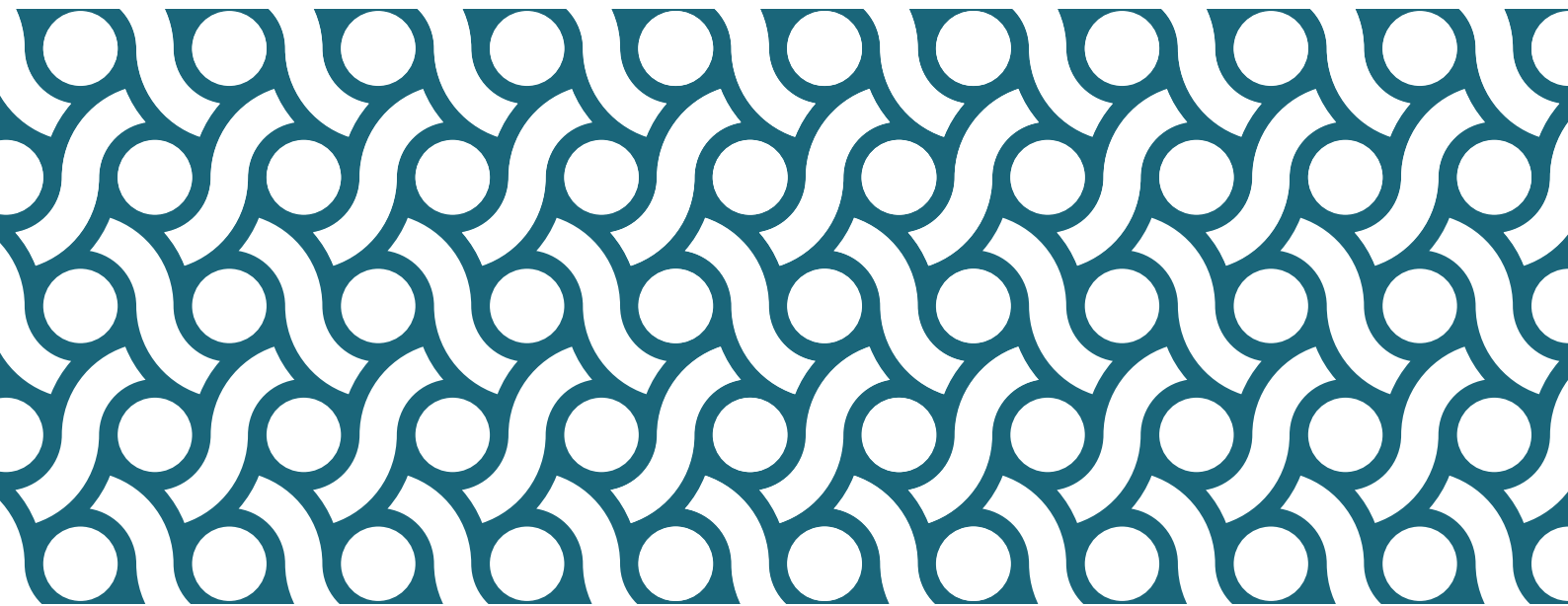


National Study of **Family Experiences of Organ and Tissue Donation**

Wave 2

2012 and 2013 – Summary Report



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

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Executive Summary

The research undertaken in the Wave 2 Donor Family Study (families who made a donation decision in 2012 and 2013) seeks to understand families' experiences before, during and after donation in order to ascertain and monitor how to best meet the needs of families. The key findings from Wave 2 are primarily in line with Wave 1 and are outlined in brief below, with significant and statistically significant differences highlighted.

Key findings from the Wave 2 Donor Family Study

Before Donation

- 59% of families had discussed organ and tissue donation with their loved one.
- 80% of families said that having a prior conversation made consenting to donation 'a lot easier'.
- 84% of donor family members were supportive of organ donation prior to their family member's death and 58% of family members who declined donation were supportive of organ donation. This difference is statistically significant.
- 78% of donor family members see organ and tissue donation as a chance for something positive to come out of a personal tragedy.
- 76% of donor family members were motivated to donate because they felt that their loved one would have wanted to help others.
- 96% of consenting families feel they were given enough time to discuss donation and to make their decision, while families who declined donation were less likely to feel they were given sufficient time (25% disagree and 12% were unsure).
- After meeting with the donor coordinator or donation specialist nurse/doctor, 83% of donor family members felt well informed and felt they knew all they needed to know about the donation process.

After Donation

During Donation

- 94% of families recall medical staff treating their family member with respect.
- The possibility of donation continues to be primarily mentioned to families by a health professional [58% amongst consenting families (a significant increase since Wave 1 of 46%) and 50% amongst families who declined donation].
- There is a statistically significant increase in the number of donation conversations instigated by Donor Coordinators between the waves of the study, with Wave 1 at 13% and Wave 2 at 21%.
- 88% of families strongly agree that they were given sufficient information to allow them to make an informed decision, while 14% of families who declined donation strongly agreed.
- 97% of families agree that their family was provided with enough opportunities to ask questions of hospital staff about donation, which is a significant increase on Wave 1 where 93% of families felt this way.
- 95% of donor families were offered ongoing contact from a range of health professionals including the Donor Family Support Coordinator, which is a statistically significant increase from Wave 1 where it was 85%.
- 85% of donor families felt the contact they had with DonateLife had been at the right level, while 11% of families felt it was not enough.
- 63% of donor families received a de-identified letter from at least one transplant recipient, providing comfort to 98% of families, while 25% had not received any correspondence from recipients even though they chose to.
- 97% of donor families reported that the donation decision they made still sits well with them today.
- 17% of families who declined donation were somewhat uncomfortable with their donation decision, which is significantly higher than families who consented to donation at 2%.
- 92% of donor families have found comfort in the donation of their loved ones organ, with 68% finding comfort at the time of donation.

