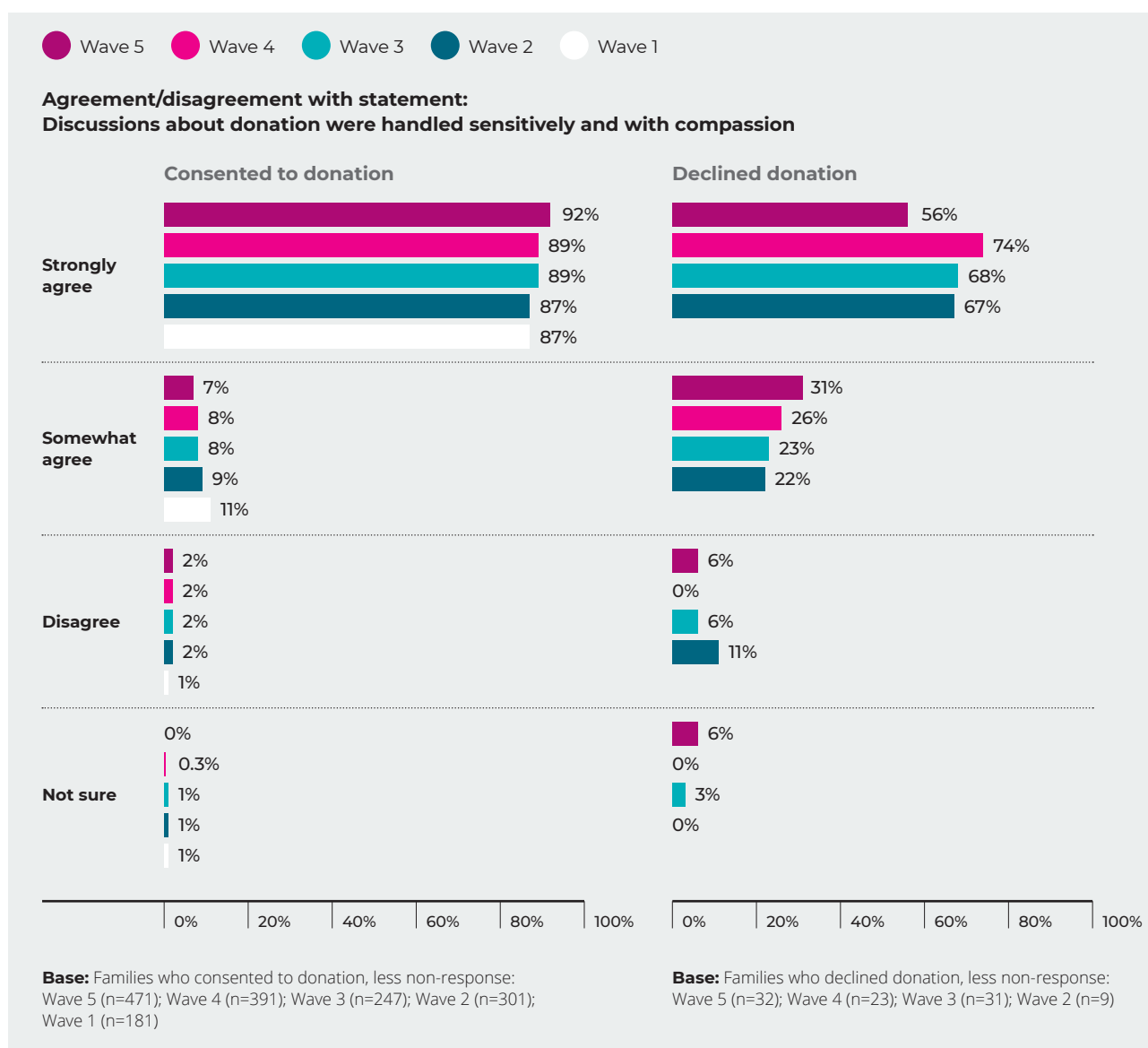
2019 – Consented to donation

Findings indicate that families are more likely to be receptive to the donation conversation when it is initiated some time after neurological death or impending death has been confirmed and understood by the family. Conversations should be separated and paced in line with the family’s needs.

8.3 Tone of conversation

In the majority of instances, family members who consented to donation felt that discussions about donation were handled sensitively and with compassion (92% of family members strongly agreed). This was significantly less so amongst families who declined donation (56% strongly agreed). Findings are consistent with previous waves (Figure 26).

Figure 26 Tone of donation conversation



When families feel that discussions about donation were not handled as well as they should have been, it tends to be about a combination of factors including *when* the conversation was raised, *who* instigated it, *how many* people were in the room, and whether families felt a sense of *pressure* and urgency.

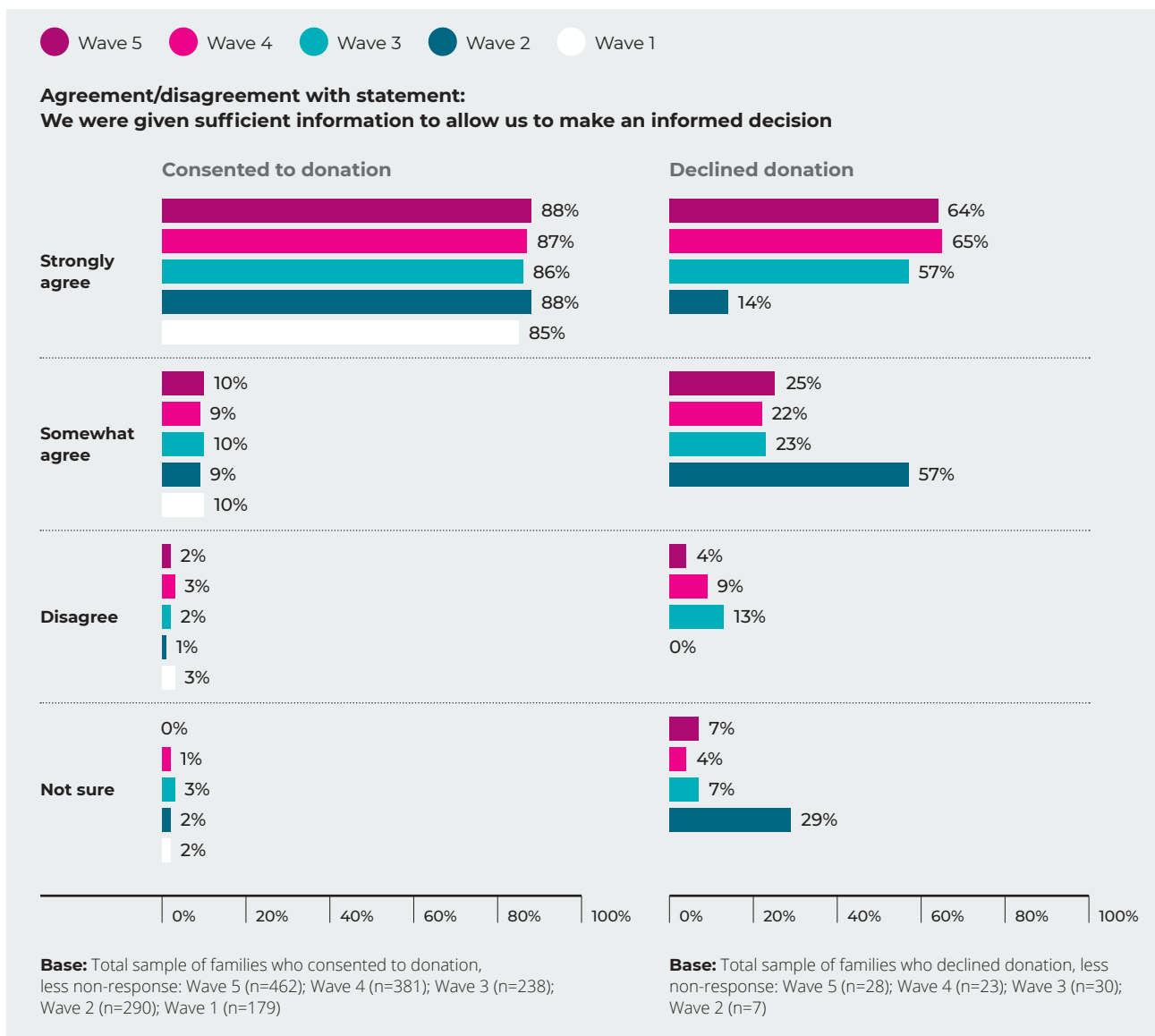
“ It was at the time when they said that there was no hope and that he won't recover. Five people came in at once and it was a bit overwhelming. Like, maybe one or two would have been better. And it wasn't the staff who were looking after him, it was different people...”

2018 – Declined donation

8.4 Information to enable an informed decision

With regards to making a decision about donation, 98% of family members who consented to donation agreed (88% strongly) that they were given sufficient information to allow them to make an informed decision (Figure 27); consistent with previous waves. Families who declined donation were significantly less likely to feel that they were given enough information to allow them to make an informed decision about donation (64% strongly agreed that they were).

Figure 27 Sufficient information to make an informed decision about donation

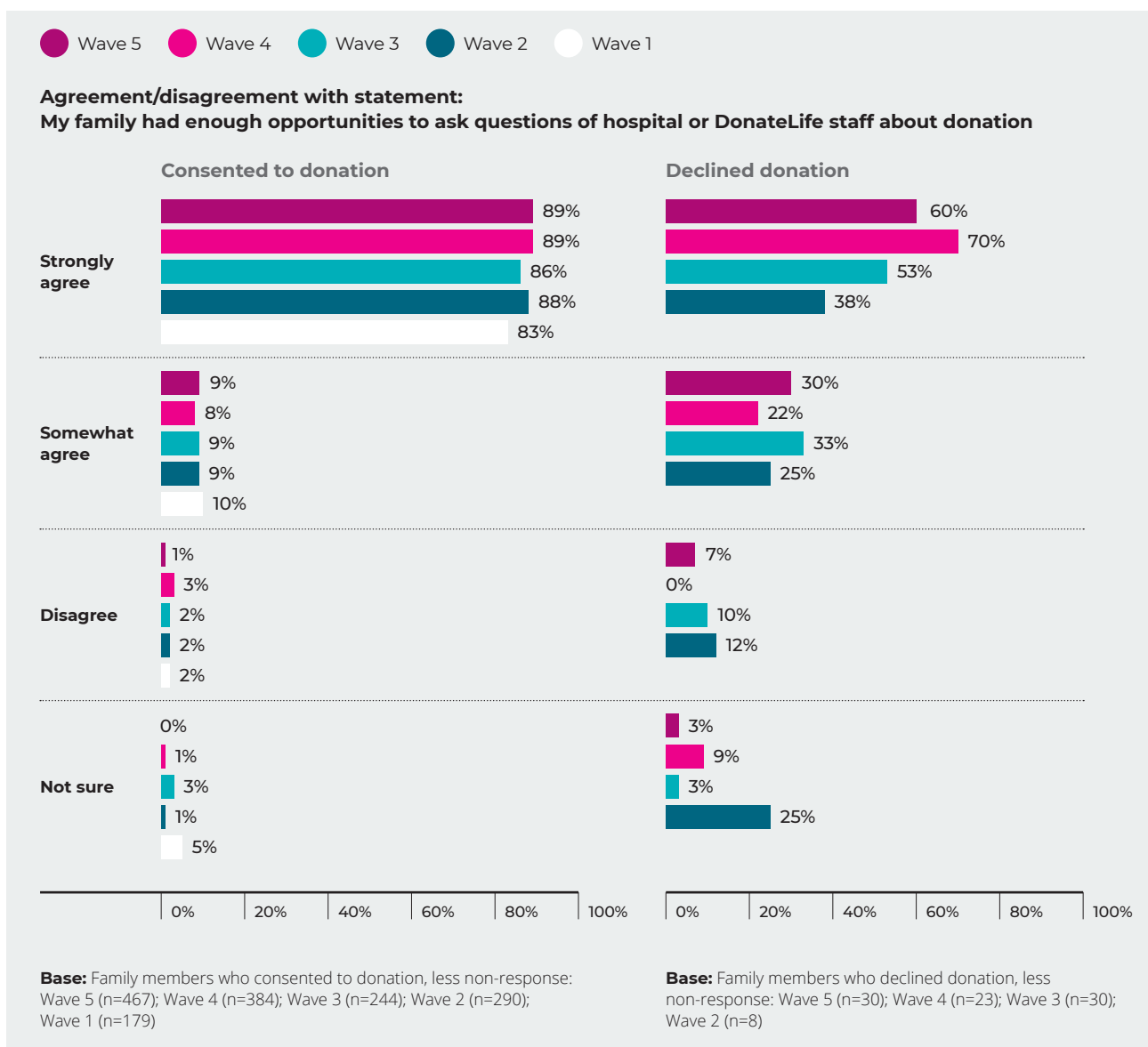


“ Donating was the best decision ever. The DonatLife Coordinator was so helpful and respectful. I received enough information before, during and after. The doctors made it very clear that the life of my partner was more important than organ donation, until there was no longer any hope. Even then a comfortable death was more important than organ donation. The teamwork, respect and empathy shown by everyone helped immensely during this horrible time.”

2018 – Consented to donation

Figure 28 shows that 89% of families who consented to donation in 2018 and 2019 strongly agreed that their family was provided with enough opportunities to ask questions of hospital or DonatLife staff about donation. Families who declined donation were significantly less likely to feel this way (60% strongly agreed).

Figure 28 Opportunities to ask questions

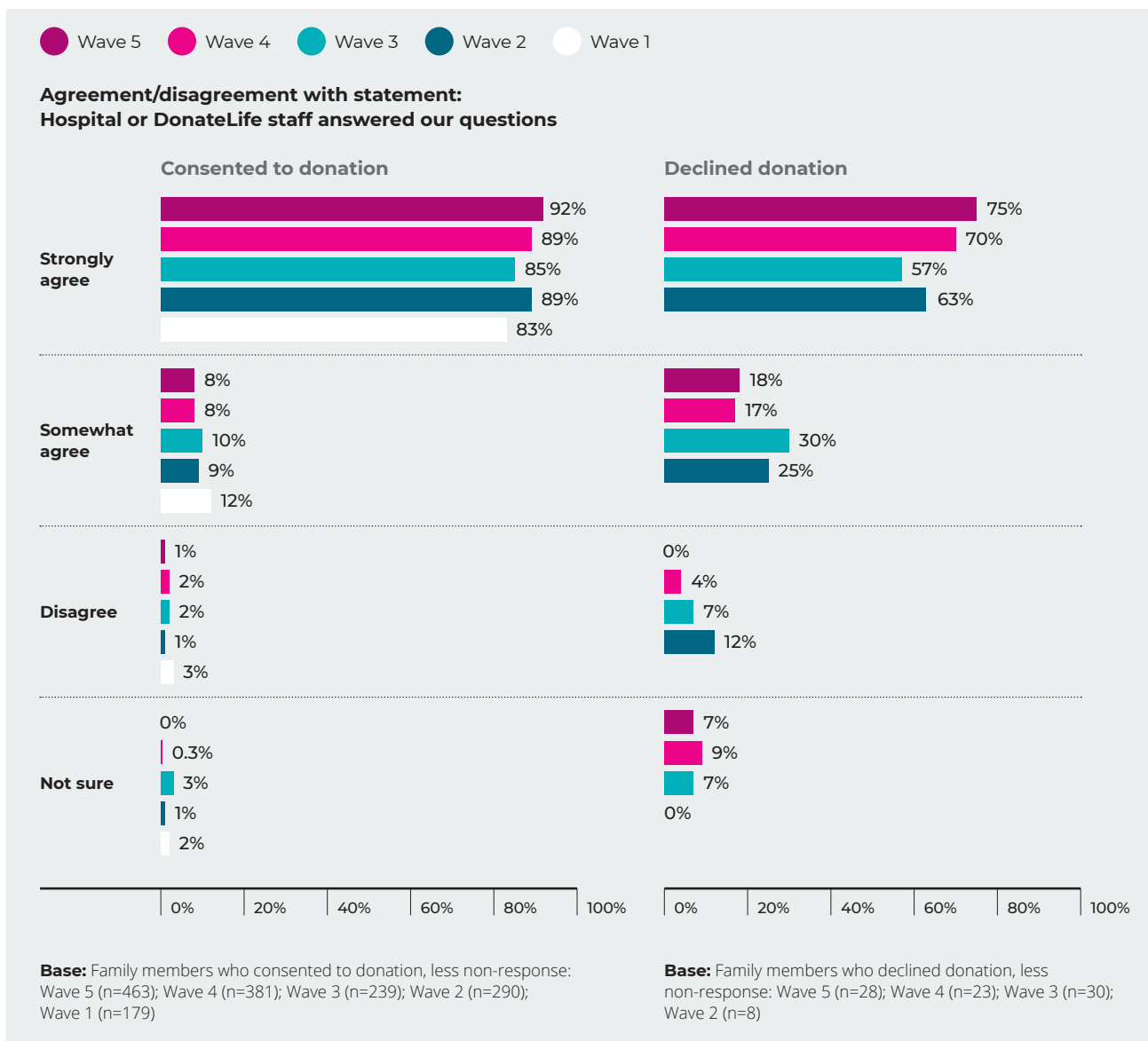


Further, 92% of family members who consented to donation strongly agreed that hospital or DonateLife staff answered their questions. This is consistent with earlier waves, as shown in Figure 29. Families who declined donation were significantly less likely to agree that this occurred (75% strongly agreed). The study indicates that families often don't know what questions to ask and find it difficult to absorb information, given their high levels of emotional upset.

“ At the time I wasn't understanding what they were asking. I don't think you are thinking straight and we were very much in shock that our brother was going to pass away, so it took a while to take it all in.”

2018 – Consented to donation

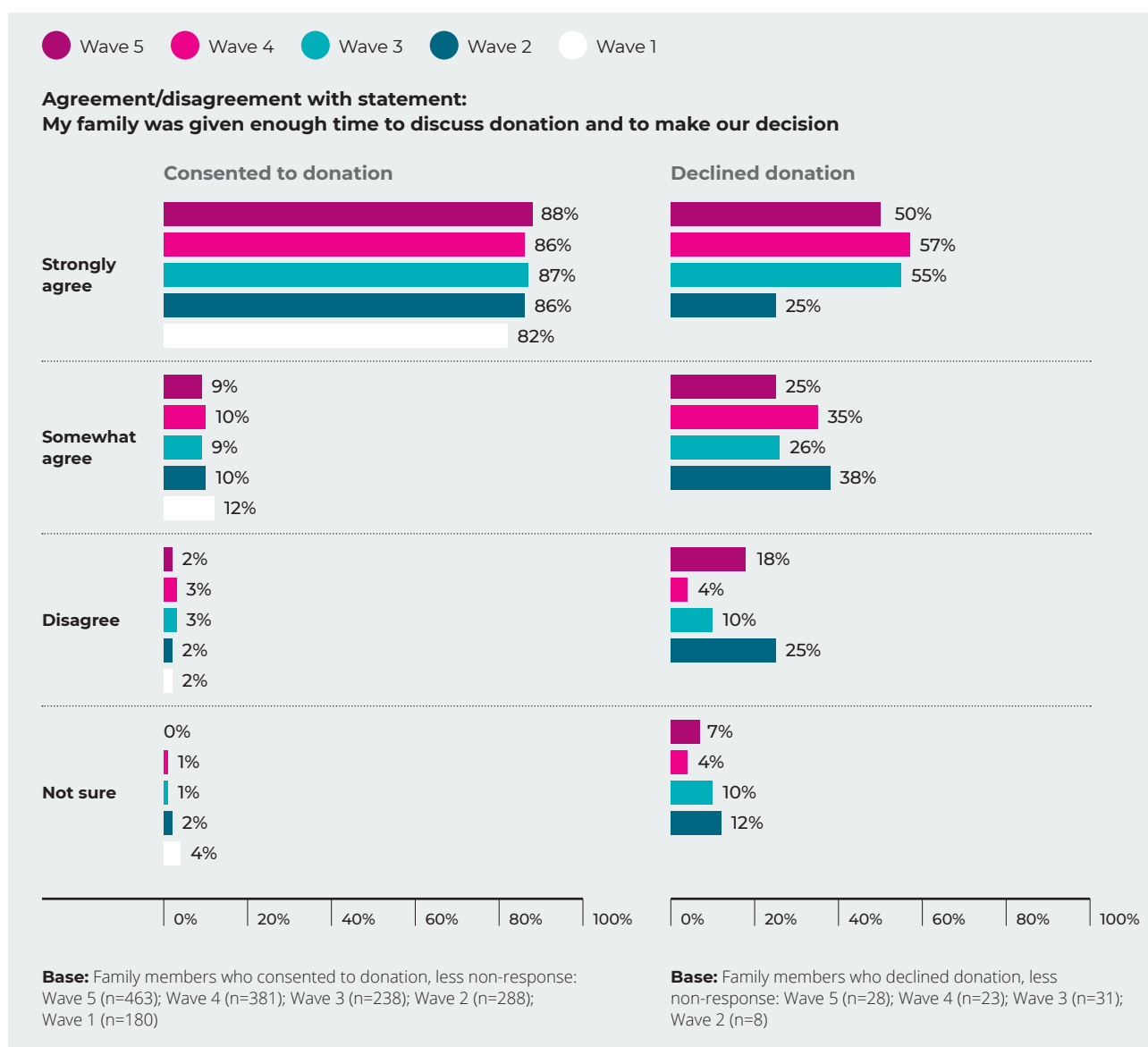
Figure 29 Hospital or DonateLife staff answered questions



8.5 Time to consider donation

Most families surveyed who consented to donation felt they were given enough time to discuss donation and to make their decision (88% strongly agreed), as shown in Figure 30. Families who declined donation were much less likely to feel they were given sufficient decision-making time (50% strongly agreed; a significant difference).

Figure 30 Time to make a decision

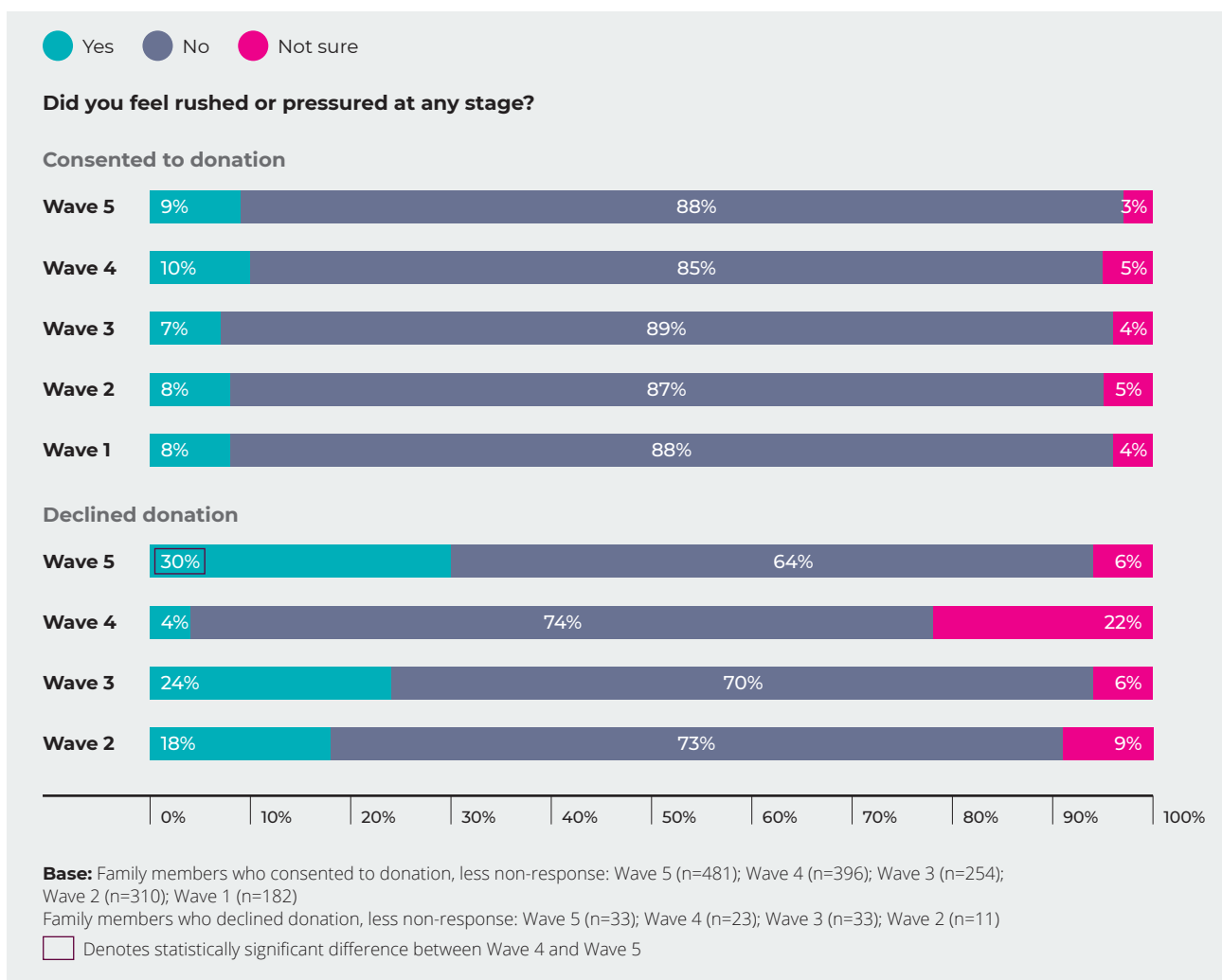


Fitting with this, 88% of consenting donor family members did not feel rushed or pressured to make a decision about donation. Families who declined donation were significantly less likely to feel this way (64%, Figure 31).

“ I do know that we never felt pressured into making a decision. They were all very kind and considerate.”

2018 – Consented to donation

Figure 31 Feeling rushed or pressured



In the study, 9% of families who consented to donation and 30% of families who declined donation felt rushed or pressured to make a decision about donation. Table 20 shows many of these declining family members felt pressure because of the way in which staff approached the donation conversation (including the timing, being too early or on the day of planned withdrawal of life support).

“ I felt rushed in as much as the issue had not been on my mind for the 11 days my husband was in ICU, nor was it raised until the day we turned off life support. I did not have donation on my mind in those 11 days. Perhaps I should have though. Perhaps it should have been raised earlier?”
 2018 – Declined donation

“ The late timing of the donation issue being raised resulted in a 24 hour delay to the ventilator being turned off as we had to discuss with family in UK. We'd all been upset by the way donation was raised, so it took a while to accept and agree. We would have agreed to more being donated had it been handled more sensitively.”
 2018 – Consented to donation

Findings indicate that the donation process itself and the time the process takes, can also create stress and pressure for families. It is therefore important to ensure that realistic timeframes are provided to families upfront, and that families are kept informed if these timeframes change. Findings show that families experienced pressure when firm time limits were placed on them to make a decision about donation.

“ There is an impasse between the surgeon group and the DonateLife personnel. The donation procedures were delayed for 48 hours longer than indicated, and would have been delayed a further 12 hours had I not threatened to reverse my decision.”

2019 – Consented to donation

Table 20 Reasons for feeling rushed/pressured

In what way did you feel rushed or pressured?	Consented to donation (n=36)	Declined donation (n=9)*
Pressure felt due to the timing of the donation conversation and approach	3%	56%
Pressure to fit in with timing of donation process (extending time in hospital or cutting time short to fit with recipients)	19%	–
Pressure from DonateLife/ hospital staff (no further information)	17%	11%
Pressure from other family members	11%	–
Given short timeframe to decide by hospital/ DL staff	8%	22%
Pressure to explain why declined / made to feel guilty for decision	–	22%
Pressure from DonateLife being present in initial family meeting	8%	11%
Felt rushed because patient was deteriorating	8%	–
Short window of time before organs not viable	8%	–
Just because of the urgency of the process	8%	–
Concern that organ donation was being ‘pushed’ at the expense of the patient	6%	–
Donation timeframes not transparent / not provided information on timing	3%	–
Other reason	11%	22%

*Caution: small sample size

8.6 Improving the donation conversation

Family members participating in the study were asked how the way in which donation was discussed with them at hospital could have been improved after they consented to donation. This was an open ended question. Findings were collected verbatim and have been grouped into similar themes and detailed in Table 21, together with findings from previous waves.

A greater proportion of families in Wave 5 spontaneously state that staff were compassionate, supportive and informative during discussions about donation (35% vs. 14% during Wave 4). Fewer families, however, stated that discussions were handled well and that they were well informed about the donation process (29% vs. 39% during Wave 4).

In terms of suggestions for improving donation conversations, 18% of family members suggested better communication and keeping families informed of the process and any delays.

Table 21 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?	W1 (n=97)	W2 (n=128)	W3 (n=121)	W4 (n=213)	W5 (n=188)
No improvements needed: Staff compassionate / supportive / informative / professional / respectful	-	16%	9%	14%	35%
No improvements needed: Discussions handled well/ was well informed about the process	49%	49%	48%	39%	29%
Keep family better informed about process / improve consultation / provide more information regarding timing and delays / arduous discussions and paperwork	6%	8%	12%	9%	18%
Improve timing of discussions / felt rushed /pressured / allow families more time to come to terms with loss before raising donation	5%	2%	4%	3%	9%
More compassion/ understanding/ empathy from staff / staff need further training / DL staff unsupportive, overly gushy, pushy, insensitive / lack of continuity of staff	1%	2%	2%	4%	7%
Provide more information around the process of turning off life support and what happens post donation surgery	-	4%	3%	3%	4%
More contact and support (before & after donation) / support for immediate family (e.g. siblings)	-	-	-	-	4%
Issues around next of kin / staff not recognising who had a right to be involved in decision-making/discussions	-	-	-	-	3%
Inform families earlier about restrictions on donation (e.g. age / medical conditions) and provide explanation	2%	1%	1%	2%	2%
Create more awareness / raise profile of organ donation	-	-	-	-	2%
Provide a private room for discussions and meeting with staff/ provide a larger room for families to gather (include tissues, tea and coffee) / a more peaceful/calming room	-	2%	3%	1%	2%
Social workers were supportive / the importance of having an independent advocate to support families (separate from Donatelife)	-	-	-	-	2%
To not discuss personal details about the donor in front of the whole family / inappropriate line of questioning / medical history questioning too taxing	1%	4%	3%	3%	1%
We had to raise the topic of donation – staff apprehensive to raise the subject	-	-	-	-	1%
Never discuss organ donation in the same room/in the presence of family member/donor	-	-	-	-	1%

□ Significantly lower than Wave 4 □ Significantly higher than Wave 4

Suggested ways for improving how donation was discussed at the hospital with families who declined donation centre around the timing and the approach. This includes who initially asks about donation, who is present in the room, and the tone used. Findings are demonstrated in the following comments from family members.

“ A separate meeting about donation would have been much appreciated. There was also no compassion from the doctor.”

2018 – Declined donation

“ I don't think it should be done at the same time it is decided to turn life support off. Allow family members some time to process before bringing it up.”

2018 – Declined donation

Wave 5 findings highlight there is room to improve communication with family members, to ensure they understand the donation process and associated timeframes.

The findings show that families should be given a private room in which they can gather, discuss donation and make a decision that is right for them. They should be given sufficient time to do this, and know who to contact if they have questions.

9 Moving towards donation

9.1 Understanding of the donation process

Nine in 10 families (92%) who consented to donation in 2018 and 2019 recall meeting or having a discussion with a DonateLife staff member (Figure 32). This is significantly lower than families in 2016 and 2017. After this meeting, 83% of donor family members felt well informed; 15% still had unanswered questions and 3% left the discussion with no clear understanding of the donation process (Table 22). These findings are consistent with previous research waves.

Figure 32 Meeting / discussion with DonateLife staff member

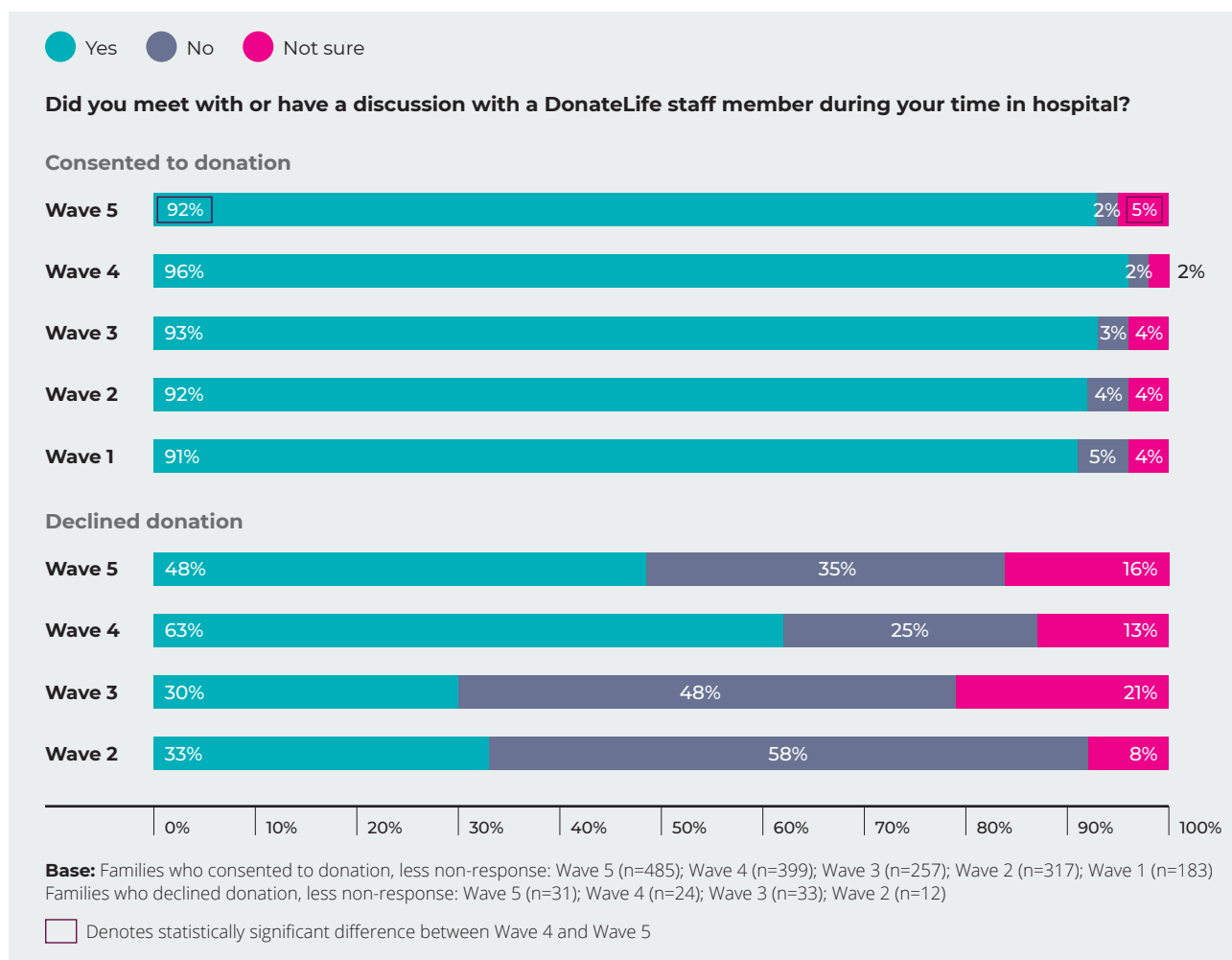


Figure 32 shows significantly fewer families who went on to decline donation had a discussion with a DonateLife staff member (48%). Of the declining families who met with a DonateLife staff member, 80% felt they were well informed after this meeting. The remaining families left the meeting with unanswered questions (7%) or with no clear understanding of the donation process (7%).

Table 22 Understanding of donation process after discussion with DonateLife staff member

Understanding of donation process after discussion with DonateLife staff member	Consented to Donation			Declined Donation*		
	W3 (n=240)	W4 (n=372)	W5 (n=442)	W3 (n=10)	W4 (n=15)	W5 (n=15)
I was well informed and knew all that I needed to know about the donation process	80%	84%	83%	50%	60%	80%
I was informed but still had some questions	18%	14%	15%	20%	20%	7%
I didn't have a good understanding of the donation process	2%	2%	3%	30%	20%	7%
Other**	-	-	-	-	-	7%

* Caution: small base

** Family member did not wish for DonateLife staff member to be present at the family meeting, but they attended

Nine in ten (92%) family members in Wave 5 who consented to donation were made aware that even if donation was agreed to, it may not happen for a number of reasons. This is consistent with previous waves and across donation pathways. Intended donor families were more likely to be aware of this (100% compared with 90% of actual donor family members).

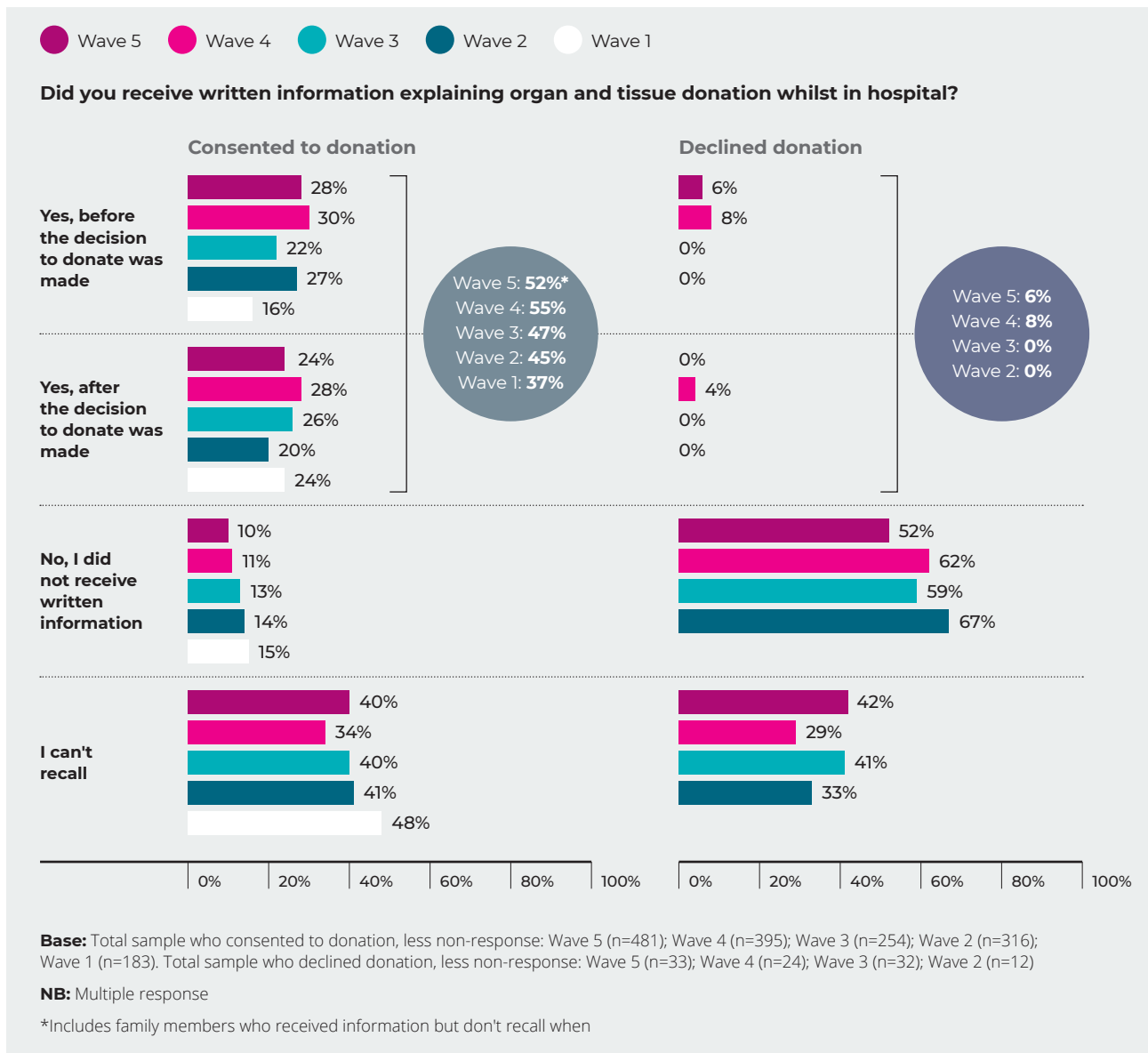
Wave 5 findings highlight the importance of managing family expectations of the donation outcome.

9.2 Provision of written information

In 2018 and 2019, 52% of donor family members recalled being provided with written information explaining organ and tissue donation whilst in hospital (Figure 33), consistent with Wave 4. One in 10 donor family members (10%) reported they were not given written information about donation and 40% could not recall.

Of the families surveyed who declined donation, just 6% (2 out of 33 family members) reported that they received written information explaining organ and tissue donation while they were in hospital. One of these family members skimmed through the information and found it quite useful.

Figure 33 Provision of written information



For donor family members who received information when in hospital, half (51%) read the information in detail, while an additional 43% skimmed through it. Six percent (6%) of family members who were given information decided not to read it (Figure 34). This is consistent with previous waves.

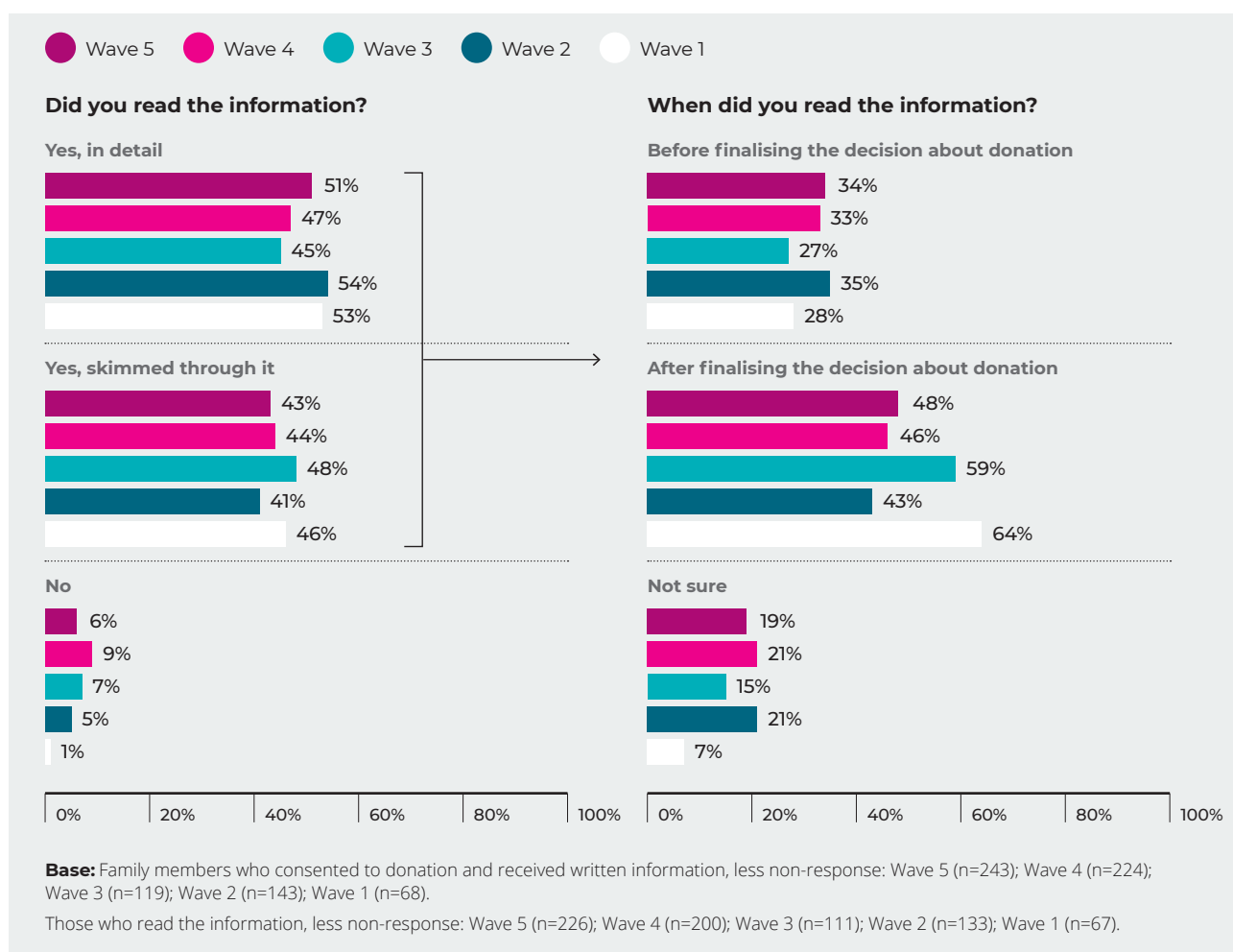
“ I was having some quiet time in the coffee room and read a pamphlet the evening before the brain testing and this gave me a better understanding of brain death and donation.”

2018 – Consented to donation

“ Handing someone in that circumstance a brochure is not helpful. My brain wasn't working well enough to read and comprehend and I consider myself a reasonably intelligent person. Doctors and nurses should tell you everything you need to hear and with simple language and evidence.”

2018 – Consented to donation

Figure 34 Reading of written information



For those donor family members who read the written information provided to them in hospital, 34% read it *before* finalising their decision about donation, and 48% read it *after* they had already made their decision about donation.

Table 23 shows that 99% of 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 25%), which emphasises the importance of encouraging family members to read the information carefully, in their own time. These findings are consistent with Wave 4.

Table 23 Usefulness of information by readership

Usefulness of Written Information	Wave 4			Wave 5		
	Total who received and read information (n=196)	Read in detail (n=103)	Skimmed through (n=93)	Total who received and read information (n=224)	Read in detail (n=122)	Skimmed through (n=102)
Very useful	47%	66%	27%	47%	66%	25%
Quite useful	47%	32%	63%	52%	33%	75%
Not useful	5%	2%	9%	1%	1%	1%

Findings indicate that verbal information, where possible, should be tailored to the needs of each family member. The study shows Hospital and DonateLife staff need to be skilled at ‘reading the room’, to be able to deduce when families need to know more and when it’s time to simply leave family members with their thoughts.

“ We should have been asked if we wanted to hear all the details of what they would do to Mum. None of us wanted to know but we had no option not to hear it. It was totally traumatic.”

2018 – Consented to donation

Wave 5 findings highlight the importance of donor families receiving written information whilst in hospital, however this should not replace verbal communication from health professionals. Verbal information should be tailored to the needs of family members – succinct and delivered in layman’s terms for ease of processing, or containing more detail when requested by the family member.

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

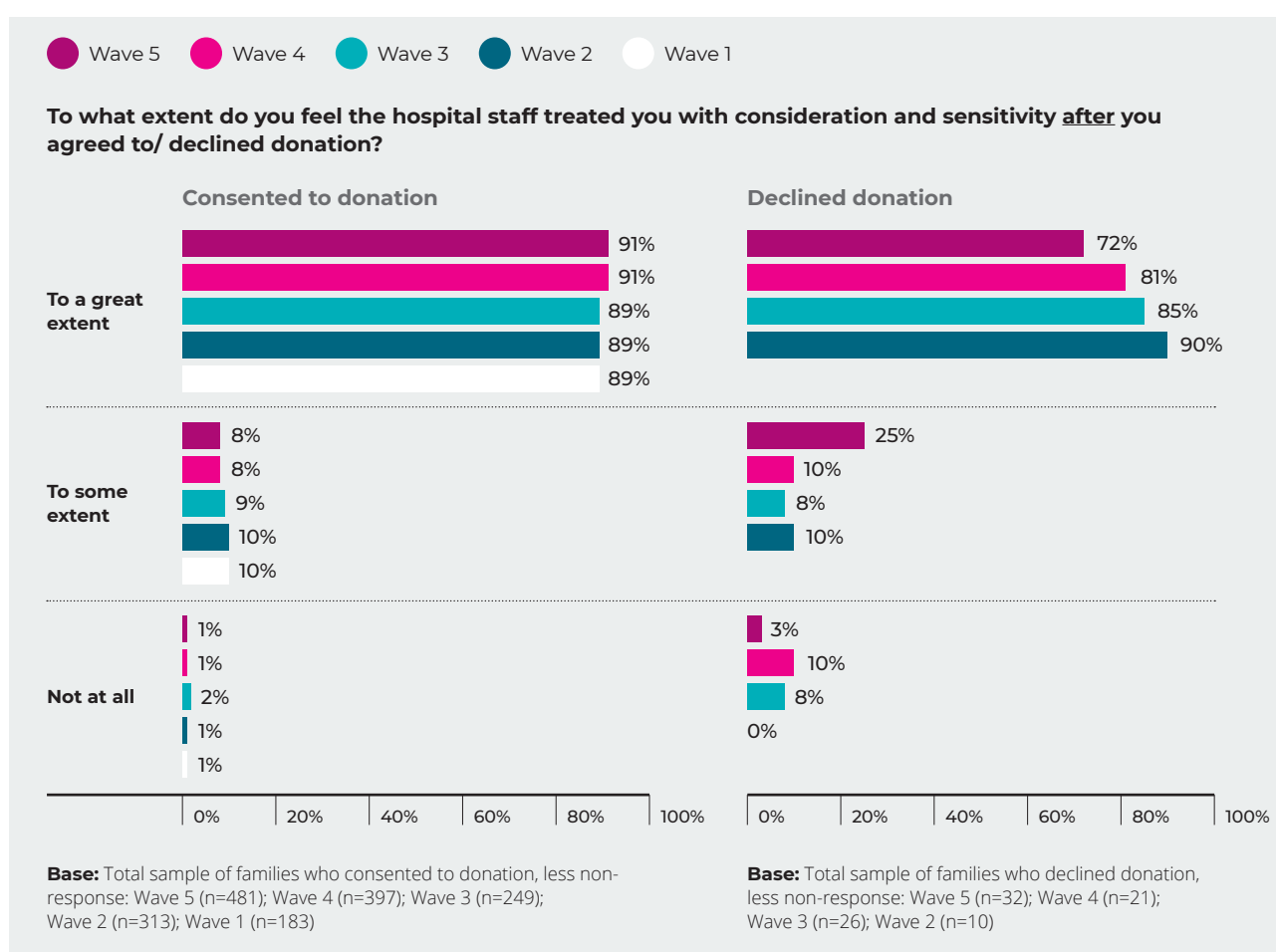
9.3 Support from health professionals – after decision about donation

Consistent with Wave 4 findings, 9 in 10 family members (91%) feel that hospital staff treated them with great consideration and sensitivity *after* they consented to donation. For families who declined donation, this figure dropped significantly to 72% (Figure 35).

“ There was no change to the way we were treated after we agreed to donation by any of the hospital staff. All sensitivity and information we received was from the amazing DonateLife team.”

2018 – Consented to donation

Figure 35 Interaction with hospital staff after decision about donation



There were no significant differences between the way that family members felt they were treated by hospital staff *prior* to making their decision about donation and *after* making that decision, although a minority of families surveyed, including some who consented to donation and some who declined, experienced a noticeable shift in the attitudes of staff towards them after their decision about donation was made known.

“ When we declined to allow organ donation, the doctor was clearly angry/disappointed and his demeanour changed towards us.”

2018 – Declined donation

“ The nurses were great and very understanding of our change in decision. They were respectful towards us and our daughter. The doctor was not so understanding. We felt that when we declined, he just wanted us out of there.”

2018 – Declined donation

9.3.1 Support of social worker or chaplain

The study shows in 2018 and 2019, 76% of donor family members were offered the support of a social worker or chaplain at some time during their family member’s stay in hospital (Figure 36). This is significantly lower than families during the preceding two years (84% were offered this type of support). Seven in 10 (70%) families who declined donation were offered this type of support, statistically consistent with family members who consented to donation.

“ I would like to acknowledge and thank the wonderful social workers we had during this time. One had the difficult task to call our family in NSW and let us know our sister's situation. The other was with us at the hospital and made herself available whenever we required anything. Both showed compassion and provided support at this very sad time.”

2018 – Consented to donation

“ The hospital social worker gave ongoing telephone support to our son's daughter who was aged 12.”

2019 – Consented to donation

Conversely, a quarter of family members (23% who consented to donation and 24% who declined donation) reported they were not offered support from a social worker, counsellor or chaplain during their time in hospital. This is significantly higher than in Wave 4.

“ A social worker would have been the connection between the medical and family, you know? It would have been great.”

2019 – Consented to donation

“ I cannot remember being offered a chaplain but certainly believe this is very important for EVERY family.”

2019 – Intended to donate

Figure 36 Support of social worker or chaplain during stay in hospital



Of those who were supported by a social worker or chaplain in hospital, 70% found their support to be 'definitely helpful'; a further 24% found it to be 'somewhat helpful'. The value of this support in an ongoing manner is further highlighted in Section 11.

The value to families of a trained and experienced social worker in hospital didn't end with the emotional support they provided. Families were grateful for social workers who took initiative and helped with the practical things that needed to be done. However, experiences did vary across families surveyed.

“ The social worker assisted us with paperwork, medical certificates etc.”

2019 – Consented to donation

“ The social worker helped with writing letters to inform the childrens' schools.”

2018 – Consented to donation

“ The social worker provided ongoing support in mainly communication and introductions to various organisations and people, which was very helpful.”

2019 – Consented to donation

Table 24 shows findings across the five waves of the Donor Family Study, split by donation pathway. There were no differences between DCDD and DNDD family members in Wave 5 in terms of the proportion who were offered the support of a hospital social worker or chaplain.

Table 24 Support of hospital social worker or chaplain, by donation pathway

Support offered	2010–2011 Family Members		2012–2013 Family Members		2014–2015 Family Members		2016–2017 Family Members		2018–2019 Family Members	
	DNDD (n=163)	DCDD (n=20)	DNDD (n=277)	DCDD (n=37)	DNDD (n=216)	DCDD (n=38)	DNDD (n=271)	DCDD (n=124)	DNDD (n=255)	DCDD (n=127)
Yes	74%	95%	78%	84%	77%	79%	82%	90%	77%	73%
No	11%	–	10%	8%	8%	5%	8%	3%	23%	24%
Not sure	15%	5%	11%	8%	15%	16%	10%	7%	–	2%

Significantly higher compared to DNDD

9.4 The donation process – from consent to surgery

Once consent to donation has been given by the family, many things begin happening in the background to facilitate donation. Whilst families typically don't want to know the minute-by-minute steps that are required, they do need to have a basic understanding of the process leading up to donation surgery. The findings show that without a basic understanding of what needs to happen and when, families can make assumptions about timelines and procedures, and incorrect assumptions can lead to disappointment and frustration.

The findings show that the time between consenting to donation and donation surgery could sometimes be viewed by family members as a blessing – more time to spend with their loved one. For other families, this could be a time that is distressing and full of second-guessing – are we doing the right thing? Is this what our family member would have wanted?

“ It seemed to drag on too long from initial admission to the surgery. I knew why as we needed to wait for test results and the recipients to be prepared but I felt my grief was getting harder each hour and I just wanted the process over.”

2019 – Consented to donation

Findings indicate that the time between consent and surgery must be handled carefully, and hospital and DonateLife staff should be aware of the multitude of emotions that family members will be experiencing during this time. Families reported that they must always feel that their family member is important to hospital staff, and not just for the donation – they need to feel that their family member still matters, as a person. It is important for staff to continue to support and care for families as the time for donation surgery nears.

“ We felt very supported through the organ donation process and felt that the doctors, nurses and DonateLife team were genuinely very compassionate and sensitive in their care of Mum and of us her family. Their warm and caring approach made the hardest time in our lives somewhat easier to cope with. They are a very special team of people who do a job that requires a deep emotional understanding and sense of compassion, and we sincerely thank them for showing this to us at such a hard time.”

2018 – 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. If a person has registered their wishes with the Australian Organ Donor Register (AODR) regarding which organs and tissues they consent to donating, family members are asked to confirm if they agree with those decisions. Families find this situation a little easier because they are, in essence, being guided by their family member.

However, in the absence of this knowledge, families were asked to provide consent for each organ and tissue. Families reported that they found this process lengthy, confronting and upsetting. Whilst families appreciated the requirement for this type of consent, they questioned if there could be an easier and less taxing approach.

“ She was running through all the other stuff that can be donated. There were eyes, his skin, parts of his... whatever, inside of his body. And, you know, I just kept saying, ‘take what you need to’, you know, ‘help as many people as you can’. You could tell she was very passionate about it, but I actually started feeling sick and I had to say again, ‘you can take whatever you need but this is making me feel like I’m going to be sick’, you know, we were actually talking about my husband! I think if there was any way to make it sound less like a checklist, it would help.”

2019 – Consented to donation

“ The consent process was very long and exhausting at a time when you are already emotionally wrung out.”

2019 – Consented to donation

Findings show that despite the perceived difficulty of the meeting to obtain consent, DonateLife staff are praised by families for their kindness, patience and non-judgemental attitude towards families during this meeting.

“ The donation support people were all amazing, patient, kind and professional whilst being considerate and supportive.”

2019 – Consented to donation

“ They were really good at that meeting, but it was hard at times.”

2018 – Consented to donation

9.4.2 Medical and personal history

Family members who took part in the in-depth interviews often talked about a meeting they attended where DonateLife staff asked questions about their family member's medical and personal history. Like the informed consent meeting, families found this meeting overly lengthy and difficult. In fact, many family members stated that they felt uncomfortable during this meeting, mostly because of the sensitive nature of the questions.

The questions are very personal in nature:

- a Sometimes intimate questions were asked in front of extended family, including adult children, which felt inappropriate.
- b Families didn't always understand the relevance of this line of questioning.

Further analysis of family responses to this line of questioning showed that at this traumatic time, some family members placed their loved one on a pedestal, so to speak. They wanted to remember all the positives about their family member, for example their kindness, generosity and sense of humour. Families in the study reported the line of questioning around sexual habits and drug use had the potential to quash these nice memories and make families feel that they were disrespecting their family member.

Prior to this meeting, the next-of-kin should be informed of the nature of the meeting and asked if they would prefer to attend alone or with other family members. Further, explaining the purpose of this line of questioning would have been helpful for family members.

“ He asked me some questions in front of his sons that I didn't really want to answer, like when was the last time we had sex – personal stuff. I had no idea they were going to ask me that. They should have had that conversation with me privately.”

2018 – Consented to donation

Some family members in the study called for greater public education around organ donation and the registration process, in an attempt to take some of the second guessing and stress out of the informed consent and medical background process.

“ A hell of a lot of the questions about his medical history I could not have answered about Dad. It was a good thing that Mum was in the room. He was always in favour of organ donation but I don't think he appreciated how much people would need to know about his history in order for him to be a donor, because if Mum had not been there, the donation would not have been able to go through because I could not have answered those questions. But if Dad had understood the sorts of things that someone making decisions had to understand, he would have ensured that I was informed about them.”

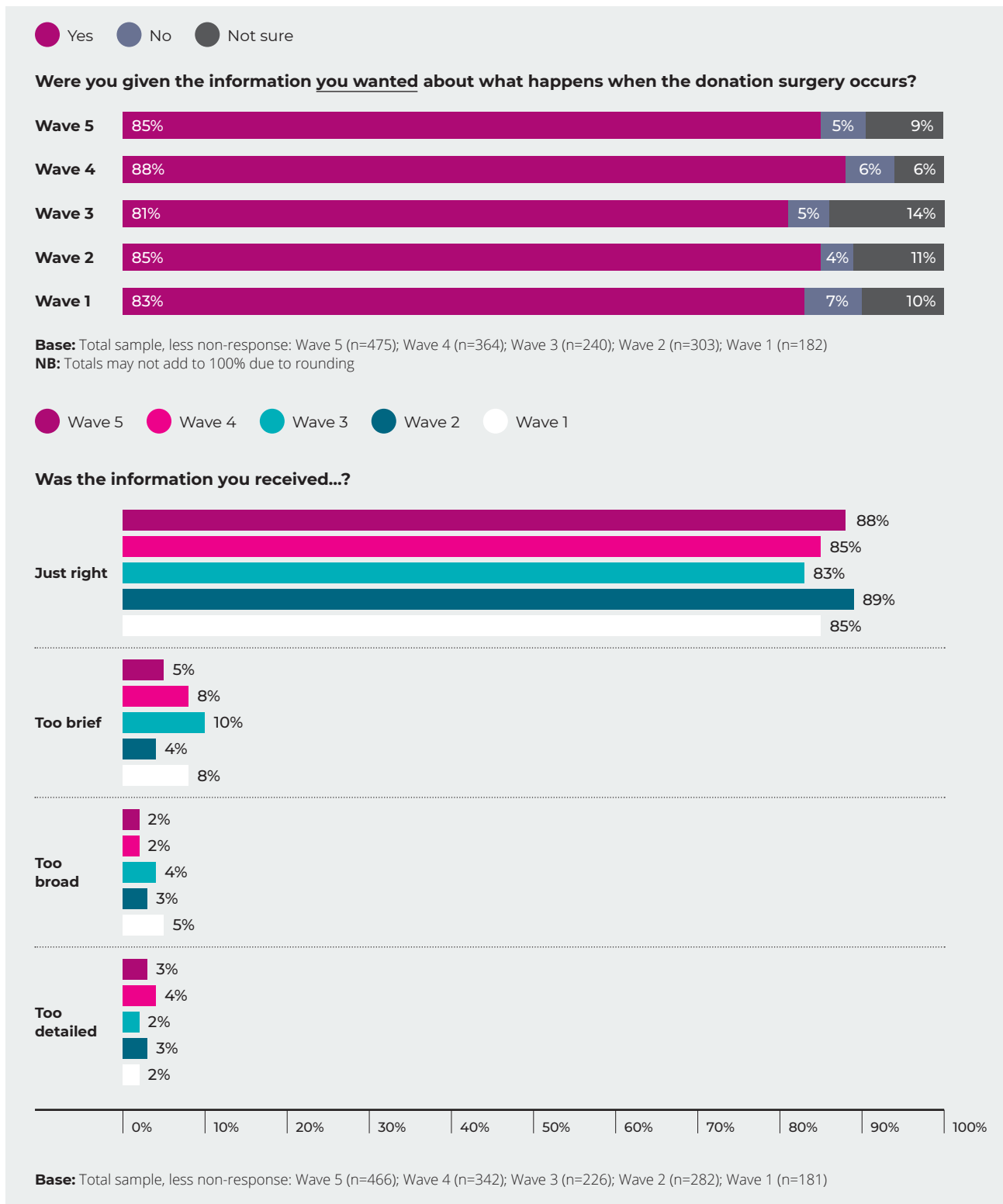
2018 – Consented to donation

Findings support that prior to all meetings, families should be informed of the expected duration of the meeting and what it involves. Family members participating in the study expressed a need for the meeting to be held in a private room and for families to be offered breaks when needed.

9.4.3 Information provided about donation surgery

In terms of the information provided to families about donation surgery, 85% of family members who consented to donation felt they were given the information *they wanted* (Figure 37).

Figure 37 Information about donation surgery



The study shows that family members have different needs when it comes to the amount of information they are given about donation surgery. Approximately nine in ten (88%) family members in the study who consented to donation felt they were given the right amount of information. Seven percent (7%) said they either didn't receive enough information (5%) or the information was too broad (2%), while 3% felt the information was too detailed.

“ I think it’s important to note that one doesn’t always have the questions in mind to ask in the middle of all the trauma. It’s difficult to know and will change from person to person.”

2018 – Consented to donation

“ I think the family member of the deceased should be given a choice if they want to hear all the details of what will happen to their loved one during the organ removal process. The information is awful and far too much to deal with when already processing the grief and shock of their loved one’s death.”

2018 – Consented to donation

The findings show families often struggle to absorb and fully understand the information provided in hospital due to their heightened emotions around losing a family member, coupled with physical and emotional exhaustion. As highlighted in Section 9.1, 17% of family members who met with a DonateLife staff member still had unanswered questions and lacked an understanding of the donation process after this meeting. The findings show that information should be paced in line with family needs, and provided in both verbal and written forms. The study shows that it also helps when families knew who they could talk to, how to reach them, and that they could ask questions at any time.

“ I think we could have been given more information around the process. There were parts of the process I didn’t understand until 18 months later. I didn’t feel like I knew the right questions to ask. Things like, ‘how does my daughter’s organs get from a to b, where are the surgeons coming from, is the recipient family at the hospital, can we meet them, what happens after the surgery for my daughter, what will she look like?’”

2018 – Consented to donation

9.4.4 Managing expectations of timelines

One of the main themes emerging from the study is the impact on donor family members of not knowing timelines, being misinformed of timelines, or not being kept up-to-date about changes to timings.

Families were often given estimates of likely timeframes by hospital staff. This included timeframes for brain death testing, a family meeting, or the expected time of donation surgery. The findings showed with so much going on and with families having no control over the events unfolding in the hospital, they tended to cling to timelines as something tangible. The expected time of removal of life support and potential donation surgery have consistently been reported as the most important for families. These milestones signified the finite loss of their family member and the end of their time in hospital. Families reported mentally preparing themselves for this. Wave 5 showed that moving timelines forward or back caused families to become distressed, especially when the change and reasons for changes were not effectively communicated.

“ I felt that the whole process took too long. First we were told it would be 5.00pm, then 7.00pm, then 9.00pm. Then it was 10.00pm and eventually it was 10.20pm that my son’s life support was turned off.”

2018 – Consented to donation

“ I feel everything was rushed in telling us he was brain dead because the doctors told us we would know about his condition in 72 hours but they only waited 48 hours to tell us our son was brain dead. Was this because his organs were being donated? It’s an answer I will never know.”

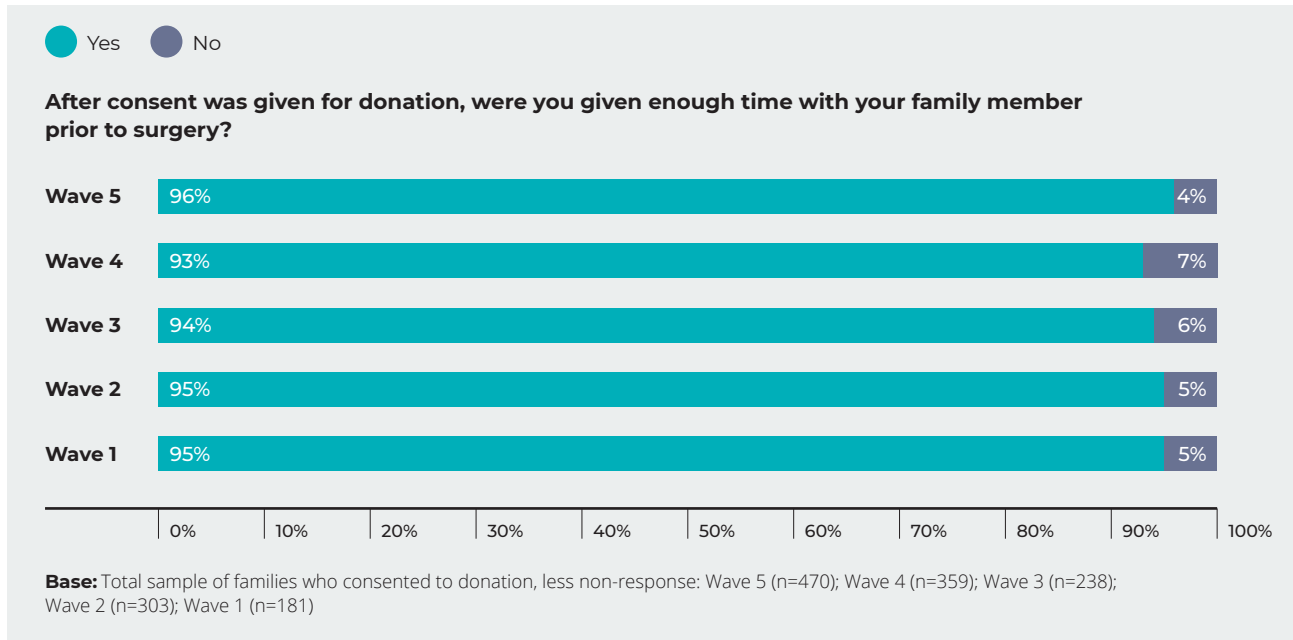
2018 – Consented to donation

Wave 5 findings show that it is important to provide families with accurate timeframes and ensure they are kept informed about any changes to timeframes through the use of clear and consistent communication. This would support families, making them feel valued and alleviating stress caused when families are not informed.

9.4.5 Time with family member prior to surgery

Almost all families (96%) participating in the study who consented to donation during 2018 and 2019 felt they were given enough time with their family member prior to donation surgery; 4% felt they were not (Figure 38). These findings are consistent with previous waves.

Figure 38 Time with family member prior to surgery



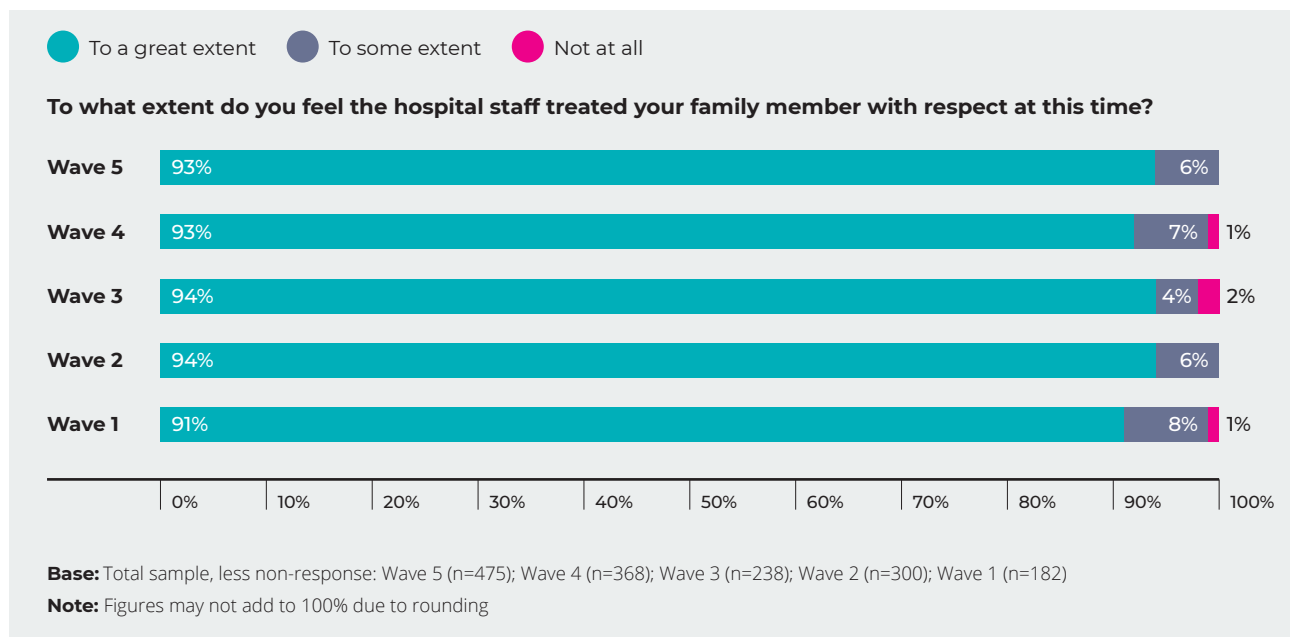
“ I was given as much time with her as I wanted. I was given privacy when I needed it and company when I needed that too. When she was being prepped and attached to the portable respirator, I was encouraged to stay right by her side with the staff respectfully working around me. Then when it was time to go, they left me alone with my wife for as long as I needed. I will NEVER forget their compassion, care and respect.”

2018 – Consented to donation

9.4.6 Hospital staff

Figure 39 shows that all donor families in Wave 5 felt that hospital staff treated their family member with respect in the lead up to donation surgery (93% felt that this happened to a great extent).

Figure 39 Treatment of donor prior to surgery



“OMG! Amazing. The doctors, nurses, pastoral workers were all amazing. Empathy, love, care, respect and most of all information and time were all seen and felt in abundance. Our family cannot speak more highly of them. I do not think the hospital could have done more.”
 2019 – Consented to donation

“The staff were so wonderful, they treated him like he was alive and never like 'just a body'. The pastor was very helpful as I am a Christian, and he was great with the kids as well. Staff made it possible for me to lie with my husband until he had to go to theatre. So much kindness was shown to us.”
 2019 – Consented to donation

During 2018 and 2019, some donor family members in the study reported that they were inadvertently exposed to the reality of donation surgery. While families of course know the purpose of the surgery, being confronted with hospital staff carrying eskies for organs either pre-surgery or post-surgery can be upsetting. Staff should try to protect donor families from witnessing any such processes as much as possible.

“ We did encounter one bad experience after the surgery. The ICU and operating theatre were adjacent to each other. The surgical team we had met prior to the surgery had to leave past the ICU waiting room to exit the hospital. I was standing in the walkway between the operating theatre and ICU waiting room when the surgical team walked out of the theatre area carrying eskies. It wasn't hard to realise what the team were carrying, however I was comforted to see the care being taken by the team and was able to thank them for their work as they walked past. However, my Mum also saw the team as they passed the ICU waiting room entry and this was not comforting to her.”

2019 – Consented to donation

Wave 5 of the study found that the following could reduce the distress of family members between the time of consenting to donation and donation surgery:

- **Being realistic with timeframes**
- **Being kept informed about timeframes**
- **Allowing private time with their family member**
- **Health professionals continuing to care for their family member with respect**
- **Being shielded from witnessing processes that directly relate to donation surgery**

9.4.7 The donation process – summary

Families who consented to donation were asked if they would like to add further comments about the donation process, via an open ended question in the survey. In total, 141 family members responded. Just over half (56%) of donor families provided a positive comment about the donation process, while 46% made a negative comment. All comments have been coded into general themes and shown in Table 25.

One third (33%) of family members surveyed made a positive comment about either the hospital or DonateLife staff, stating that they were kind, helpful, supportive and compassionate. The behaviour of staff towards families has the power to influence their experience, and for these families, the staff made their experience a more positive one. Around 1 in 8 family members (13%) spontaneously mentioned the paperwork, meetings and questioning as a negative part of the donation process.

Table 25 Unprompted comments about the donation process

What else would you like to add about the donation process?	W5 (n=141)
Positive sentiment	(n=79)
NET: Positive comments about DonateLife/ hospital staff	33%
• Hospital staff kind/ helpful/ compassionate/ considerate/ supportive	18%
• DonateLife staff respectful/ supportive/ compassionate/ kind	11%
• Staff (unspecified) kind/ treated us well/ supportive/ understanding	10%
Happy with process/ all good	16%
We were kept informed during the process/ questions were answered/ informative	10%
Family member was treated with respect and dignity	10%
We were given the time we needed with our family member/ didn't feel rushed	9%
Grateful to be given a private space for family to say goodbye/ to create an atmosphere to honour family member	2%
Was allowed to walk alongside family member on way to theatre/ guard of honour by hospital staff	2%
Negative sentiment	(n=65)
NET: Intensity of process (including paperwork, meetings, questions)	13%
• Painful process/ asking of intimate questions in front of others is awkward	8%
• Not enough time allowed to comprehend the situation/ felt pressure	6%
• Paperwork is onerous/ could be streamlined/ families may not always know answers	2%
NET: Donation did not end up proceeding / some organs not suitable	10%
• Disappointed donation did not proceed /lack of suitable recipients	6%
• Distressed/angry/blaming hospital/DonateLife staff for donation not proceeding / disagree with age restrictions / lack of communication about organs taken but not used	4%
Lengthy timeframes/ waiting period was difficult/ timeframes not communicated/ unnecessary delays	7%
NET: Lack of communication and information	8%
• Lack of communication and information from hospital/DonateLife to family	6%
• Lack of information post-donation about progress of recipients	1%
Wanted more time with family member/ less interruptions being asked to leave the room/ felt rushed	4%
Unhappy about the timing of the organ donation conversation/ how it was raised	3%
Difficult to accept death of family member when body is warm and 'breathing' on ventilator	3%
DonateLife/ hospital staff insensitive/ did not provide support we needed	3%
Process felt very clinical/ focus on getting donation	1%
Poor experience due to hospital including or excluding certain family members from discussions	1%

9.5 Withdrawal of treatment / going to theatre

The Donor Family Study shows an important time for families is their final moments of saying goodbye to their family member, whether in ICU or just before their family member goes into theatre for donation surgery. The withdrawal of life support was reported as a painful experience for families in the study, and as such, they needed:

- 1 Knowledge (of what was likely to happen/ what they would see)
- 2 An accurate timeframe for when it would occur
- 3 Privacy
- 4 Understanding and respect from hospital staff

For the most part, these things were delivered by hospital staff, however not always consistently. The findings showed that providing families with time to mentally prepare for this eventuality was important. The following comment from a family member who declined donation demonstrates the importance of providing families with an accurate timeframe for when withdrawal of life support will take place.

“ I was trying to reassure Mum. I was saying to her, ‘there's no rush, we've just had the family conference, you know, there isn't a rush about when we're going to extubate.’ But then just before 6 o'clock, just towards the end of the day, the consultant came to us and actually said, ‘I think it's a good idea to do the extubation now before I finish for the day.’ I understand where he was coming from but for Mum I think it was all just a bit of a rush, because they'd just told us that they were going to withdraw, but they hadn't actually given us a timeframe. In my head, I thought they would let us know when they were ready to go through with the process. So, that was a little bit... it threw us because it was, ‘oh okay, so we're doing it now?’ It was really like, ‘yep, let's go, let's get this over and done with.’

2018 – Declined donation

Demonstrating respect for families at this time can be delivered by points 1–3 above; by helping families to prepare for what they may experience during the withdrawal of life support, making sure that they are given advance notice of when this is likely to occur, and making sure that they have lots of private time with their family member before it happens.

Families also felt respected when they were offered to walk alongside their family member on the way to surgery. Not all family members want to do this, but the offer is important.

“ I was told that I was able to be with my sister all the way up until surgery and could walk with the staff as they wheeled her bed to the operating theatre, even though it was in the early hours of the morning. Although I decided not to, this meant a great deal to me and showed how considerate all the staff were.”

2019 – Consented to donation

“ Walking alongside my sister as she was wheeled into surgery was a moment of unspeakable sadness, but the staff gave me a hug and that was a priceless act of love on their behalf.”

2018 – Consented to donation

“ I would have liked to be offered to walk my partner to the operating room.”

2018 – Consented to donation

The other very touching way that some hospitals demonstrate respect for the donor and the donor's family, was by forming a guard of honour as the donor was being taken to surgery. When this happens, it means a great deal to family members.

“ When our son was taken to theatre for donation, the staff formed a guard of honour. It still brings tears to my eyes but made my heart swell with pride. It made our great loss easier to bear and brings comfort to us.”

2019 – Consented to donation

9.5.1 When the theatre doors close

An issue raised by families in the 2016 and 2017 study, and again by families in 2018 and 2019, was the overwhelming feeling of loss felt by family members when their family member was taken to donation surgery. Family members felt lost and alone at this stage, and they didn't know what to do or where to go. Do they wait? Do they go home? How should they respond to this situation?

As hospital staff were in theatre with their family member, some families reported feeling that they no longer had any support. They sometimes felt that all of a sudden, they didn't matter.

“ They wheeled him in and then it was kind of a bit like, ‘what do you do now?’ Do we hang around? It feels like we need to leave but it also feels like we need to stay.”

2019 – Consented to donation

“ After Dad went through into theatre, we were left at a bit of a loose end. The donation surgery was pretty invasive so we elected not to see him afterwards. As a result, we pretty much just left the anaesthetic bay, walked down the hospital entrance and hailed a taxi. It was fairly anticlimactic and we felt very alone. It would be good if there was some way to provide some clearer conclusion to the donation process before leaving the hospital.”

2018 – Consented to donation

Whilst not every family member reported that they felt like being in the company of others at this specific time, they did respond that at the very least, support should have been offered and ideally it should have been offered by somebody the family was familiar with. The offer of a cup of tea, a chat, helping them to their car, or arranging for a driver to take them home, would have gone a long way to helping families at this time.

The following comments from family members demonstrate two different experiences from this point in the donation process:

“ The ICU nurse and staff and donation team looked after us and made sure we were okay. The ICU nurse even came and helped us collect our things and took us to our cars.”

2019 – Consented to donation

“ It was very disappointing that after our son was led away, we just stood there. There was no one to speak to. No one asked if we were okay. We were just left!!”

2019 – Consented to donation

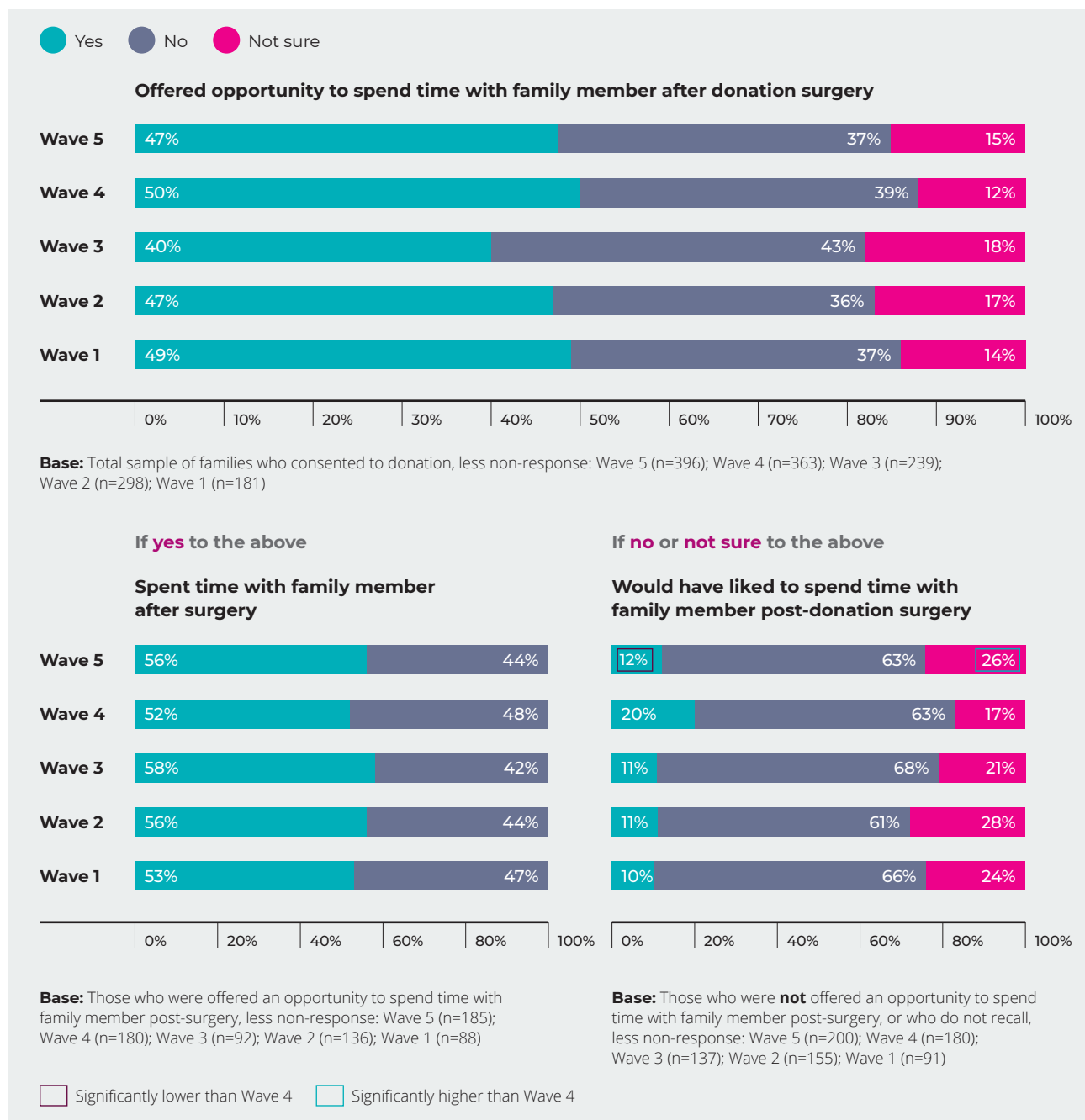
Wave 5 shows more support should be given to families when their family member is taken to surgery, and that families may benefit from having a social worker or suitable person available at this time.

10 After donation surgery

Figure 40 shows 47% of donor family members in 2018 and 2019 were offered an opportunity to spend time with their family member after donation surgery. This is consistent with families in the 2016 and 2017 study.

Of those family members who were offered, just over half (56%) opted to see their family member after surgery. Most of these family members (84%), described the experience as a positive one; 1% described the experience negatively, while 15% were still unsure how they felt about it. This is consistent with Wave 4 findings.

Figure 40 Time with family member after donation surgery



Those family members who described this experience as positive were grateful for the extra time spent with their family member and for the 'closure'.

“ After surgery they came and got us and we were able to spend as much time as we liked with her. We have a big family and we were allowed to be together with her.”

2018 – Consented to donation

“ We spent time with my brother after the surgery. It was 1:30am. The staff were very supportive and made every effort to make sure we had as much time as we needed.”

2018 – Consented to donation

“ That was my final goodbye because he was no longer on machines. It was heartbreaking, of course, but that was final. There's no more suffering then. That was my peace.”

2019 – Consented to donation

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 26. Positive sentiment was the strongest response, with 27% of family members spontaneously commenting that staff were compassionate and supportive.

Table 26 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?	W3 (n=73)	W4 (n=118)	W5 (n=142)
Positive sentiment			50%
Hospital staff compassionate/ respectful/ supportive/ kind / informative	14%	18%	27%
Received results of surgery by phone/ received phone call when surgery had taken place	7%	8%	8%
Was given enough time before surgery / understood timeframe / said goodbyes before surgery	5%	3%	10%
DonateLife team wonderful/ kind/ compassionate/ respectful	–	3%	9%
Good experience/ moving experience/ tastefully handled	21%	1%	8%
Donation gave us more time to spend with family member	5%	12%	6%
Appreciated being given a private room	–	–	4%
Our family member was cared for and respected	3%	–	4%
Happy that donation was successful/ someone else would be helped	–	–	4%
Negative sentiment			38%
Agonising/ distressing/ felt numb / felt lost/ too stressful/ exhausting	8%	9%	11%
Regret not seeing family member after donation surgery	5%	6%	9%
Hospital staff were insensitive / no support from DL staff post-donation	1%	3%	6%
Took a long time / process dragged on / waiting was difficult	–	2%	4%
No support after surgery/ didn't know where to go	5%	6%	4%
Had minimal time to spend with family member pre-surgery	7%	1%	4%
More clarity around timeframes is needed / did not understand process post-surgery	–	–	4%
Need to provide a quieter/ private room for family to gather and grieve, without being told to leave (including post-donation surgery)	–	–	4%
Was not given opportunity to see family member after surgery/ felt rushed	4%	6%	2%

Is there anything else you would like to add about your experience at the hospital after the donation took place?	W3 (n=73)	W4 (n=118)	W5 (n=142)
Need preparation for what to expect after surgery/ upsetting to see how family member looked after surgery	-	6%	1%
Phone calls would have been good (to update/ check in after donation)	-	3%	2%
Needed more time with family member post-donation surgery	-	-	1%
Neutral sentiment			
Didn't stay/ was not present/ didn't return to hospital/ other family members saw loved one after surgery	15%	7%	24%
Didn't want to see family member after surgery	19%	4%	8%
Experience was surreal/ strange	1%	-	2%
Other comments (each totalling < 1% of responses)	11%	21%	10%

Significantly lower than the previous wave
 Significantly higher than the previous wave

Findings show that seeing their family member after donation surgery is a personal decision to be made by individual family members, and as such, the opportunity should be offered to all. The findings reinforced the importance of letting family members know about any physical changes that may have taken place in their family member post-surgery, so that a fully informed decision could be made.

A key finding was that in order for families to feel respected, consideration should be given to the environment in which their family member 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). Families advise that they should not be made to feel rushed during this last goodbye.

11 Follow-up services

11.1 Ongoing support

In Australia, donor families are offered support through the National DonateLife Family Support Service, providing resources and access to support for the donor's family.

During 2018 and 2019, 95% of family members surveyed who consented to donation were offered ongoing contact with DonateLife staff or a hospital support person, such as a social worker or chaplain. This included 97% of donor family members where donation occurred, and 84% of intended family members where donation had not gone ahead (Figure 41). The findings show that intended family members were more likely to not be offered ongoing contact (14% vs. 3% of families where donation occurred).

Figure 41 Ongoing contact offered

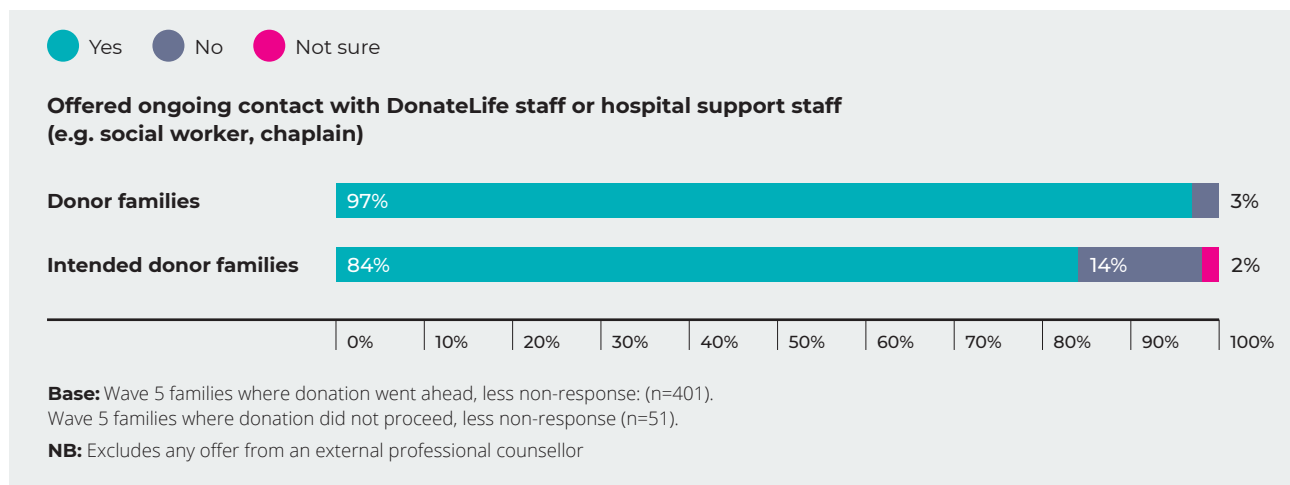
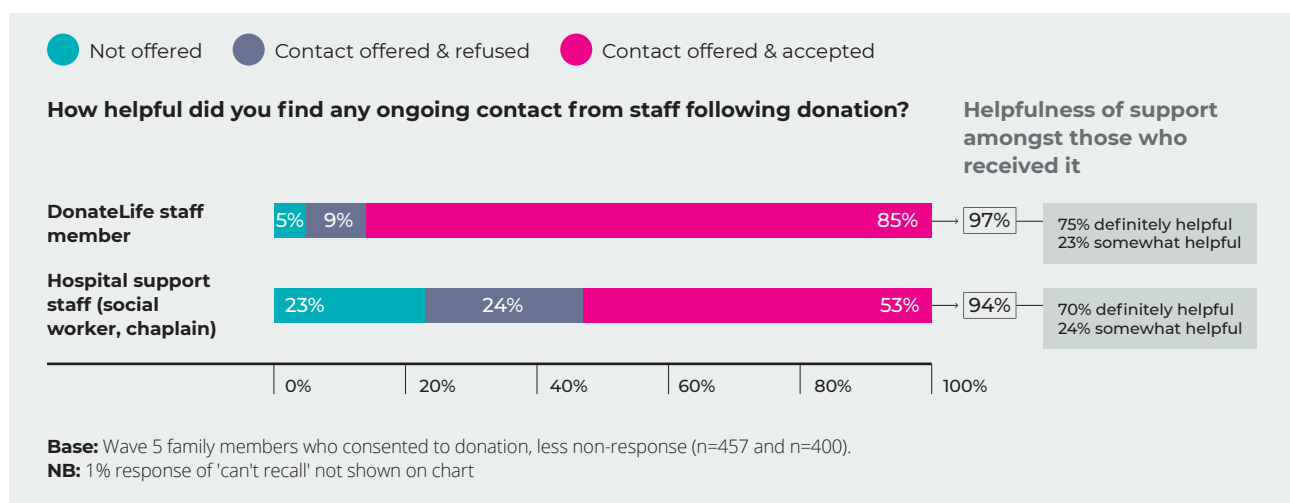


Figure 42 shows the proportion of family members who were offered ongoing contact from either a DonateLife staff member or a hospital staff member. As shown, it was more common for DonateLife staff to offer support to families than it is for a hospital staff member such as a social worker.

Figure 42 Offer and helpfulness of ongoing contact with DonateLife staff or hospital staff



11.1.1 DonatLife staff member

During 2018 and 2019, 94% of donor family members were offered ongoing contact from a DonatLife staff member; 85% of family members accepted support, while 9% chose not to. The support from a DonatLife staff member was considered helpful by the majority (97%) of family members; 75% stating that it was 'definitely helpful'.

“ We were offered counselling and they kept in contact for about 3 months after.”

2018 – Consented to donation

It may be difficult for DonatLife staff to gauge the amount of contact and support needed by individual family members, as every person's grief journey is different, and people will vary in terms of the type of support they find helpful. Findings suggest that some family members may not even be ready to connect with DonatLife straight away, and some will need to dip in and out of contact as time goes on.

At a minimum, findings suggested that DonatLife staff should check that family members know the support is there for them, whenever they feel ready.

“ The first month or two with DonatLife was awesome but it hasn't been so great since. I got a card on his one year anniversary, and I haven't really heard from them since. They offered counselling and they sent out a really nice pack with information and a book. I didn't know what to expect.”

2019 – Consented to donation

Interestingly, of the families included in the study, 21% who declined donation reported that a follow-up phone call from a DonatLife staff member would have been helpful.

11.1.2 Hospital support staff

Ongoing contact from a hospital support staff member, such as a social worker or chaplain, was offered to three quarters (76%) of family members who consented to donation (consistent with Waves 3 and 4). Just over half (53%) of the family members accepted this offer of contact (again, consistent with previous waves) and of these, 94% found the support helpful (70% found it 'definitely helpful').

Feedback from families regarding hospital social workers was mixed, with some families having a positive experience and finding them incredibly supportive and helpful, and a small number reporting their interaction with a social worker to be less than satisfactory.

“ The hospital social worker did her best and was very empathetic and sensitive, but was not familiar with all the issues and was sometimes difficult to reach.”

2019 – Consented to donation

11.2 Helpfulness of ongoing contact

Family members who took part in the Donor Family Study were asked, "If you found ongoing contact helpful, please provide comments on the ways it was helpful to you". Table 27 outlines coded responses to this question.

As shown by the variety of responses, ongoing contact was considered helpful for a range of reasons. The most common response, from 29% of family members who consented to donation, was finding out the outcome of the donation and receiving progress updates on recipients helped them because it reinforced that their decision about donation was helping others.

Approximately one in five (18%) family members felt that ongoing contact helped them because it made them feel less alone, valued and not forgotten.

“ Our donor nurse simply 'checked in' with us. It was comforting to know our pain was not forgotten.”

2018 – Consented to donation

“ It was lovely to have a staff member acknowledge and just check in. It is such a personal, gut-wrenching situation. The DonateLife staff just know how to communicate without any pressure or expectation.”

2018 – Consented to donation

“ Made me feel that my husband was appreciated and made me feel less alone in the whole process of his death and donation.”

2018 – Consented to donation

“ The day she died, I felt we were given a new family – the DonateLife family.”

2019 – Consented to donation

Table 27 Helpfulness of ongoing contact

Ways ongoing contact was helpful	W3 (n=128)	W4 (n=220)	W5 (n=239)
Found out the outcome of the donation / gave us progress updates on recipients / to know our decision was helping others	35%	17%	29%
Felt like we weren't forgotten/ not alone / felt like we were cared for / felt like we were valued / nice to be checked up on	9%	9%	18%
Provided comfort and support/ very compassionate	18%	9%	19%
Follow-up calls were helpful / follow-up contact appreciated / ongoing contact helped (no further information)	12%	12%	16%
It provided useful information / answered our questions / gave helpful advice / updates of upcoming events	7%	10%	12%
DonateLife Coordinator was helpful, supportive and understood my situation	13%	5%	11%
Helped being able to talk about my family member / someone to talk to / someone external from the family to talk to	3%	5%	8%
Helped the grieving process / gave us closure / brought healing	9%	9%	8%
Our family member is recognised and appreciated for their contribution	2%	4%	6%
Social worker kept in contact / social worker was helpful	–	–	5%
The support helped validate/ reinforce our decision	4%	2%	5%
Counselling was helpful / follow-up by counsellor was good/ DonateLife events helpful	5%	10%	5%
Ongoing correspondence with recipients is very helpful	10%	5%	3%
Resources and keepsakes – hair and handprint was lovely / lapel pin helpful / liked receiving the anniversary card, book and invitation to Remembrance day	2%	–	5%
Nice to know the support is there if we need it	7%	4%	5%
Private counselling / grief support group was helpful	5%	4%	2%
Helped to be able to volunteer / felt connected through volunteering and being an advocate for donation	–	–	2%
Appreciated additional support for children	–	–	2%
Made me feel like I am part of a new family – a DonateLife family	–	–	1%

□ Significantly lower than the previous Wave □ Significantly higher than the previous Wave

Whilst ongoing contact for families is helpful and much needed, care should be taken to ensure consistency of contact, as demonstrated in the following two comments from family members.

“ There were follow up phone calls from DonateLife staff but always someone different and not anyone who had been present at the hospital or who had been with us and met any of our family.”

2019 – Consented to donation

“ It was helpful until it wasn't. The worker left his job and I haven't heard anything since. It would have been good if it had continued.”

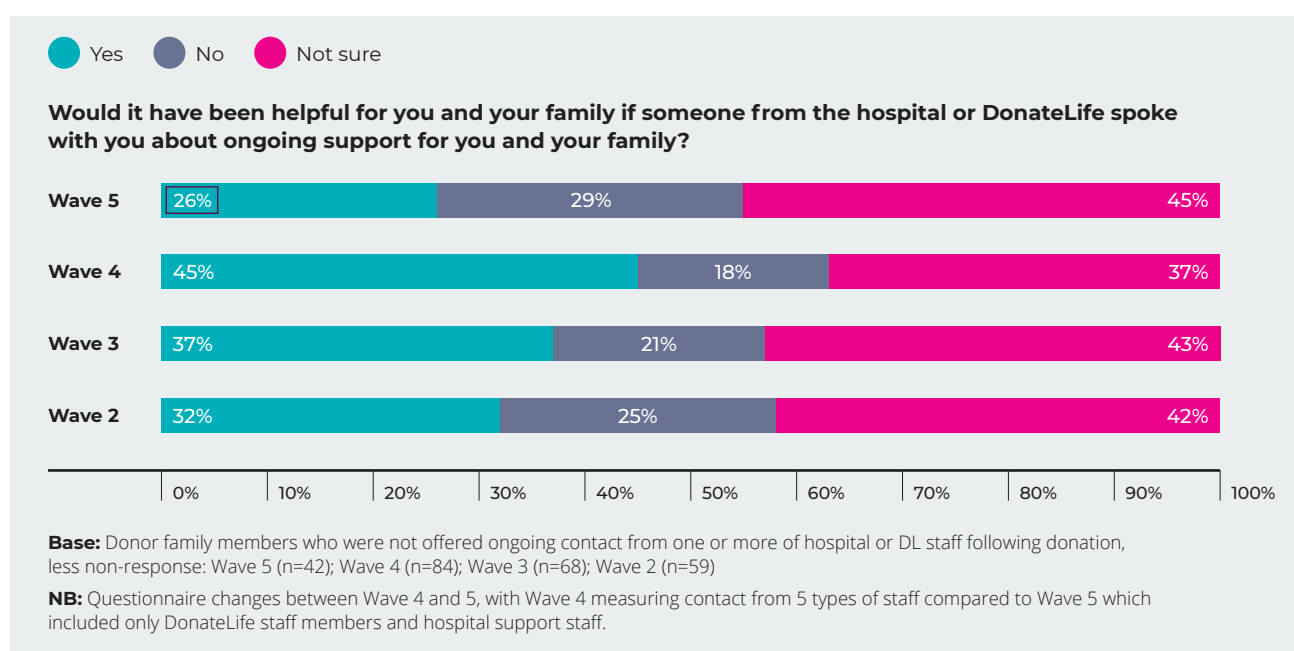
2019 – Consented to donation

As part of the study, donor family members who were not offered ongoing contact from DonateLife or hospital support staff were asked if this would have been helpful. Figure 43 shows mixed responses with 26% of these donor family members saying they would have found this helpful, while 29% would not; 45% were undecided.

“ No ongoing hospital support or bereavement support – felt quite lost.”

2018 – Consented to donation

Figure 43 Perceived helpfulness of ongoing support, if it had been offered



Findings show the type of support needed is likely to vary for each family member and this may even change for them over time. DonateLife staff should be guided by family members as to the right level of contact for them.

It should be made clear to all families who consented to donation that 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 from DonateLife if needed.

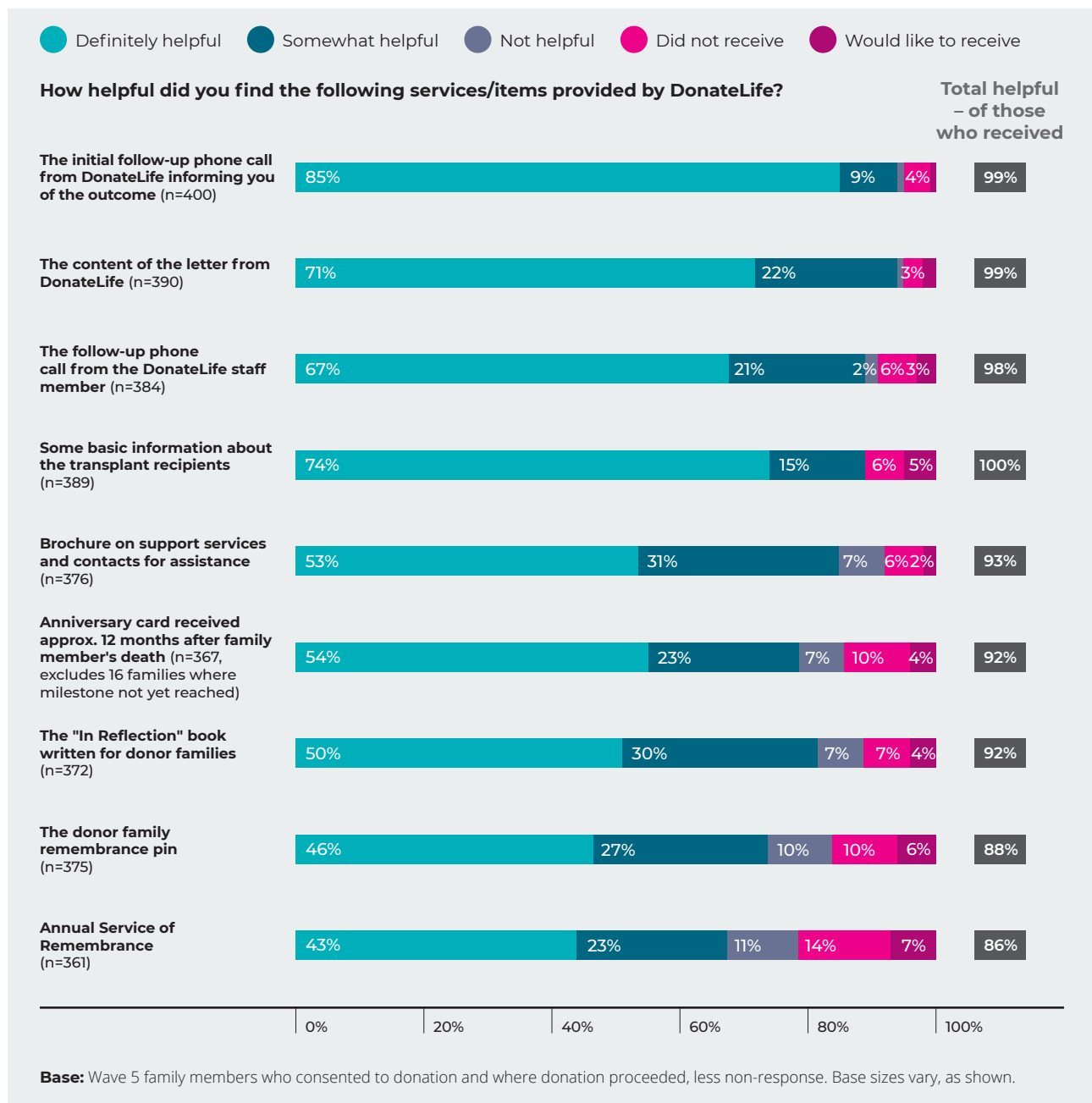
The study found that particular care should be taken to ensure donor families in regional areas are supported and directed to local organisations that may be able to provide support in their area.

11.3 DonateLife resources

Family members who consented to donation were asked if they received any number of support services and/or items from DonateLife and if so, how helpful each of these were. Findings are shown in Figure 44 and compared with earlier waves in Table 28.

Figure 44 shows that 94% of family members where donation proceeded received a call from DonateLife informing them of the outcome of the donation surgery. Of these, 99% found this to be helpful. Further detail on each of the services and items is provided later in this section.

Figure 44 Helpfulness of resources provided to donor families



As shown in Table 28, the majority of families who received these services found them helpful.

Table 28 Helpfulness of DonateLife 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)				
	W1	W2	W3	W4	W5
Initial phone call from DonateLife informing of the outcome	99%	99%	99%	97%	99%
The content of the letter from DonateLife	99%	98%	97%	96%	99%
Follow-up phone call from DonateLife staff member*	92%	97%	95%	94%	98%
Basic information about the transplant recipients	100%	99%	99%	97%	100%
Brochure on support services and contacts for assistance**	Not measured	91%	86%	92%	93%
Anniversary card	90%	91%	85%	89%	92%
'In Reflection' book	93%	92%	89%	91%	92%
Donor family remembrance pin	Not measured	88%	84%	86%	88%
Annual Service of Remembrance	82%	83%	76%	85%	86%

□ Significantly lower than the previous Wave □ Significantly higher than the previous Wave

* Wording of statement changed in Wave 5 from 'Follow-up phone call from the Donor Family Support Coordinator'

** Wording of statement changed in Wave 5 from 'Resources and Assistance leaflet'

“ The written resources were well written, well presented and easy to read. The personal contact was very supportive.”

2019 – Consented to donation

“ Everything helped me to understand the process and also to understand my grief and what I was feeling.”

2019 – Consented to donation

However, some family members reported they did not find the resources provided by DonateLife to be helpful. Often these families had a less than positive experience in the hospital, and receiving information from DonateLife brought back painful memories. The findings showed this was especially so for intended donor families.

“ I was so angry, upset and felt used that any contact or information from DonateLife made it worse. I needed to ring them and tell them how I felt, but just couldn't bring myself to speak to them.”

2018 – Intended to donate

“ All information was received. It was just too close in time to consider fully and for it to be of any practical use.”

2018 – Consented to donation

Nevertheless, findings indicate that as families work their way through their grief, in their own time, resources may be referred to at various points in time, and found to be helpful at that time.

“ I did receive a lot of resources. I did look at most of it, if not all. I was quite overwhelmed with everything and didn't find any of it particularly useful. I guess it was still good to read it.”

2019 – Consented to donation

“ Maybe a month after it happens, you get a letter from DonateLife that tells you what organs they took and who they went to, as in generalising. And it was horrible. They put it in a double envelope so you don't have to open it, you know, they're very considerate, and I remember reading it and just thought, 'oh, I just hate this'. It gave me no comfort whatsoever. It's such a roller coaster. I don't feel like that now, but I did at the time and I put it away, I put the letter away and I don't think I've read it again.”

2018 – Consented to donation

When asked for feedback on Donatelife resources, 87% of donor family members spontaneously mentioned something positive, including that the resources were helpful and appreciated (42%), that they were well presented (12%), and well written and informative (10%). A full list of responses is shown in Table 29.

“ The folder has a prominent place on my bookcase and its rigid plastic folder makes it easy to find and preserve the contents. I've recently shared the grief section of In Reflection with a close friend recently bereaved and they found it just as helpful as I did.”

2018 – Consented to donation

“ I thought it was really nice, especially the handprints of Dad. I wear the DonateLife pin every day I work. It makes me think of Dad every day and hopefully lets people notice the pin and think about donating themselves.”

2019 – Consented to donation

“ The Reflections book in particular was really useful. I could open it up to any page and read feelings that were my own and it helped me to feel normal. I've shared and recommended it to many people.”

2018 – Consented to donation

Table 29 Feedback on DonateLife resources

Feedback on DonateLife resources (amongst those who received them)	W5 (n=201)
NET: Positive comments about DonateLife resources	87%
Resources are helpful/ appreciated	42%
DonateLife phone calls/ letters helpful	14%
Resources are well presented/ neatly presented/ professional/ excellent quality	12%
Resources are comprehensive/ informative/ well written/ helped in understanding donation	10%
Resources are tastefully done/ respectfully written	8%
Resources are sufficient/ satisfactory/ adequate	8%
Resources helped with the grieving process/ validated my feelings	8%
Resources are easy to read/ easy to understand/ clearly written	7%
Books: Positive mentions of 'In Reflection' book and 'Coping with Grief' booklet	7%
Remembrance pin: Positive mentions of pin (wear it every day/ acknowledges our loss)	6%
Resources are helpful for children	3%
Annual Service of Remembrance: nice/ helpful/ great	3%
Keepsakes: Lock of hair/ handprints very special/ beautiful	2%
Resources have helped me to speak to others about donating/ helped me speak with others about dealing with grief	2%

Feedback on DonateLife resources (amongst those who received them)	W5 (n=201)
NET: Negative comments about DonateLife resources	17%
Resources are overwhelming/ a lot to take in while grieving/ a painful reminder	7%
Resources are unnecessary: Did not need them/ did not want them/ want to forget about the process	7%
Room for improvement (personalise anniversary card/ better resources for children/ promise of sending information not met)	3%
Lack of information about recipients/ lack of updates on recipients	2%
Remembrance pin: Negative mentions of pin (waste of money/ cheap looking)	1%
Resources should be sent to all family members who want them	1%

Negative comments about the resources were reported by 17% of donor family members surveyed. This feedback centred mostly around families not wishing to receive anything from DonateLife, because it is too painful or because they don't feel they need the support.

“ It has been more distressing receiving follow-up resources than the death itself. We have our own reflections and do not take any comfort from the reminders sent out by DonateLife.”
2018 – Consented to donation

11.3.1 Initial call from DonateLife informing family member of donation outcome

Of great importance to the majority of donor family members surveyed, is the initial follow up phone call from DonateLife informing them of the outcome of donation (94% remembered receiving this call and of those, 99% found it to be helpful). This was perhaps the most important contact for families from DonateLife after the donation process, and findings highlight the value in it occurring for all families. When donation went well, this information provided solace to families and often reinforced their decision about donation.

“ I think I asked if they could call me and I think they may have called me a couple of days after to let me know. For me, perhaps it was a control thing. We were proud to have done what we did and I think to know it was successful, it was important, you know, to know it wasn't all in vain.”
2019 – Consented to donation

11.3.2 Letter from DonateLife

Similarly, 94% of donor family members surveyed recalled receiving a letter from DonateLife. Almost all of these family members (99%) found the content of the letter helpful. This letter is usually sent to the nominated senior next-of-kin. As stated earlier, the National 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.

“ Some resources went to my Mum who didn't share it with us. Addressing all family with the letters or calling different members would have been helpful.”
2018 – Consented to donation

“ My mother was the primary contact for DonateLife. She may have received resources but didn't always share this with the rest of the family. My brother and I probably felt more out of the loop post-donation because of this.”
2018 – Consented to donation

11.3.3 Information about transplant recipients

Approximately 9 in 10 donor family members (89%) in the study received basic information about the transplant recipients from DonateLife. This is an improvement on Wave 4 findings, where 82% of family members received this information. All donor family members (100%) who received basic information about recipients found the information to be helpful.

Exploring the motivations for donation in Section 6.3, 78% of donor families saw donation as an opportunity for something positive to come out of a tragedy (the positive being to help others), and 74% of families wanted someone else to benefit from their family member's donation so that they may live a better life. The only way these motivations can be reaffirmed is if families are told the outcome of their family member's donation. Knowing a recipient's health is improving gave many of the donor families in the study a sense of relief and also a sense of pride in their family member. It solidified their decision about donation.

“ I would have liked to have had an update the first year on how the recipients were, to feel that it's not in vain. Maybe all three were still going the second year, but it would be good just to know.”

2019 – Consented to donation

“ Calls from DonateLife about recipients' progress was very helpful and brought peace and less worry.”

2018 – Consented to donation

11.3.4 Annual Service of Remembrance

A National DonateLife Service of Remembrance is held annually to commemorate the generosity of donors and their families. Events are also held across states and territories. These events offer an opportunity for families to gather and remember.

During 2018 and 2019, DonateLife's Services of Remembrance were held in person. However, due to COVID hitting Australia in early 2020 and the subsequent restrictions, most services in 2020 and 2021 were cancelled. Table 30 shows which jurisdictions were able to hold services, and which were not.

Table 30 Service of Remembrances held during 2020 and 2021

Year	ACT	NSW	NT	QLD	SA	TAS	VIC	WA
2020	Yes	No	No	No	Yes	No	No	Yes
2021	Yes	No	Yes	No	Yes	No	No	No

During 2020 and 2021, the Organ and Tissue Authority coordinated the online 'DonateLife National Service of Remembrance'. These were pre-recorded services that could be accessed via the DonateLife Facebook page and website at a specific advertised time for the live event, or at a later time that suited the viewer. During the live service and after, viewers could light a virtual candle via a link provided.

Approximately 4 in 5 (78%) donor family members in the study were informed about DonateLife's Annual Service of Remembrance. These figures don't significantly change when filtering the data to unique donor families (77% were informed of the service). Of these family members, 86% found the services helpful.

“ The service is very helpful for younger members of the family who attended.”

2018 – Consented to donation

Whilst the views reported in Wave 5 towards the Annual Service of Remembrance differed between donor family members (some didn't feel the need to attend; some had attended and found it unhelpful and distressing; some have attended and found it to be moving and worthwhile), findings indicate that donor family members should always be informed of upcoming services, so they can make an informed decision about their attendance.

“ I expected an invite to the Annual Service of Remembrance but didn't receive one. I'm not sure how to attend this.”

2018 – Consented to donation

“ To be truthful, after going to the remembrance ceremony, it put me off donating my organs. I felt that some of the recipients had no concept of the pain that was endured in order to have life. Some came across as not quite appreciating the enormity of how they received their gift.”

2018 – Consented to donation

11.3.5 Anniversary card

Among families who took part in the National Donor Family Study, who had reached the 12 month anniversary of their family member's death and donation, 84% had received an anniversary card (86% amongst unique donor families). The vast majority (92%) of those who received a card found it helpful. Receiving the anniversary card makes families feel that their family member is still being thought of and remembered. It means a lot to these families.

“ The thank you card 12 months later was just beautiful.”

2018 – Consented to donation

“ The card marking one year was unexpected, but very gratefully received. The one year mark is very difficult, and this gesture made it a little easier.”

2019 – Consented to donation

Three quarters (74%) of family members who intended to donate, also reported receiving a 12 month anniversary card. Almost all (94%) of these families found this gesture helpful.

“ DonateLife contacted us and sent a card. It's lovely because one of the things is that all these little things bring your loved one back to you, you know what I mean? It means they are remembering him as well.”

2018 – Intended to donate

The following comments from family members demonstrate that although the gesture of the anniversary card is appreciated, if not executed thoughtfully, it may not have the desired effect.

“ The anniversary card 12 months after donation was a lovely idea, but the writer of the card misspelt my daughter's name. This made me cry. It felt like her donation was not valued enough to even get her name right.”

2019 – Consented to donation

“ I felt the anniversary card was a little impersonal. However, I possibly wasn't in the greatest frame of mind to receive it.”

2019 – Consented to donation

Wave 5 results highlight that at a minimum, care should be taken by DonateLife staff to ensure details of the donor are completely accurate, prior to sending the anniversary card to families. Personalising the card (not simply a standard card that all families receive), will go a long way to demonstrating the genuineness of this gesture.

11.3.6 Donor family remembrance pin

Donor family lapel pins are given to families to wear to commemorate their family member's donation. During 2018 and 2019, 83% of donor families surveyed recalled receiving a pin. While a minority of family members found these pins 'gimmicky', most family members (87%) felt they were helpful.

“ They sent me some little hearts, it was so beautiful. The children all put them on their jackets, they wear them all the time. I thought that was beautiful.”

2019 – Consented to donation

“ Professional, informative, well thought out information at a time of such grief. My Mum took comfort in the pin, which acknowledges her loss.”

2019 – Consented to donation

“ The donor remembrance pins (we have received about 15!) seem like a waste of money. I'd rather see the dollars go to support services. It makes it feel cheap and gimmicky.”

2019 – Consented to donation

11.3.7 Other services to support families

Even though not every donor family member responds positively to all services and or items offered by DonateLife, findings indicate that it is still important to offer these to families. These resources let families know that they are being thought of and that their family member is still remembered. Even family members who initially opted-out of communication from DonateLife sometimes changed their minds as they progressed through their grief journey. Findings indicate that all families need to know that they can dip in and out of contact with DonateLife whenever they like.

Table 31 lists the responses to an open ended question asked of donor family members in the survey, “What other services could be offered to better support family members?”. As shown in the table, the highest responses centre around recipients – wanting to be updated more regularly, wanting to know more about the recipients, and wanting recipients to write to them. Almost three in 10 (29%) family members spontaneously raised this.

Table 31 Other services to support donor families

What other services could be offered to better support family members?	Wave 5 (n=167)
No other services necessary/ can't think of any/ not sure	31%
Nothing – I received all the information and support needed	5%
NET: Information/updates/ contact with recipients	29%
• How recipients are doing/ updates on recipients	22%
• Would like to meet recipients/ have more contact with recipients	7%
• Disappointed didn't receive letter from recipients	4%
More access to social workers/ counsellors/ chaplains (faith based counselling)/ CBT	9%
More contact in general/ more check-ins/ some contact from DonateLife after donation	7%
NET: Services and support for specific groups:	10%
• Support for specific groups: children/ young people/ men/ young widows/ widowers	4%
• Local donor family groups/ online support groups	7%
More information about the donation process/ keep families better updated throughout the donation process	2%
Allow more than one relative to be a contact person for DonateLife/ provide support for all family members	3%
More information and resources on how to cope with grief and trauma	2%

What other services could be offered to better support family members?	Wave 5 (n=167)
Nothing needed from DonateLife – prefer to source own support and resources	1%
Tailor support to each individual's situation/ need / ask people what type of support they want	5%
Case studies and/or stories of previous donations	1%
Create more awareness about donation/ strive for a higher profile of organ donation	1%
Other (1 mention each)	4%

“ I didn't really hear how the people were going after the initial phone call. I ended up calling DonateLife late last year to find out how the recipients were doing.”

2018 – Consented to donation

One in 10 (10%) families spontaneously stated that they were looking for more tailored resources and support, including for children and young people, men, widows/ers and those who had lost a family member to suicide.

“ Perhaps to offer specific support for children. My young adult sons and my teenage daughter may have benefited from separate specific support for them.”

2018 – Consented to donation

Families who declined donation felt they would have benefited most from bereavement counselling and support from a social worker. In fact, 41% of families who declined donation stated that information about bereavement support services would have helped them.

“ The offer of counselling. Having a bereavement group get in touch with you. It would be great to have a young widows group.”

2019 – Declined donation

11.4 Amount of contact with DonateLife

Most donor family members (85%) surveyed felt the level of contact they have had with DonateLife since their family member's death has been just right (Figure 45). This is a significant improvement on Wave 4, where 77% of family members felt this way.

“ We found all we needed through DonateLife. They weren't overbearing nor too minimal.”

2019 – Consented to donation

Conversely, 13% of donor family members felt they had not had enough contact with DonateLife since their family member died, a significant decrease since Wave 4's finding of 20%.

Figure 45 Contact with DonateLife staff

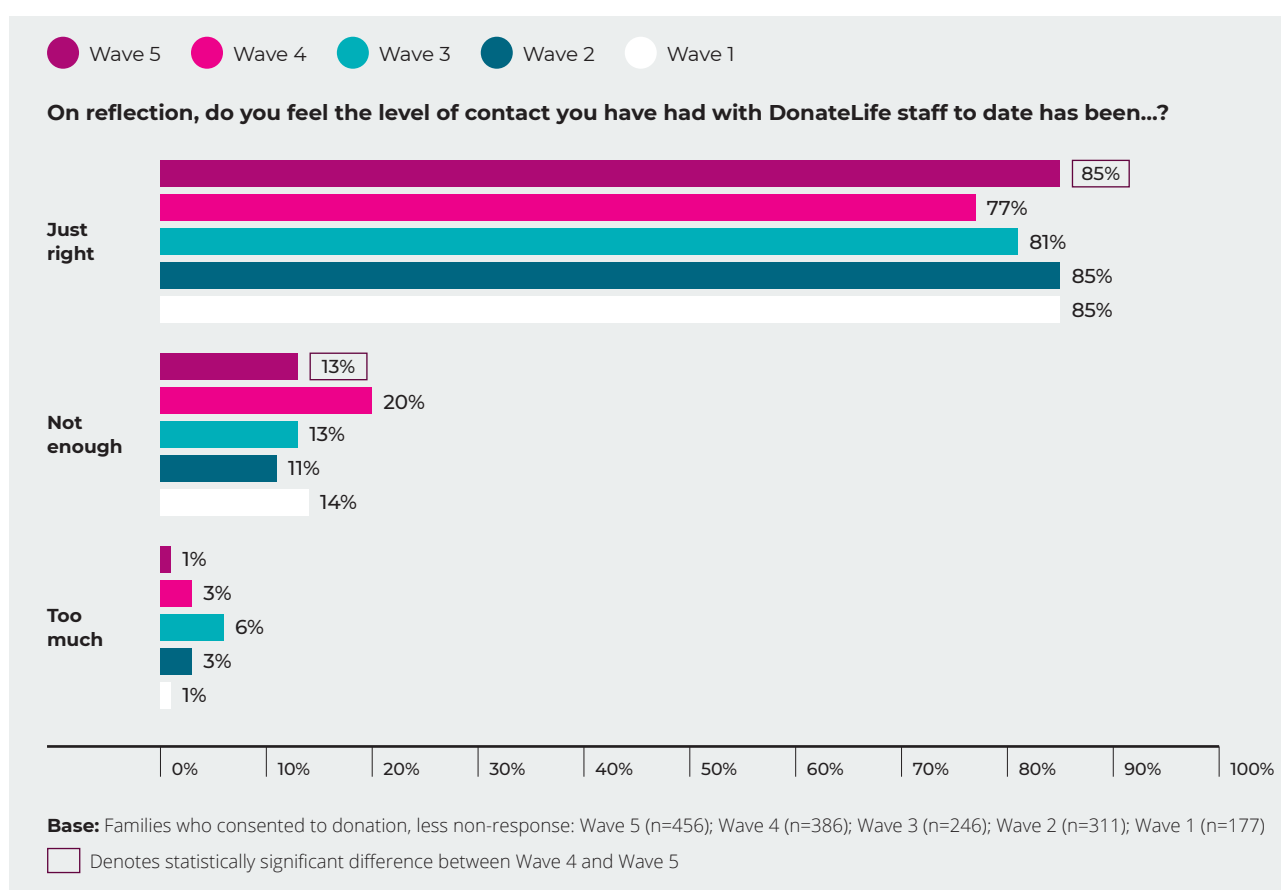


Table 32 shows the responses to the level of contact with DonateLife by state/territory.

Table 32 Level of contact with DonateLife staff, by state/territory

Amount of information	National (n=456)	QLD (n=91)	ACT (n=18)*	NSW (n=143)	VIC (n=131)	WA (n=33)	NT (n=4)*	SA (n=15)	TAS (n=21)
Just right	85%	89%	94%	79%	87%	82%	75%	93%	90%
Not enough	13%	9%	6%	20%	11%	15%	–	7%	10%
Too much	1%	1%	–	–	2%	3%	25%	–	–

* Caution: Small sample size

□ Significantly higher

“ I sent a text message to my Donor Coordinator just after the one year anniversary of my husband's death, thanking her for the card and asking for any news on how the recipients are going. I did not receive any response from her, even though we had communicated by text a number of times in the past. Having completed this survey, I am motivated to follow up my request for news on the recipients by phoning the organisation directly.”

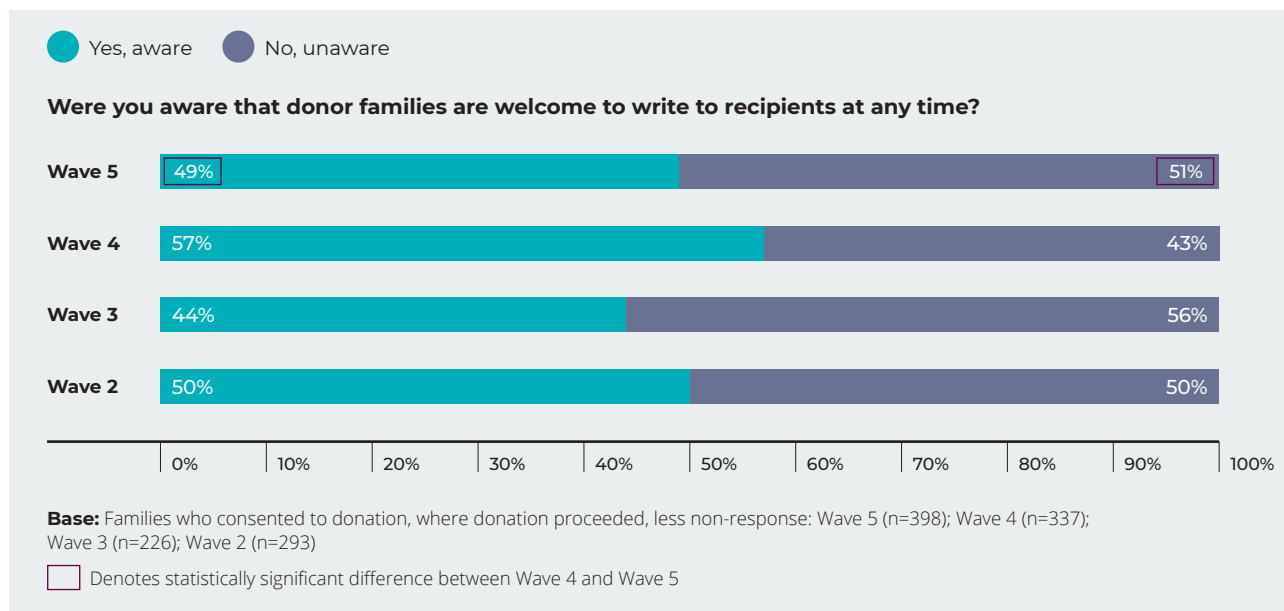
2019 – Consented to donation

12 Contact with recipients

12.1 Writing to recipients

In Wave 5, half (49%) of donor family members knew that they may write to recipients at any time. This is a significant decrease since Wave 4, down from 57% (Figure 46).

Figure 46 Writing to recipients



“ If I had known I could write to recipients I would have done so. Would still be willing to do this if the opportunity were given to me.”

2019 – Consented to donation

“ I did know we could write to a recipient but I thought it was only in response to the recipient making contact.”

2019 – Consented to donation

Wave 5 findings indicate that not every donor family member felt the need to write to recipients, however it is valuable for all families to know that this option is available. As shown in the following comment, even though this option is overtly stated in the DonateLife resources provided to family members, resources were not always read thoroughly and families have felt overwhelmed with the amount of information provided.

“ In looking at the ‘In Reflection’ book again today, I can see that it does say, ‘you may wish to write to recipients or respond to their letters through the same channels’, but that information did not sink in for me at all. I knew there could be non-identifying correspondence, but I believed it was the recipient’s choice to initiate that if they wanted to, and since I didn’t hear from either of them, I thought they must not want contact.”

2019 – Consented to donation

Consistent with feedback from families in previous waves, there were mixed views about writing to recipients. Some donor families felt that recipients should initiate contact; others wanted to write but didn’t know where to start or if their correspondence would be welcome; and others had no desire to write to recipients. In any case, DonateLife has a place in managing expectations, as there is the potential for donor families to be disappointed if they write to recipients and their correspondence is not reciprocated, or they may wonder if their letters have been sent and received in the first place.

“ I bought beautiful cards and wrote letters to these two people and I’ve never ever heard anything back from one. What I found really disappointing was that I sent those two cards to the recipients and there’s no evidence that they have received them. I honestly believe that if she had received that letter, she would have responded. You make this huge decision to be involved in the donation process on behalf of someone you love so much and then to feel like ... I just feel like even though they are grateful that you’ve been involved and you do it not to be thanked, but because you really want to know you’ve helped someone, but how do you ever know if you’ve helped? Even if DonateLife could just let you know that.”

2018 – Consented to donation

While not asked as part of the research, some donor families spontaneously raised their disappointment in not being able to talk openly about their family member in correspondence to recipients. Using their family member's name and talking about the type of person he/she was helps families with the grieving process. In a way, this helps to keep their family member's memory alive. Families reported finding the restrictions regarding what can and can't be said in communications frustrating.

“ We did receive a letter from one of the recipients which was nice, in that it showed someone had benefited. But it was weird as well, so strangely anonymous and de-identified. That still makes me feel uncomfortable.”

2018 – Consented to donation

Wave 5 results demonstrate that further communication is needed to ensure donor family members are aware that they may write to recipients at any time, via DonateLife.

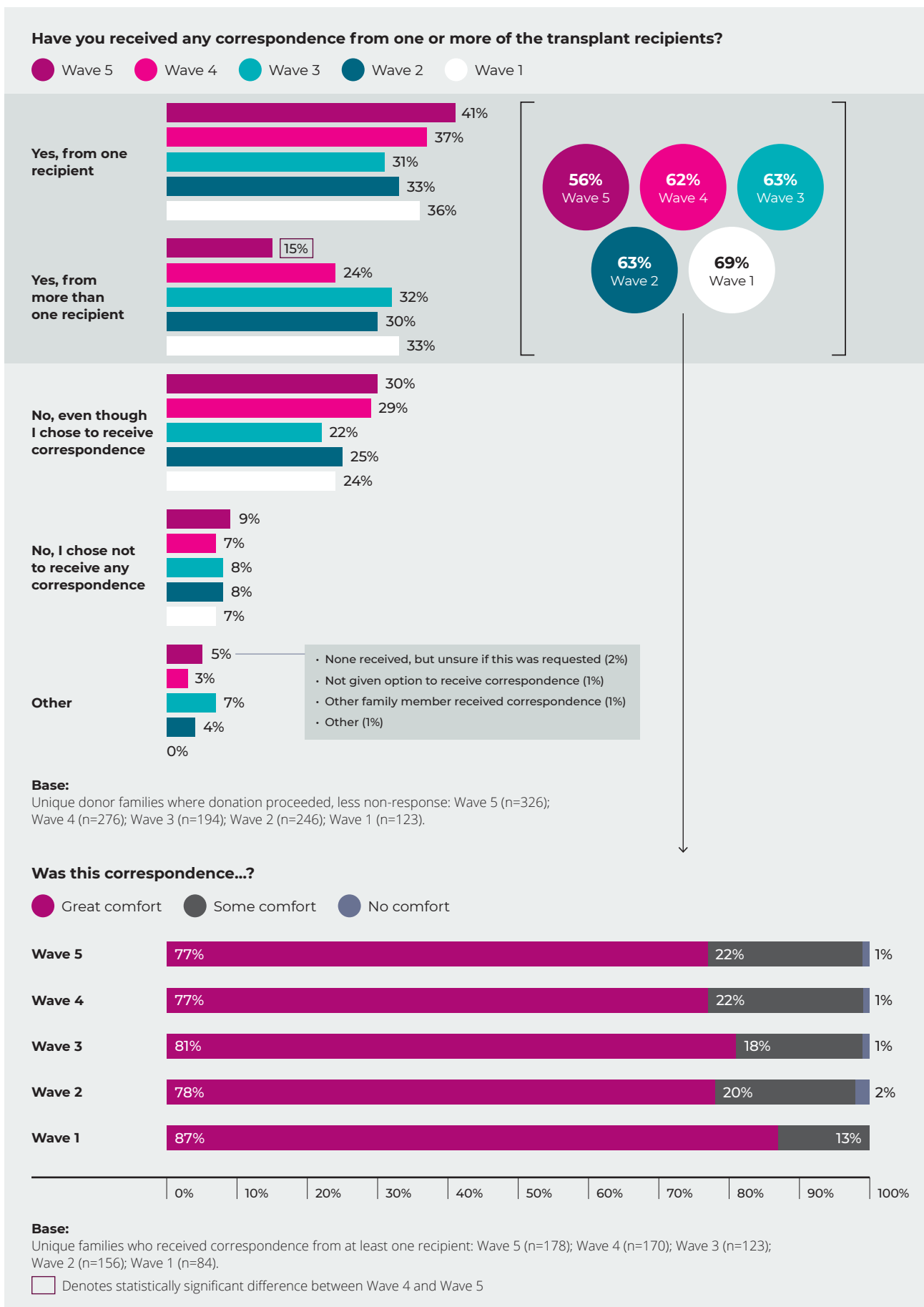
It is important to manage expectations by not promising a response from the recipient.

It is also important to explain to families why correspondence is anonymous in line with Australian legislation and policy to protect donor and recipient identification.

12.2 Deidentified contact with recipients

More than half (56%) of Wave 5's unique donor families have received a letter from at least one transplant recipient (Figure 47) since donation. This is consistent with earlier waves. The vast majority of those who received correspondence from recipients were comforted by this (77% found the correspondence to be of great comfort; 22% of some comfort). This is further explored in the following section.

Figure 47 Deidentified contact with recipients



12.2.1 The benefit of hearing from recipients

The moment when a donor family member receives a letter or card from a recipient or a recipient's family was described by families in the study as bittersweet. It stirred up feelings of loss and heartbreak, but at the same time, knowing that another person benefited from their family member's donation gave some meaning to their loss.

“ I most appreciated the letters and cards from recipients. I cried each time receiving them but they are so touching and their gratitude is beautiful. I found the acknowledgement of what a great gift his donations were really helped me.”

2019 – Consented to donation

As shown in Figure 47, 99% of family members who received correspondence from recipients felt comforted at that time. However, it is often reported as more than this; hearing from recipients reaffirmed the donor family's choice to donate (see Figure 48). It made them feel that their family member's death wasn't in vain, it filled them with pride for their family member, and most importantly, hearing from recipients helped donor families to heal.

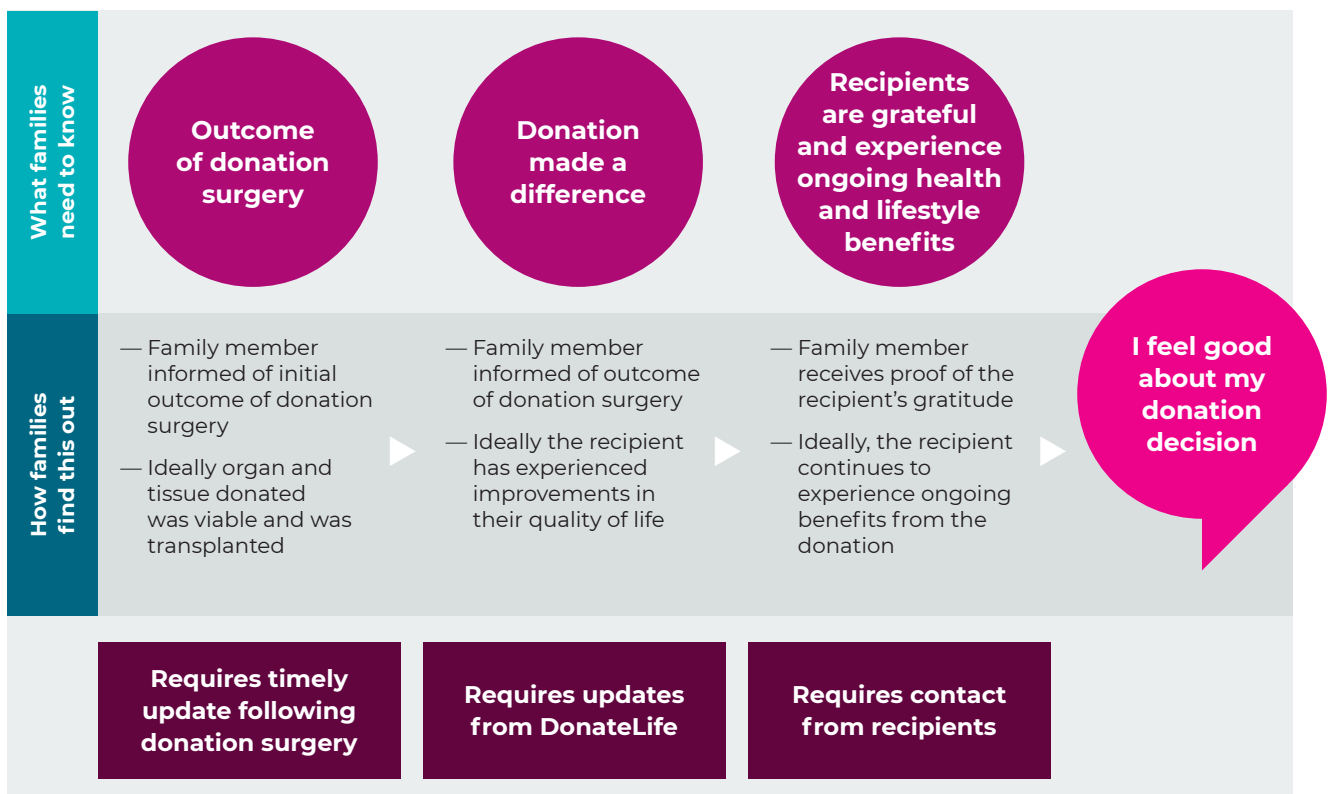
“ Oh, it was the most beautiful thing to know that they're grateful. It was like healing for us, especially for my kids. I've got adult daughters and they were healed to know that their Dad has saved someone's life.”

2019 – Consented to donation

“ It would make my day... make my year. It would make everything if I did hear from them. That would be incredible. Just to know that they are doing well and getting on with their life. I would love to hear from them because there is always something missing. There is always a very small element of doubt, 'have I done the right thing? Have I made the decision that my daughter would have made?'. I think even just hearing from them would help that....”

2018 – Consented to donation

Figure 48 Affirming the choice to donate – The role of information about recipients



The study showed that when recipients do not reach out to donor families, the next best thing is for DonateLife agencies to provide donor families with broad health updates on the recipients. It is important to note that not all donor families reported the need for this. For the most part, however, donor family members looked for and were appreciative of updates.

“ Since donation, I've had to request numerous updates on how the recipients are progressing because it is very important to me to know this. After learning all recipients are progressing well, it brought so much warmth to my broken heart. The only disappointing aspect about this was that I had to chase this information up myself. In fact, the only time I get to hear how the recipients are progressing is if I ask for this specific information. I actually feel like I am bothering my contact at DonateLife when I request an update, and I don't think it should feel like this.”

2018 – Consented to donation

“ We would like to see more on the recipients who received our son's organs and a regular update on how they are.”

2018 – Consented to donation

“ Maybe DonateLife could give more updates to the donors about the recipients e.g. after 1 year, 5 years, 10 years.”

2019 – Consented to donation

12.2.2 Impact of no contact from transplant recipients

At the time of the study, 30% of families who donated organs and/or tissue in 2018 and 2019 had not received any correspondence from recipients, even though they had chosen to (Figure 47). This is consistent with previous waves.

Family members who had yet to hear from recipients were asked how they felt about this. Responses have been coded and are shown in Table 33, tracked against findings from previous research waves. Those who wanted to hear from recipients were disappointed and sad that that this had not happened. They would love to know how recipients are progressing. Those who opted out of contact with recipients mostly felt fine about not hearing (40%) or felt that the act of donating was enough (47%).

“ It doesn't bother me. As long as it helps someone with future quality of life.”

2018 – Consented to donation

“ It's fine. I don't need that for closure. I don't want the recipient to feel under obligation.”

2019 – Consented to donation

Table 33 Impact of not receiving correspondence from recipient

How do you feel about not receiving any correspondence from transplant recipients?	Wave 3 (families in 2014/15)		Wave 4 (families in 2016/17)		Wave 5 (families in 2018/19)	
	Wanted to receive (n=43)	Chose not to receive (n=12)*	Wanted to receive (n=75)	Chose not to receive (n=16)*	Wanted to receive (n=106)	Chose not to receive (n=30)
Disappointed/ bitter/ sad	23%	–	36%	–	28%	–
Would like to receive correspondence from recipient	30%	17%	25%	25%	24%	3%
Would like to know the progress of recipients/ how donation helped/ who received organs	26%	–	33%	13%	25%	3%
A thank-you would be nice/ would show recipients' appreciation	21%	–	4%	–	10%	–
Fine/ ok about no correspondence	19%	33%	13%	13%	11%	40%

How do you feel about not receiving any correspondence from transplant recipients?	Wave 3 (families in 2014/15)		Wave 4 (families in 2016/17)		Wave 5 (families in 2018/19)	
	Wanted to receive (n=43)	Chose not to receive (n=12)*	Wanted to receive (n=75)	Chose not to receive (n=16)*	Wanted to receive (n=106)	Chose not to receive (n=30)
Feel disappointed, but accept that it may not be easy to write & respect privacy of recipient	14%	–	–	–	5%	–
Would help in the grieving process / would help provide closure and meaning	7%	–	3%	–	3%	–
Ambivalent / not sure I would want it	7%	17%	1%	13%	2%	7%
Would have liked correspondence but didn't know it was allowed/ wasn't offered this option	2%	–	1%	6%**	8%	3%**
Not entirely comfortable with receiving correspondence/ would rather not know	2%	17%	–	25%	2%	7%
Understand if recipients aren't up to it/ might not be easy/ it's their decision/ they will write when ready	–	–	13%	13%	16%	–
Donation was enough/ not necessary to receive correspondence/ enough to know others were helped	–	–	3%	13%	8%	47%
Another family member received correspondence	–	8%	1%	–	1%	7%
Other	5%	17%	4%	13%	4%	–

* Caution with small base

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

As stated earlier, hearing from recipients goes a long way towards healing for donor families. When donor families didn't receive any communication from recipients, the impact ranged from disappointment and sadness that their loss and gift had not been acknowledged, through to devastation and strong negativity about organ and tissue donation. This could lead to negative word of mouth and could potentially discourage others from deciding to donate.

“ If recipients are progressing well, I wonder if they were made to understand how much a letter could help a family on the other end? It would mean the world to me, especially when it feels like I have lost my world.”

2018 – Consented to donation

“ I think it would help if transplant recipients were advised that it might help donor families to write a short note to let them know they are well.”

2019 – Consented to donation

“ Sometimes I'm annoyed that I haven't got a letter from someone to say that they got her organ. You almost want people to be thankful. I don't regret it but sometimes it pisses me off because she meant so much to us so it should mean so much to them.”

2018 – Consented to donation

The findings support that there is benefit in DonatLife and the Organ and Tissue Authority continuing to work with transplant teams to convey the importance of recipients and recipient families corresponding with donor families.

13 On reflection

13.1 Gestures appreciated by families

Families who reflected positively on their hospital experience remembered how hospital staff made them feel. They recalled how staff treated their family member with respect and kindness, and how staff showed empathy and consideration towards them.

The following list collated from families in Wave 5 is not exhaustive; it provides examples of gestures and acts of kindness towards families and their family members that they remembered years later. These acts of kindness provided comfort for families when they needed it most. They let families know, in a subtle way, that they were valued and that their family member was important.

- Using their family member's first name when referring to them
- Speaking to their family member as if they can hear them (e.g. when conducting medical procedures)
- Suggesting that family members play their loved one's favourite music in ICU and/or theatre
- Suggesting that family members bring in photos from home to put around their loved one's bed
- Performing basic hygiene tasks on their family member (e.g. washing hair, moisturising hands and feet) and letting family members be involved in these tasks
- Letting family members stay overnight in the ICU with their loved one
- Making sure that family members look after themselves (get some rest, something to eat, coffee/ tea, etc.)
- Offering keepsakes (hand prints, locks of hair, photos etc.)

“ I can remember the nurse putting clean socks on his feet because his feet were rough. I remember them letting us sit with him all night and because we're Christians, we were able to speak blessings over him all night. That meant a lot to us. And they were not just treating us as a client or a number but they treated us as if they themselves understood what it would be like to lose someone you love.”

2018 – Intended to donate

“ The nurse said to me, ‘what's his favourite songs? What does he like?’ So he played the songs that he liked while he was doing the computer work. I thought that was wonderful.”

2018 – Consented to donation

“ We were able to set up a private area, have a photo board, flowers and music while waiting for the day of his donation. It was an incredibly moving experience.”

2019 – Consented to donation

“ When I went to visit him they said, ‘the room is yours’, so I really appreciated that. I created music and I danced around with him. I was quite loud, so I thought, ‘okay, I'm being me with my husband’ and they allowed it! They allowed me to grieve, however abnormal that was. And then after when we were going to turn him off, they let the whole family come in. They let groups of 10 people at a time come to sing to him, and it was beautiful. In our culture, this is how we grieve. In his dying bed we come in mass. And they allowed it. They just gave us so much accommodation to let that happen. It was kind of like a service because each culture or each family group who came was able to sing a song and say a prayer, in the ICU, and I really appreciated that. It was beautiful, it really was. It made me feel heaps better.”

2019 – Consented to donation

“ We asked if we were able to make a playlist for them to play in the theatre, which they agreed to, so that was good. That almost gave us a mission, you know, a project to do that night. He loved music, that was his thing. You know, obviously he had passed away but in our minds he was going out with his favourite tunes.”

2019 – Consented to donation

These little actions and gestures were the things that families remembered. They provided some light to the dark memories that families had of their time in hospital with their family member.

The Donor Family Study continues to highlight that the level of care, consideration and compassion shown to family members and their loved ones must continue to be consistently high at all times – before and after the decision about donation has been made, irrespective of a consent or a decline response.

Continuing to demonstrate kindness and thoughtfulness towards families and their loved ones, is reported by families to help tremendously.

13.2 Reflecting on the decision to donate

Families who consented to donation were asked to reflect on their decision about donation and their time in the hospital, and asked if they would like to add anything to their survey responses about their decision to donate. Coded responses are shown in Table 34. The most common responses from families were that donation provided comfort to them and helped the grieving process (26% spontaneously said this), and that donating was the right decision (25%).

Table 34 Additional comments from consenting families about decision about donation

Is there anything else you'd like to add about your decision to donate?	Wave 4 (n=171)	Wave 5 (n=178)
Donation provided comfort/ some good in a bad time/ knowing they saved lives made their life feel more meaningful / helps the grieving process	24%	26%
Happy with decision to donate/ thought it was the right decision	13%	25%
Support organ donation/ believe Australia should have an "opt out" system	6%	14%
Our family wanted to help others / opportunity to help others	5%	11%
It was our family member's wish to donate	11%	10%
Support and contact from hospital staff and donate team was excellent (comforting/ informative)	10%	10%
We felt by his/her nature that they would have wanted to help others	5%	7%
Very difficult decision	2%	6%
Would choose to donate again / have encouraged others to register	2%	4%
Sad and disappointed that some organs were not used / recipients were not found	–	4%
Was a positive experience / an honour / privilege	2%	4%
Needs to be a faster process once the decision to donate has been made / timeframes should be better explained	4%	3%
Felt pressured to donate / were not given sufficient time to think about it	–	3%
Would like more information/ updates on recipients/ to hear from recipients	5%	3%
Receiving updates about recipients provides comfort/ makes us think that donation was appreciated	2%	3%
Donation process is difficult/ arduous/ stressful / could put some people off	–	3%
Hospital staff/ donate team need to be better trained	2%	3%
Dispute about next of kin in hospital/ staff not recognising or including certain family members in discussions	–	2%
Would not choose to donate again	5%	1%
Meeting with Donatelife staff too lengthy/ questions too personal	–	1%
Other (one response each)	12%	7%

Significantly higher than Wave 4

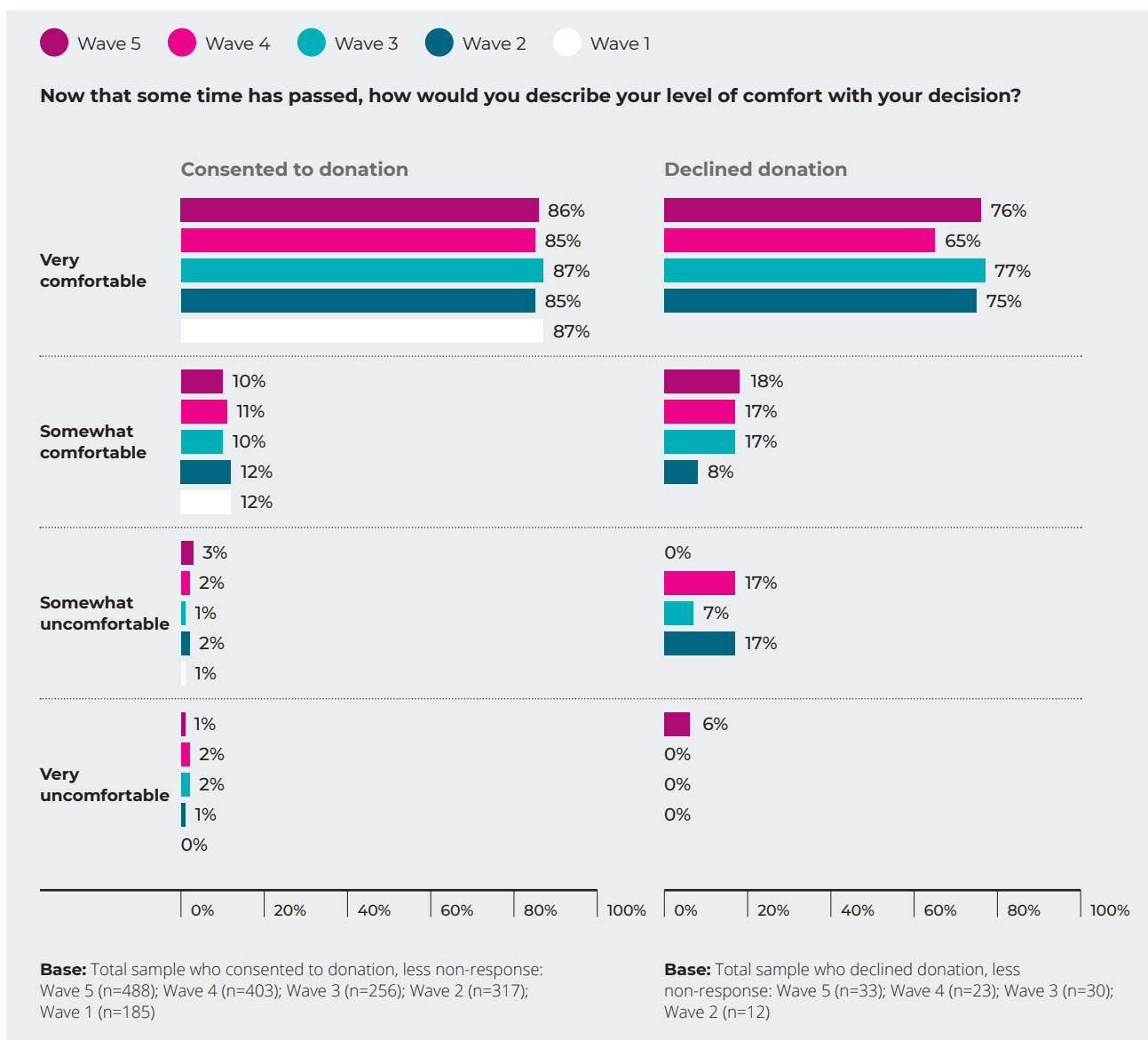
13.3 Level of comfort in decision about donation

For 96% of families who consented to donation, the decision about donation made in 2018 and 2019 still sits well with them now; 86% very much so (Figure 49). This is consistent with families in 2016 and 2017. However, *intended* donor families are less likely to feel comfortable with their decision about donation (14% feel uncomfortable with their decision, compared to 3% of families where donation proceeded).

“The people involved were excellent; very supportive and informative. Still, I wish we had known that the chances of finding a recipient were almost impossible.”

2019 – Intended to donate

Figure 49 Level of comfort with decision about donation



Almost all families surveyed (94%) who declined donation were still comfortable with their decision to decline (76% very comfortable). The 24% of families who declined donation who were not entirely comfortable with their decision said that it is because they went against their family member's wishes to donate, because they were swayed by the views of others in their family. Others found the approach to donation by hospital and DonateLife staff, the pressure to decide, or the description of the donation process at the time, to be off-putting. They declined donation but now feel that if they had more time to make their decision, or if the approach was different, they may have consented instead.

“ I think his organ donation would have been very useful. He was fit, healthy and strong. The suddenness of his death didn't give me time to think through more clearly what would have been a positive thing (donation).”

2018 – 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 35.

Table 35 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)	Wave 5 (n=58)
Not sure if decision was right/ not sure what family member would have wanted	18%	13%	23%	8%	21%
Difficult coming to terms with the death	9%	10%	4%	12%	19%
Donation process was unsatisfactory / time consuming/ intrusive	9%	5%	4%	16%	16%
Donation didn't proceed: disappointment and unwanted stress and subsequent loss of time with family member	5%	5%	12%	6%	10%
Not all family members agreed	–	–	–	4%	10%
Not enough information about recipients/ not enough communication from recipients/ no 'thank you' from recipients	14%	15%	19%	18%	9%
Felt rushed and pressured	9%	10%	19%	12%	7%
Difficult to come to terms with family member's body not being 'whole'/ hard to 'give away' part of family member	9%	10%	12%	4%	5%
Was treated insensitively by hospital staff	5%	5%	8%	4%	5%
Feels macabre / ghoulish going through every body part during informed consent	–	–	–	–	5%
Unsure whether family member was dead at time of retrieval / wonder if family member felt pain during donation surgery	5%	10%	4%	2%	3%
Feels strange that a part of our family member is in someone else's body	–	–	–	–	3%
Felt misled by hospital staff about donation due to family member's age	–	–	–	–	3%
Religious beliefs / afterlife beliefs	–	–	–	–	3%
Lack of compassion and support after / once decision was made / felt like donor and family no longer mattered	5%	5%	8%	4%	2%
Fear that consenting to donation influenced clinical decisions / was life support removed too soon?	5%	5%	8%	6%	–
Other response	32%	13%	12%	10%	7%

Key triggers that have led to some level of regret for families include; not knowing their family member's donation wishes (21%), a time consuming and difficult donation process (16%), and lack of contact from recipients or information about recipients (9%).

In addition, 10% of family members surveyed were not comfortable with their decision to consent to donation because all or some organs could not be used.

“ I didn't fully understand that there may be organs that would not be viable. I think that was the hardest part that every time another organ was rejected, it was adding to the impact of losing a loved one.”

2018 – Consented to donation

13.4 The impact of donation

Almost all (96%) family members where donation proceeded found comfort in donation. This is significantly higher than Wave 4 families (91%). As shown in Figure 50, the times when donation provided the greatest comfort were:

- Immediately, at the time of donation – 74%
- When receiving initial letter from DonateLife – 55%
- When receiving correspondence from recipient – 49%

These findings show that donor families need to know that their donation served a worthwhile purpose – that it made a positive difference to another person's life.

“ They did tell me what they took; his kidneys and liver. Oh, I was happy as. I was so happy, I really was, because my husband was selfless. He would have been happy too.”

2019 – Consented to donation

“ It helped the family in knowing my son has helped four people who otherwise may not still be around.”

2018 – Consented to donation

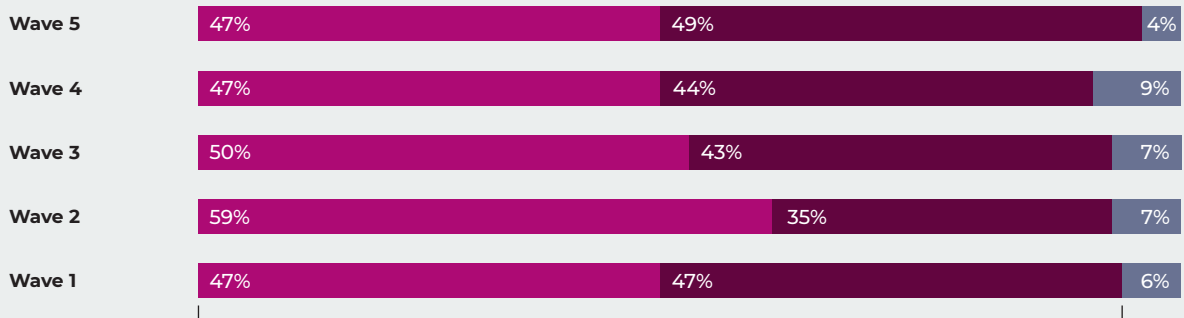
“ I was very fortunate to receive one letter from a recipient's mother. She told me all about her son and about his new lease on life. This letter made it all worthwhile. Knowing my daughter gave him another opportunity to live his life to the fullest gives so much to myself, it's beyond words.”

2019 – Consented to donation

Figure 50 The impact of donation

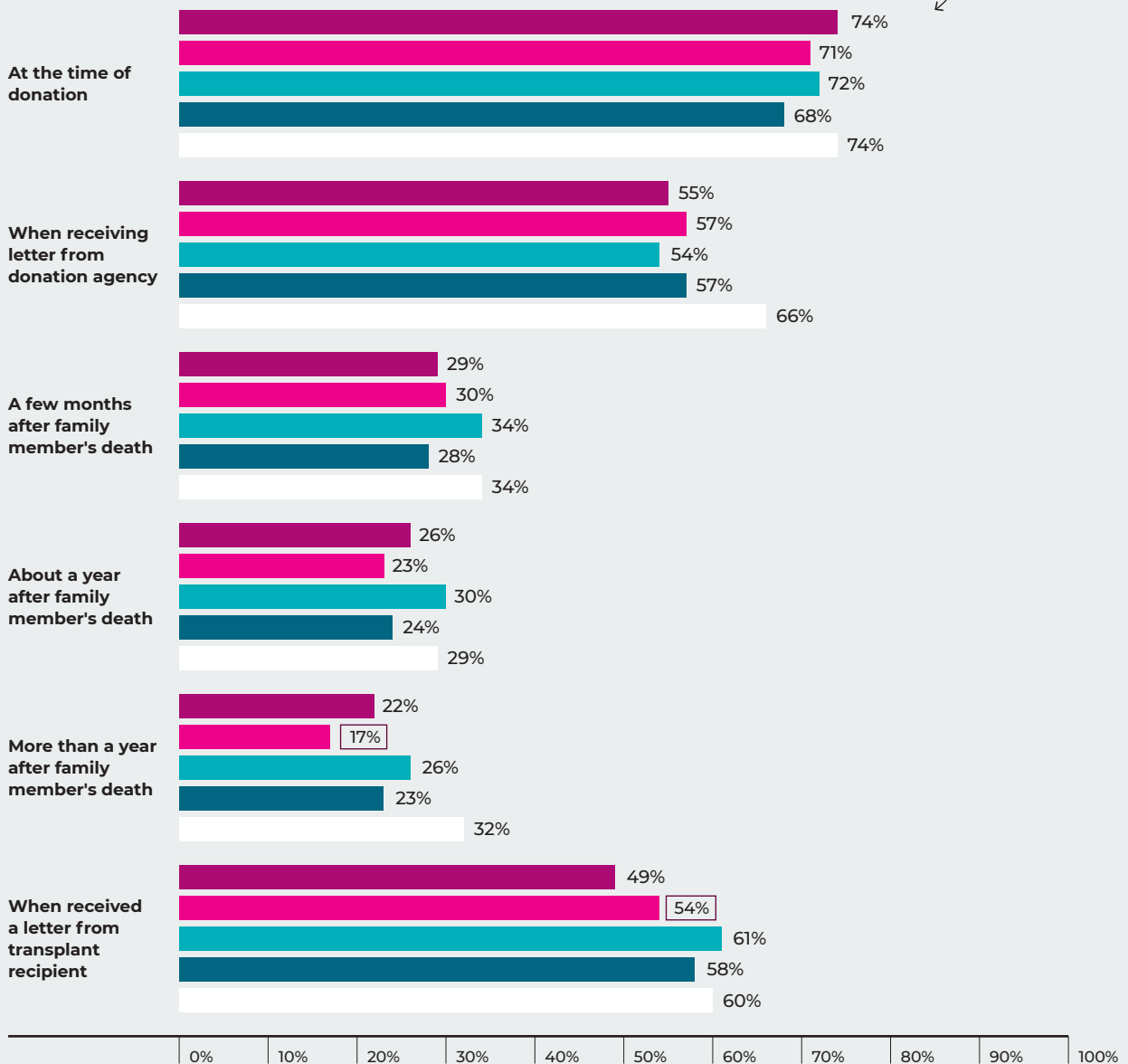
Has donation provided you with any comfort in your loss?

● Yes, a great deal of comfort
 ● Yes, some comfort
 ● No



When have you found comfort in the donation?

● Wave 5
 ● Wave 4
 ● Wave 3
 ● Wave 2
 ● Wave 1



Base: Total sample where donation proceeded, less non-response: Wave 5 (n=401); Wave 4 (n=344); Wave 3 (n=234); Wave 2 (n=302); Wave 1 (n=180). Those who found comfort in donation, less non-response: Wave 5 (n=370); Wave 4 (n=304); Wave 3 (n=207); Wave 2 (n=276); Wave 1 (n=167). Multiple responses allowed.

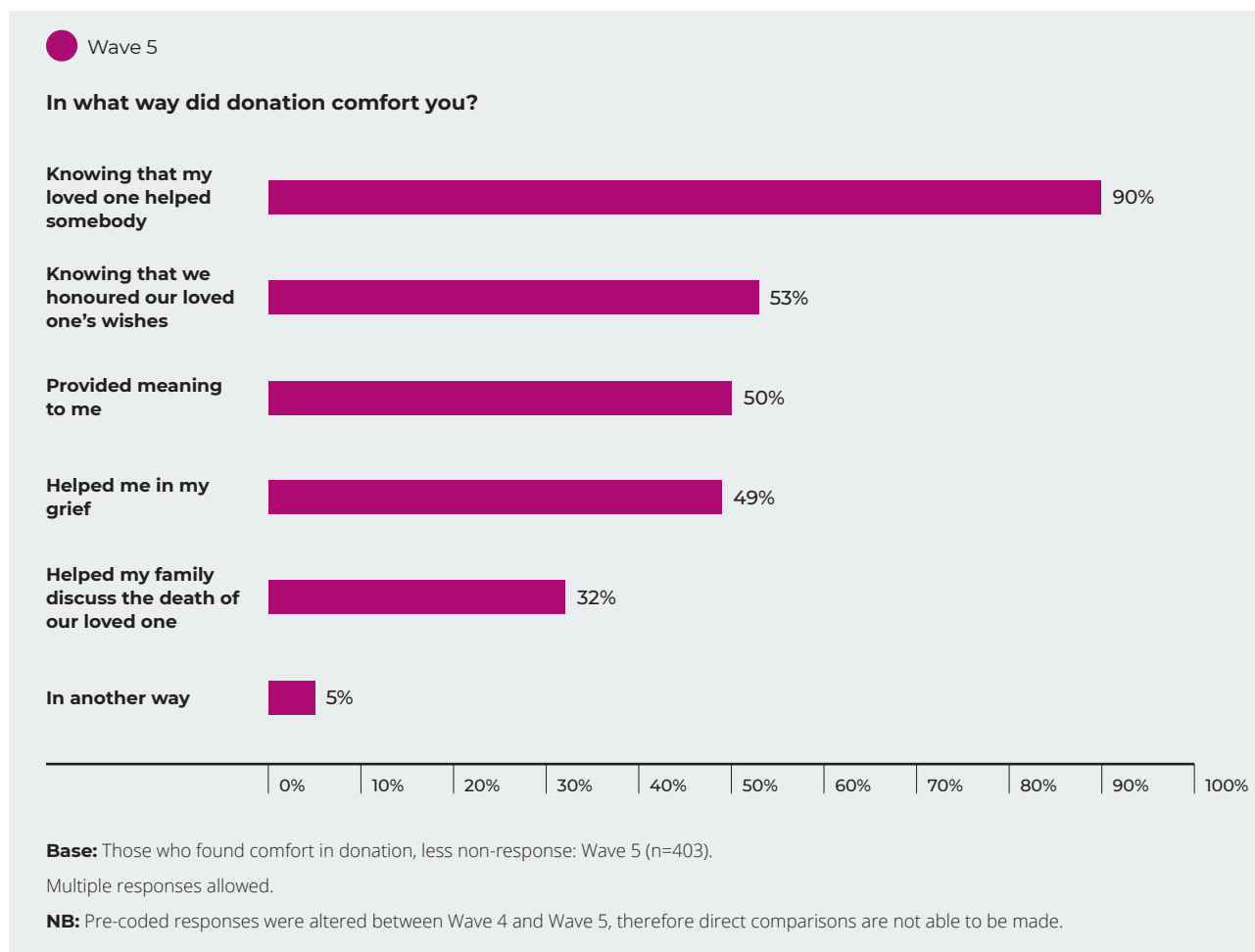
 Denotes statistically significant difference from previous wave

In terms of *how* donation provided comfort, 9 in 10 donor families (90%) felt comfort in knowing that their family member's donation had helped another person. Half (53%) of donor families in Wave 5 were comforted by knowing that they did what their loved one wanted – they honoured their loved one's final wish. In addition, half of donor families (49%) stated that donation helped them in their grief (Figure 51).

“ It is nice to know that he has helped other people and having the contact giving us updates when we ask about the recipients has been helpful in our healing process. It also gives us the feeling that his donation was meaningful and we haven't just been forgotten. We have felt appreciated for helping others.”

2018 – Consented to donation

Figure 51 The ways in which donation has provided comfort



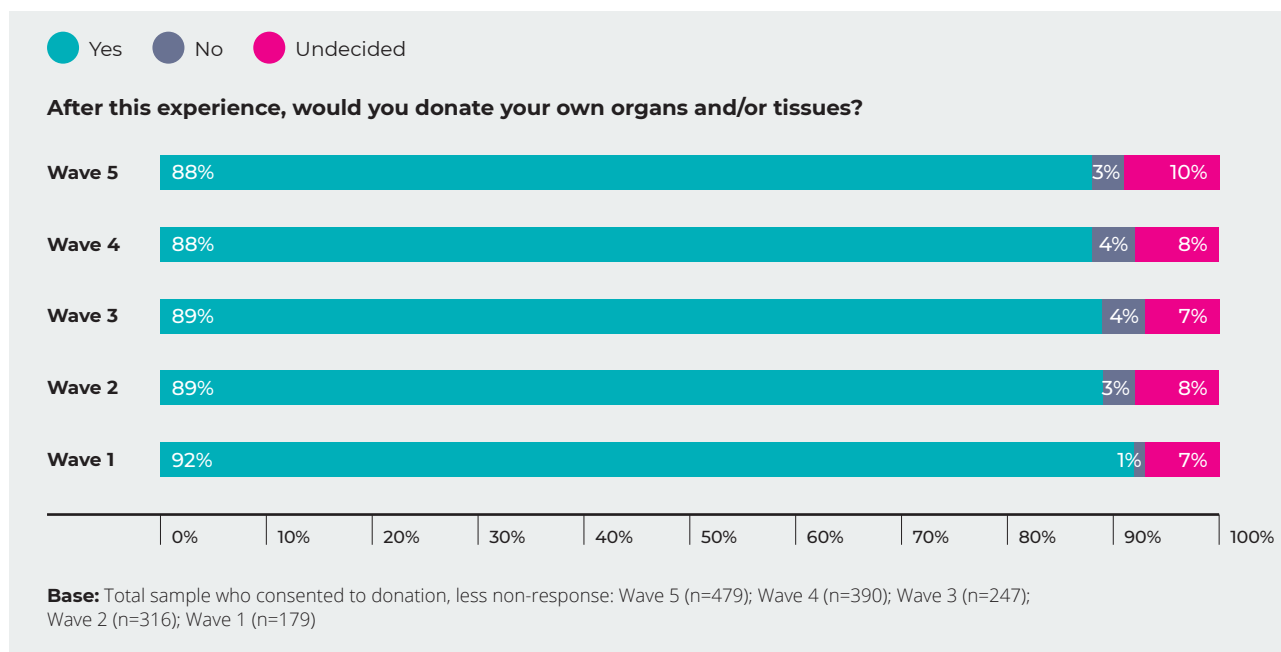
13.5 Future intentions

After the donation experience, 88% of family members surveyed who consented to donation, would donate their own organs and/or tissues after death (Figure 52). There has been no significant change in this sentiment since Wave 1 of the Donor Family Study. Ten percent (10%) of donor family members are undecided, while 3% state that they would not wish to donate.

“ It is the morally correct thing to do. It gave me great joy to know the impact organ donation from my brother gave to the recipient. I would like to think I could maybe do that for someone one day.”

2018 – Consented to donation

Figure 52 Impact of experience on decision to donate own organs and/or tissues



The 12% of family members who consented to donation but now, after their experience, oppose it for themselves or who are undecided, mostly felt this way because they found the donation process to be too traumatic (30%), or they were disappointed with DonateLife (9%). In addition, 9% felt that their donation wasn't valued because they have not heard from recipients, and this negatively impacted their view of organ donation.

“ I was always very pro-organ donation, but after my experience with my brother, I don't know if I'd put my family through it. It was trauma on top of trauma.”

2019 – Consented to donation

“ Before the donation, we were told that we would be kept in close contact and updated with information about the recipient, and donor family gatherings would be organised. However, these were not honoured.”

2019 – Consented to donation

Further, a substantial proportion (26%) of family members in Wave 5 felt that their organs would not be useful because of their age or medical history. Coded responses are shown in Table 36.

Table 36 Reasons for not wishing to be a donor if situation arose

Please share your reasons for feeling this way (if answered 'no' or 'not sure' about intentions to donate own organs and/or tissues)	W5 (n=43)
Process too traumatic/ difficult/ confronting/ lengthy/ insensitive/ pressurised	30%
Not sure if organs would be viable (due to medical reasons or age)	26%
Ambivalent/ undecided (no further information provided)	16%
Unhappy with DonateLife/ pressure/ not kept us informed/ broken promises	9%
Gift not appreciated/ haven't heard from recipients	9%
Will leave decision up to my family	5%
Death was prolonged because of donation	5%
Fear of organs not being put to good use	5%
Not treated well in hospital/ lack of support after donation surgery	2%
No explanation given/ would rather not say	2%
Our family has done our part	2%
Religious reasons	2%
Don't want to be on life support	2%

Findings show families who intended to donate but donation could not proceed were less likely to feel positively about their experience, and therefore less likely to wish to donate their own organs and/or tissues after death (77% compared with 89% of family members where donation proceeded, as shown in Table 37).

Table 37 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?	DCDD (n=152)	DNDD (n=304)	Donated (n=407)	Intended (n=56)
Yes	88%	87%	89%	77%
No	2%	3%	2%	7%
Undecided	11%	10%	9%	16%

□ Significantly lower □ Significantly higher

“ I am 65 and my husband was the same age and they couldn't use any of his organs so I find it a waste of time that my children don't need to go through.”

2019 – Intended to donate

Among families in the study who declined donation in 2018 and 2019:

- 83% would make the same decision again (consistent with Wave 4, at 83%)
- 7% would make a different decision about donation (i.e. they would consent)
- 10% are unsure (17% in Wave 4)

“ I would need the discussion about organ donation to be handled with a higher level of care and sensitivity and with more careful timing.”

2018 – Declined donation

“ We respected our loved one’s belief. We, as a family, made the correct decision.”

2019 – Declined donation

Table 38 shows that prior to their donation experience, 86% of family members held positive views about donation, 12% had mixed feelings and 1% held negative views. This is consistent with Wave 4 findings.

As seen in previous comments from families in Wave 5, 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 family member’s death, half (53%) are now in favour of donation for themselves (Table 38).

Table 38 Impact of donation experience on personal views

Previously held views about donation	Total (n=490)	Would donate own organs and/or tissues?	
Generally positive (n=413)	86%	Yes	93%
		No	1%
		Undecided	5%
Mixed feelings (n=59)	12%	Yes	53%
		No	12%
		Undecided	36%
Generally negative (n=6)	1%	Yes	33%
		No	–
		Undecided	67%

14 Summary of comparison between waves

This section of the report provides a reference to observe the comparison between research data collected from families who **consented to donation** from all waves of the Donor Family Study, comprising:

- Wave 1 – sample size of n=185 family members
- Wave 2 – sample size of n=319 family members
- Wave 3 – sample size of n=257 family members
- Wave 4 – sample size of n=405 family members
- Wave 5 – sample size of n=491 family members

Statistically significant differences between Wave 4 and Wave 5 are denoted by the following symbols:

□ Significantly lower than Wave 4 □ Significantly higher than Wave 4

14.1 The decision to donate

Experience		W1	W2	W3	W4	W5	Location
Prior discussion – Consented to donation	Yes and knew wishes	59%	59%	63%	54%	50%	Figure 8
	Yes, but unclear on wishes	9%	9%	8%	12%	11%	Figure 8
	Did not discuss	32%	32%	29%	34%	38%	Figure 8
Impact of knowing wishes of family member (amongst those who had previously had discussion):	Made decision a lot easier	76%	80%	74%	70%	67%	Table 11
	Made decision a bit easier	13%	11%	15%	17%	13%	Table 11
	No impact	10%	8%	7%	12%	17%	Table 11
	Made decision a bit more difficult	2%	1%	4%	2%	2%	Table 11
	Made decision a lot more difficult	–	–	–	–	1%	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%	78%	Figure 11
	For someone else to live a better life	74%	66%	72%	67%	74%	Figure 11
	Family member would have wanted to help others	80%	76%	76%	77%	72%	Figure 11

14.2 At the hospital (prior to consenting)

Experience		W1	W2	W3	W4	W5	Location
Hospital staff treated family with consideration and sensitivity	To a great extent	89%	91%	90%	91%	91%	Figure 12
	To some extent	11%	8%	9%	9%	8%	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%	97%	Figure 13
	No	4%	2%	4%	4%	1%	Figure 13
	Not sure	2%	3%	1%	2%	2%	Figure 13
Was given enough information to understand that death was expected	Total agree	99%	97%	98%	95%	98%	Figure 14
	Disagree/not sure	1%	3%	2%	5%	2%	Figure 14
Language used by medical staff was clear and easy to understand	Total agree	99%	98%	96%	98%	99%	Figure 14
	Disagree	1%	2%	4%	2%	1%	Figure 14
Hospital staff treated me with compassion and sensitivity	Total agree	99.5%	99%	99%	98%	99%	Figure 14
	Disagree	0.5%	1%	1%	2%	1%	Figure 14
Hospital staff treated my family member with respect	Total agree	99%	99%	98%	98%	99%	Figure 14
	Disagree	1%	1%	2%	2%	1%	Figure 14
Had sufficient opportunity to ask questions of hospital staff	Total agree	97%	96%	97%	96%	98%	Figure 14
	Disagree/not sure	3%	4%	3%	4%	2%	Figure 14
Had enough private time with family member <u>after</u> receiving grave news	Yes	91%	91%	89%	89%	91%	Figure 18
	No	7%	6%	5%	7%	5%	Figure 18
	Not sure	2%	3%	6%	4%	4%	Figure 18
Brain Death Testing							
Offered to be present during brain death testing	Yes	24%	24%	25%	36%	25%	Figure 16
	No	50%	62%	56%	46%	54%	Figure 16
	Not sure	26%	14%	19%	18%	21%	Figure 16
Chose to be present during brain death testing (among those who were offered)	Yes	55%	73%	68%	66%	67%	Figure 16
	No	45%	27%	32%	34%	33%	Figure 16
Seeing tests helped in understanding that loved one had died (among those who attended brain death testing)	Yes	91%	91%	72%	85%	86%	Figure 16
	No/not sure	9%	9%	28%	15%	14%	Figure 16
Would have helped to have option of being present (among those who were not offered)	Yes	18%	20%	22%	24%	17%	Figure 16
	No/not sure	82%	80%	78%	76%	83%	Figure 16

14.3 The donation conversation

Experience		W1	W2	W3	W4	W5	Location
Who initially raised donation	Doctor	29%	34%	26%	29%	30%	Figure 19
	DonateLife staff member	13%	21%	26%	27%	28%	Figure 19
	Nurse	4%	7%	9%	6%	5%	Figure 19
	Health professional - Net	46%	58%	53%	57%	60%	Figure 19
	Self	20%	22%	26%	22%	20%	Figure 19
	Family/friend	10%	11%	9%	15%	8%	Figure 19
Self/family - Net	30%	33%	33%	33%	27%	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%	10%	Figure 23
	At the same time	40%	38%	28%	29%	36%	Figure 23
	Within 1 hour	24%	17%	26%	24%	17%	Figure 23
	More than 1 hour	12%	19%	14%	19%	22%	Figure 23
Appropriateness of timing	Yes	74%	73%	74%	77%	76%	Figure 24
	No/not sure	26%	27%	26%	23%	24%	Figure 24
Discussions with hospital staff about donation prior to decision about donation being made							
Discussions were handled sensitively and with compassion	Total agree	98%	96%	97%	97%	98%	Figure 26
	Disagree/not sure	2%	4%	3%	3%	2%	Figure 26
Family had enough opportunities to ask questions about donation	Total agree	93%	97%	95%	96%	98%	Figure 28
	Disagree/not sure	7%	3%	5%	4%	2%	Figure 28
Hospital or DonateLife staff answered questions	Total agree	95%	98%	95%	98%	99%	Figure 29
	Disagree/not sure	5%	2%	5%	2%	1%	Figure 29
Given sufficient information to allow an informed decision to be made	Total agree	95%	97%	96%	96%	98%	Figure 27
	Disagree/not sure	5%	3%	4%	4%	2%	Figure 27
Given enough time to discuss donation and make decision	Total agree	94%	96%	96%	96%	97%	Figure 30
	Disagree/not sure	6%	4%	4%	4%	3%	Figure 30
Felt pressured or rushed	Yes	8%	8%	7%	10%	9%	Figure 31
	No	88%	87%	89%	85%	88%	Figure 31
	Not sure	4%	5%	4%	5%	3%	Figure 31

14.4 Moving towards donation

Experience		W1	W2	W3	W4	W5	Location
Met with DonatLife staff member	Yes	91%	92%	93%	96%	92%	Figure 32
	No	5%	4%	3%	2%	2%	Figure 32
	Not sure	4%	4%	4%	2%	5%	Figure 32
Understanding of donation process after meeting with DonatLife staff member	Well informed	82%	83%	80%	84%	83%	Table 22
	Still had questions	16%	14%	18%	14%	15%	Table 22
	Not a good understanding of donation process	2%	2%	2%	2%	3%	Table 22
Made aware that donation may not happen even after consent	Yes	90%	88%	91%	91%	92%	Section 9.1
Written information							
Received written information	Before decision was made	16%	27%	22%	30%	28%	Figure 33
	After decision was made	24%	20%	26%	28%	24%	Figure 33
	Did not receive written information	15%	14%	13%	11%	10%	Figure 33
	Can't recall	48%	41%	40%	34%	40%	Figure 33
Read information (amongst those who received it)	Yes, in detail	53%	54%	45%	47%	51%	Figure 34
	Yes, skimmed through it	46%	41%	48%	44%	43%	Figure 34
	Did not read	1%	5%	7%	9%	6%	Figure 34
When information was read (amongst those who read information)	Before finalising decision	28%	35%	27%	33%	34%	Figure 34
	After finalising decision	64%	43%	59%	46%	48%	Figure 34
	Not sure	7%	21%	15%	21%	19%	Figure 34
Usefulness of written information (amongst those who read it)	Very useful	55%	52%	42%	47%	47%	Table 23
	Quite useful	41%	44%	53%	47%	52%	Table 23
	Not useful	5%	2%	5%	5%	1%	Table 23
Support from health professionals – after consenting to donation							
Hospital staff treated family with consideration and sensitivity after consenting to donation	To a great extent	89%	89%	89%	91%	91%	Figure 35
	To some extent	10%	10%	9%	8%	8%	Figure 35
	Not at all	1%	1%	2%	1%	1%	Figure 35
Offered support of a social worker or chaplain	Yes	76%	79%	78%	84%	76%	Figure 36
	No	10%	10%	7%	7%	23%	Figure 36
	Not sure	14%	11%	15%	9%	1%	Figure 36

Experience		W1	W2	W3	W4	W5	Location
Donation process							
Given enough time with family member prior to surgery	Yes	95%	95%	94%	93%	96%	Figure 38
	No	5%	5%	6%	7%	4%	Figure 38
Given the information you wanted about donation surgery	Yes	83%	85%	81%	88%	85%	Figure 37
	No/not sure	17%	15%	19%	12%	15%	Figure 37
Information about donation surgery	Too detailed	2%	3%	2%	4%	3%	Figure 37
	Too broad	5%	3%	4%	2%	2%	Figure 37
	Too brief	8%	4%	10%	8%	5%	Figure 37
	Just right	85%	89%	83%	85%	88%	Figure 37
Hospital staff treated family member with respect	To a great extent	91%	94%	94%	93%	93%	Figure 39
	To some extent	8%	6%	4%	7%	6%	Figure 39
	Not at all	1%	–	2%	1%	–	Figure 39

14.5 After donation surgery

Experience		W1	W2	W3	W4	W5	Location
Offered opportunity to spend time with family member after donation surgery	Yes	49%	47%	40%	50%	47%	Figure 40
	No	37%	36%	43%	39%	37%	Figure 40
	Not sure	14%	17%	18%	12%	15%	Figure 40
Spent time with family member after surgery (amongst those who were offered)	Yes	53%	56%	58%	52%	56%	Figure 40
	No	47%	44%	42%	48%	44%	Figure 40
Would have liked the opportunity to see family member post-surgery (amongst those who were not offered)	Yes	10%	11%	11%	20%	12%	Figure 40
	No	66%	61%	68%	63%	63%	Figure 40
	Not sure	24%	28%	21%	17%	26%	Figure 40

14.6 Follow-up services

Experience		W1	W2	W3	W4	W5	Location
Offered ongoing contact after donation from Donatelife staff or hospital support staff	Yes	85%	95%	97%	97%	96%	Figure 41
Level of contact with Donatelife agency staff to date	Too much	1%	3%	6%	3%	1%	Figure 45
	Not enough	14%	11%	13%	20%	13%	Figure 45
	Just right	85%	85%	81%	77%	85%	Figure 45

14.7 Contact with recipients

Experience		W1	W2	W3	W4	W5	Location
Awareness of donor families being able to write to recipients (amongst families where donation proceeded)	Aware	N/A	50%	44%	57%	49%	Figure 46
	Unaware	N/A	50%	56%	43%	51%	Figure 46
Received correspondence from any transplant recipient (amongst unique donor families):	Yes, from one or more	69%	63%	63%	62%	56%	Figure 47
	No, even though I wanted to	24%	25%	22%	29%	30%	Figure 47
	Chose not to receive any	7%	8%	8%	7%	9%	Figure 47
Correspondence from recipients (amongst unique donor families who received any correspondence from recipients):	Of great comfort	87%	78%	81%	77%	77%	Figure 47
	Of some comfort	13%	20%	18%	22%	22%	Figure 47
	Of no comfort	-	2%	1%	1%	1%	Figure 47
<ul style="list-style-type: none"> Wave 1: n=123 Wave 2: n=246 Wave 3: n=194 Wave 4: n=276 Wave 5: n=312 							
<ul style="list-style-type: none"> Wave 1: n=84 Wave 2: n=156 Wave 3: n=123 Wave 4: n=170 Wave 5: n=173 							

14.8 On reflection

Experience		W1	W2	W3	W4	W5	Location
Level of comfort with decision to agree to donation	Very comfortable	87%	85%	87%	85%	86%	Figure 49
	Somewhat comfortable	12%	12%	10%	11%	10%	Figure 49
	Somewhat uncomfortable	1%	2%	1%	2%	3%	Figure 49
	Very uncomfortable	-	1%	2%	2%	1%	Figure 49
Donation provided comfort in loss	Great deal of comfort	47%	59%	50%	47%	47%	Figure 50
	Yes, some comfort	47%	35%	43%	44%	49%	Figure 50
	No	6%	7%	7%	9%	4%	Figure 50
After donation experience, feelings towards donation	Would donate after death	92%	89%	89%	88%	88%	Figure 52
	Would not donate after death	1%	3%	4%	4%	3%	Figure 52
	Undecided	7%	8%	7%	8%	10%	Figure 52

“ I can see this research is a genuine effort to improve the system. It is important for us to be providing feedback.”

2018 – 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 neurological determination of brain death (DNDD)	When organ donation occurs after neurological death has been determined.
Donation after circulatory death (DCDD)	When organ donation occurs after circulatory 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 who 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 or by telephone 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 <i>Australian Organ and Tissue Donation and Transplantation Authority Act 2008</i> 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://wave5-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,

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Section 1 – Your family member and the decision to donate

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 loved one die? (Please tick one box only)

- | | | | |
|------------------------------|----------------------------|--------------------|----------------------------|
| Queensland | <input type="checkbox"/> 1 | Tasmania | <input type="checkbox"/> 5 |
| Australian Capital Territory | <input type="checkbox"/> 2 | South Australia | <input type="checkbox"/> 6 |
| New South Wales | <input type="checkbox"/> 3 | Northern Territory | <input type="checkbox"/> 7 |
| Victoria | <input type="checkbox"/> 4 | Western Australia | <input type="checkbox"/> 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 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 **▶ Go to Q11**
- It made our decision a bit more difficult 4
- It made our decision a lot more difficult 5

10 Please explain how it made your decision easier or more difficult?

11 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

12 Now that some time has passed, how would you describe your level of comfort with your decision to agree to donation, even if donation did not go ahead? (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 donate?

Section 2 – At the hospital

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

- 15 During the time your family member was in the Intensive Care Unit (ICU) or the Emergency Department (ED), 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 that the hospital staff treated you with consideration and sensitivity at this time? (Please tick one box only)

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

- 17 Depending on the individual circumstances of your family member, hospital 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 enough information to fully understand that death was expected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b The language used by hospital staff was clear and easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c Hospital staff treated me with compassion and sensitivity at this time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d Hospital staff treated my family member with respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e I had sufficient opportunity to ask questions of hospital staff at this time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 18 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

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

Please only answer Q20–24 if brain death testing occurred in your experience

20 Were you offered to be present during the brain death testing? (Please tick one box only)

- Yes 1
No 2 ▶ Go to Q23
Not sure 3 ▶ Go to Q23

21 **If you answered 'yes' to Q20.** Did you choose to be present during the brain death testing?
(Please tick one box only)

- Yes 1
No 2 ▶ Go to Q24

22 **If you answered 'yes' to Q21.** Did seeing the testing help you to understand that your family member had died? (Please tick one box only)

- Yes 1 ▶ Go to Q24
No 2 ▶ Go to Q24
Not sure 3 ▶ Go to Q24

23 **If you answered 'no' or 'not sure' at Q20.** Would it have helped you to have the option of being present during the brain death testing?

- Yes 1
No 2
Not sure 3

24 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

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

- Doctor 1 ▶ Continue
- Nurse 2 ▶ Continue
- DonateLife staff member 3 ▶ Continue
- Family member/close friend 4 ▶ Go to Q30
- Other (relationship to you:) 5 ▶ Go to Q30
- I raised it myself 6 ▶ Go to Q30
- Can't remember 9 ▶ Continue

26 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

27 Do you think this timing was appropriate? (Please tick one box only)

- Yes 1 No 2 Not sure 3

28 Is there anything else you would like to add about the timing?

29 If donation was first raised by a hospital or DonateLife 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

30 Thinking back to the discussions you had with hospital or DonateLife 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b My family had enough opportunities to ask questions of hospital or DonateLife staff about donation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c Hospital or DonateLife staff answered our questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d We were given sufficient information to allow us to make an informed decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e My family was given enough time to discuss donation and to make our decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31 Did you feel rushed or pressured at any stage? (Please tick one box only)

- Yes 1
- No 2 **▶ Go to Q33**
- Not sure 3 **▶ Go to Q33**

32 In what way did you feel rushed or pressured?

Consenting to organ and/or tissue donation

33 Did you meet or have a discussion with a DonateLife staff member? (Please tick one box only)

- Yes 1
- No 2 **▶ Go to Q35**
- Not sure 3 **▶ Go to Q35**

34 Which of these statements best describes your understanding of the donation process after speaking with the DonateLife staff member? (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

35 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

36 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 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 hospital staff treated you with consideration and sensitivity after you agreed to donation? (Please tick one box only)

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

41 How could the way in which donation was discussed with you at the hospital be improved and/or do you have any other comments?

After consenting to donation

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

- Yes 1 No 2

43 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

44 Was the information you received...? (Please tick one box only)

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

45 To what extent do you feel the hospital staff 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

46 What else would you like to add about the donation process?

If donation did not proceed, please go to Section 4, Q52

After the donation surgery

47 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 Q50
Not sure 3 ▶ Go to Q50

48 If you answered 'yes' at Q47. Did you spend time with your family member after the donation surgery? (Please tick one box only)

Yes 1
No 2 ▶ Go to Q51

49 If you answered 'yes' at Q48. How would you describe this experience? (Please tick one box only)

Positive 1 Negative 2 Not sure 3

50 If you answered 'no' or 'not sure' to Q47. 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

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

Section 4 – Follow-up services and resources

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

	Contact received			Contact not offered	Chose not to receive
	Definitely helpful (3)	Somewhat helpful (2)	Not helpful (1)		
a DonateLife staff member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b Hospital support staff such as a social worker or chaplain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c Other – please specify <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

54 If you ticked that ongoing contact was not offered to you in 52.

Would it have been helpful for you and your family if someone from the hospital or DonateLife spoke with you about ongoing support for you and your family? (Please tick one box only)

Yes 1 No 2 Not sure 3

55 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/ NA	Would like to receive	Milestone not yet reached
a The initial follow-up phone call from DonateLife informing you of the outcome and how many people had been helped	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
b Some basic information about the transplant recipients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c The content of the letter from DonateLife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
d The "In Reflection" book written for donor families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
e The follow-up phone call from the DonateLife staff member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
f An anniversary card received approximately 12 months after your family member's death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g Annual Service of Remembrance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
h The donor family remembrance pin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
i Brochure on support services and contacts for seeking assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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

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

Too much 1 Not enough 2 Just right 3

58 What other services could be offered to better support family members?

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

Yes 1 ► Go to Q61
No 2
Not sure 3

60 Please share your reasons for feeling this way.

If donation did not proceed, please go to Q68

Your feelings about organ and tissue donation

61 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 Q64**

62 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

63 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
Knowing that we honoured our loved one's wishes 4
Knowing that my loved one helped somebody 5
In another way (please specify) 9

Contact with recipients

64 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 Q66**
No, even though I chose to receive correspondence 4 **▶ Go to Q66**

65 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

66 If you answered 'no' to Q64. How do you feel about not receiving any correspondence from the transplant recipients to date?

67 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

68 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 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
Kerry Duncan
08 8207 7117

VIC

DonateLife VIC
Michelle Skinner
03 8317 7411

TAS

DonateLife TAS
Verity Shugg
03 6166 7806

WA

DonateLife WA
Sussan Fowler
08 9222 0222

National

Lifeline 24hr Crisis
13 11 14

A4.2 Questionnaire – families who declined donation

Participation is voluntary

PROOF
RESEARCH



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.

The survey is designed to help staff involved in organ and tissue donation provide the best possible service to the 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://wave5hospitalstudy.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.

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,

A handwritten signature in black ink that reads 'R McLaren'.

Rhonda McLaren
Director | Proof Research

PROOF
KNOW HOW. KNOW MORE.

Tel. +617 3392 4446 | Mob. 0419 706 801
Email. Rhonda@proofresearch.com.au
Web. www.proofresearch.com.au

Kangaroo Point QLD 4169
PO Box 6987, Upper Mount Gravatt QLD 4122
ABN. 86 723 358 016

Section 1 – Your family member and the decision to decline donation

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 | <input type="checkbox"/> 1 | Tasmania | <input type="checkbox"/> 5 |
| Australian Capital Territory | <input type="checkbox"/> 2 | South Australia | <input type="checkbox"/> 6 |
| New South Wales | <input type="checkbox"/> 3 | Northern Territory | <input type="checkbox"/> 7 |
| Victoria | <input type="checkbox"/> 4 | Western Australia | <input type="checkbox"/> 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 **▶ Go to Q11**
- It made our decision a bit more difficult 4
- It made our decision a lot more difficult 5

10 Please explain how it made your decision easier or more difficult?

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
- He/she was not registered on the Australian Organ Donor Register (AODR) 13
- Another reason: 14

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 (ICU) or the Emergency Department (ED), 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 hospital staff treated you with consideration and sensitivity at this time?
(Please tick one box only)

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

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, hospital 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 (0)
a I was given sufficient information to fully understand that death was expected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b The language used by hospital staff was clear and easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c Hospital staff treated me with compassion and sensitivity at this time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d Hospital staff treated my family member with respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e I had sufficient opportunity to ask questions of hospital staff at this time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Yes 1 No 2 Not sure 3

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

Please only answer Q21–25 if brain death testing occurred in your experience

21 Were you offered to be present during the brain death testing? (Please tick one box only)

Yes 1
No 2 ▶ Go to Q24
Not sure 3 ▶ Go to Q24

22 If you answered 'yes' at Q21. Did you choose to be present during the brain death testing?
(Please tick one box only)

Yes 1
No 2 ▶ Go to Q25

23 If you answered 'yes' at Q22. Did seeing the testing help you to understand that your family member had died? (Please tick one box only)

Yes 1 ▶ Go to Q25
No 2 ▶ Go to Q25
Not sure 3 ▶ Go to Q25

24 If you answered 'no' or 'not sure' to Q21. Would it have helped you to have the option of being present during the brain death testing?

Yes 1
No 2
Not sure 3

25 Would you like to add anything else about the process of brain death testing?

Section 3 – Discussing organ and tissue donation

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

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

- | | | | |
|---|--------------------------|---|-------------|
| Doctor | <input type="checkbox"/> | 1 | ▶ Continue |
| Nurse | <input type="checkbox"/> | 2 | ▶ Continue |
| DonateLife staff member | <input type="checkbox"/> | 3 | ▶ Continue |
| Family member/close friend | <input type="checkbox"/> | 4 | ▶ Go to Q31 |
| Other person (relationship to you: <input type="text"/>) | <input type="checkbox"/> | 5 | ▶ Go to Q31 |
| I raised it myself | <input type="checkbox"/> | 6 | ▶ Go to Q31 |
| Can't remember | <input type="checkbox"/> | 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 | <input type="checkbox"/> | 1 |
| At the same time as I was told of my family member's death or expected death | <input type="checkbox"/> | 2 |
| Within an hour of being told of my family member's death or expected death | <input type="checkbox"/> | 3 |
| More than 1 hour after being told of my family member's brain death or expected death | <input type="checkbox"/> | 4 |
| Can't remember | <input type="checkbox"/> | 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 or DonateLife 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 | <input type="checkbox"/> | 1 |
| My reaction would have been the same, irrespective of who first mentioned it | <input type="checkbox"/> | 2 |
| It was preferable coming from a hospital staff member first | <input type="checkbox"/> | 3 |
| We expected to be asked about donation | <input type="checkbox"/> | 4 |

31 Thinking back to the discussions you had with hospital or DonateLife 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b My family had enough opportunities to ask questions of hospital or DonateLife staff about donation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c Hospital or DonateLife staff answered our questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d We were given sufficient information to allow us to make an informed decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e My family was given enough time to discuss donation and to make our decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 or have a discussion with a DonateLife staff member during your time in the hospital?
(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 staff member? (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 hospital staff treated you with consideration and sensitivity after you declined donation? (Please tick one box only)

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

41 Are there any further comments you would like to make about this time?

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

- Yes 1
- No 2 ▶ Would you have liked to be offered this support? Yes 1 No 2
- Not sure 3

43 How could the way in which donation was discussed with you at the hospital have been improved?

Section 4 – Follow up services

Follow up services from the hospital and the organ and tissue donation agency

44 To help hospitals and DonatLife 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 a DonatLife staff member 1
Information about bereavement support services 2

45 What other services do you feel could be offered to better support family members?

Your feelings about organ and tissue donation

46 On reflection, would you make the same decision now? (Please tick one box only)

- Yes 1 No 2 Not sure 3

47 Is there anything else you would like to share about your decision?

48 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 families can be cared for and supported.

Please return the survey by 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

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Kerry Duncan
08 8207 7117

VIC

DonateLife VIC
Michelle Skinner
03 8317 7411

TAS

DonateLife TAS
Verity Shugg
03 6166 7806

WA

DonateLife WA
Sussan Fowler
08 9222 0222

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 DonatLife 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 DonatLife 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@donatlife.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.

DonatLife donor family support coordinators

ACT	DonatLife ACT	Sean Dicks 02 6174 5625
NSW	DonatLife NSW	Clare Lynch 02 8566 1705
NT	DonatLife NT	Shan Cairnes 08 8922 6700
QLD	DonatLife Qld	Diane Murphy 07 3176 2350
SA	DonatLife SA	Natalia Jastrzebski 08 8207 7117
TAS	DonatLife Tas	Verity Shugg 03 6166 7806
VIC	DonatLife Vic	Michelle Skinner 03 8317 7411
WA	DonatLife 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:



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



Study of family experiences of organ and tissue donation

Participant Information Statement



This information is for you to keep

A4.4 Consent form



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 _____

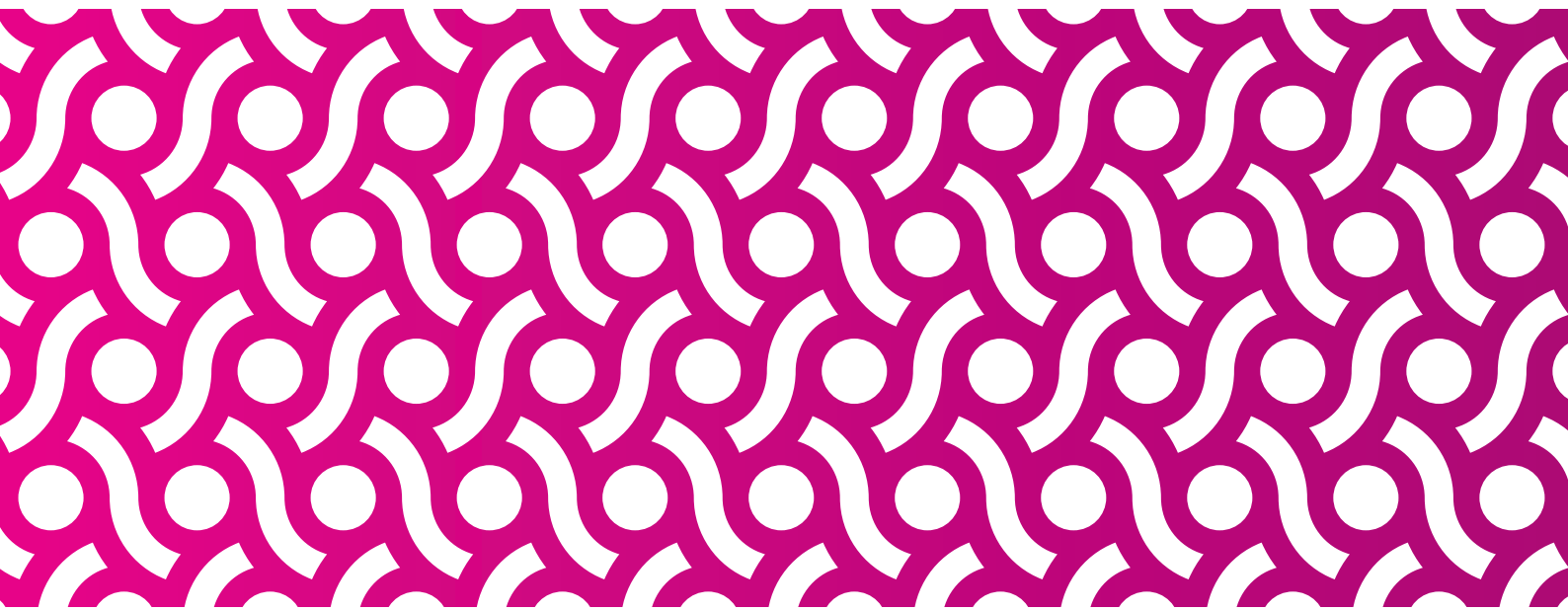
Email _____

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.



PROOF



Australian Government
Organ and Tissue Authority