Background

The Organ and Tissue Authority (OTA) commissioned Proof Research Pty Ltd to conduct a series of national studies of family experiences of organ and tissue donation for transplantation.

The purpose of this Wave 2 (2012-2013) study was to provide evidence-based insight into families' experiences of the donation process from initial donation conversations through to the follow-up support provided to families after a donation decision has been made. The study included both quantitative and qualitative components aimed at gaining data to inform improvements in the care and support provided to donor families by:

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

Building on the Wave 1 (2010-2011) study, the Wave 2 study provides feedback from families who had a donation experience including families that consented to or declined donation. The Wave 1 report is available at the following link: www.donatelife.gov.au/national-wave-1-donor-family-study

Notes

Comparisons between Wave 1 and Wave 2 are outlined in this Summary Report and the full Wave 2 report, with a summary of comparisons included at Chapter 14. Figure and table numbers in this Summary Report differ from those in the Wave 2 Research Report.

Research Methodology

A mixed methodology research program, with quantitative and qualitative components, was designed to address the aim and objectives of the Wave 2 study.

Human Research Ethics Clearance (HREC) and Research Governance Office (RGO) Submission Process

An extensive consultation and submission process for ethics approval was carried out to include families who consented to organ and tissue donation and families who were eligible for donation but who declined. The ethics approval process for Wave 2 commenced in October 2014 and concluded in June 2017. Significant delays were experienced in receiving RGO approval from a number of states¹.

Wave 2 Sample size and response rates

The study commenced in October 2014 and invited 1,751 Australian families to participate in the study by completing a survey questionnaire (quantitative) and/or participate in a face-to-face interview (qualitative). Of the 1,751 families, 1,428 families had consented to donation and 323 families had declined donation.

A total of 319 individual family members (representing 263 donor families) who consented to donation completed the survey questionnaire, which equates to **an overall response rate of 24.3%, an improvement on the response rate of 18% with Wave 1**. In terms of the qualitative research strand, 105 individual donor family members agreed to participate in a personal interview, with 30 interviews conducted face-to-face. In Wave 2, the families that consented to donation were located in all jurisdictions of Australia which was also the case in Wave 1.

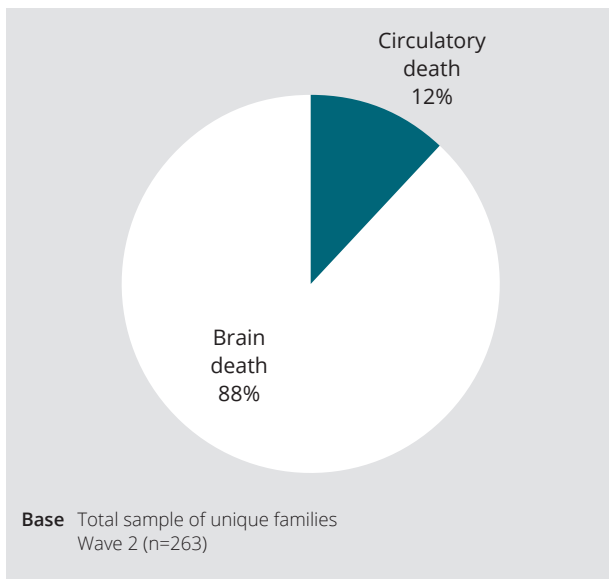
A total of 12 families (12 individuals) who declined donation completed the survey questionnaire which equates to an overall response rate of 4.3%, which is similar to that of Wave 1 at 3.8%, however the sample size is higher compared to Wave 1, where only 1 family participated. In terms of the qualitative research strand, one individual who declined donation consented to a personal interview. In Wave 2, the families that declined donation were located in six states and one territory, whereas in Wave 1, families were located in two states and two territories. Wave 2 offered many more families an opportunity to provide their feedback.

¹ Families who declined donation in the Australian Capital Territory (ACT) were unable to participate and provide feedback due to approval not being provided by the ACT Health HREC.

Donation Pathway

There are two pathways to deceased donation: donation after brain death (DBD) and donation after circulatory death (DCD). As shown in Figure 1, DBD comprises 88% of the Wave 2 sample (which is higher than the incidence of Australian DBD donation for this time period), while DCD comprises 12% (lower than the incidence of Australian DCD donation for this time period). The Wave 2 sample distribution is consistent with the Wave 1 sample distribution (89% DBD; 11% DCD).

Figure 1 Wave 2 Sample – Donation Pathway
(listed as Figure 2 in Wave 2 Research Report)



Ethnicity

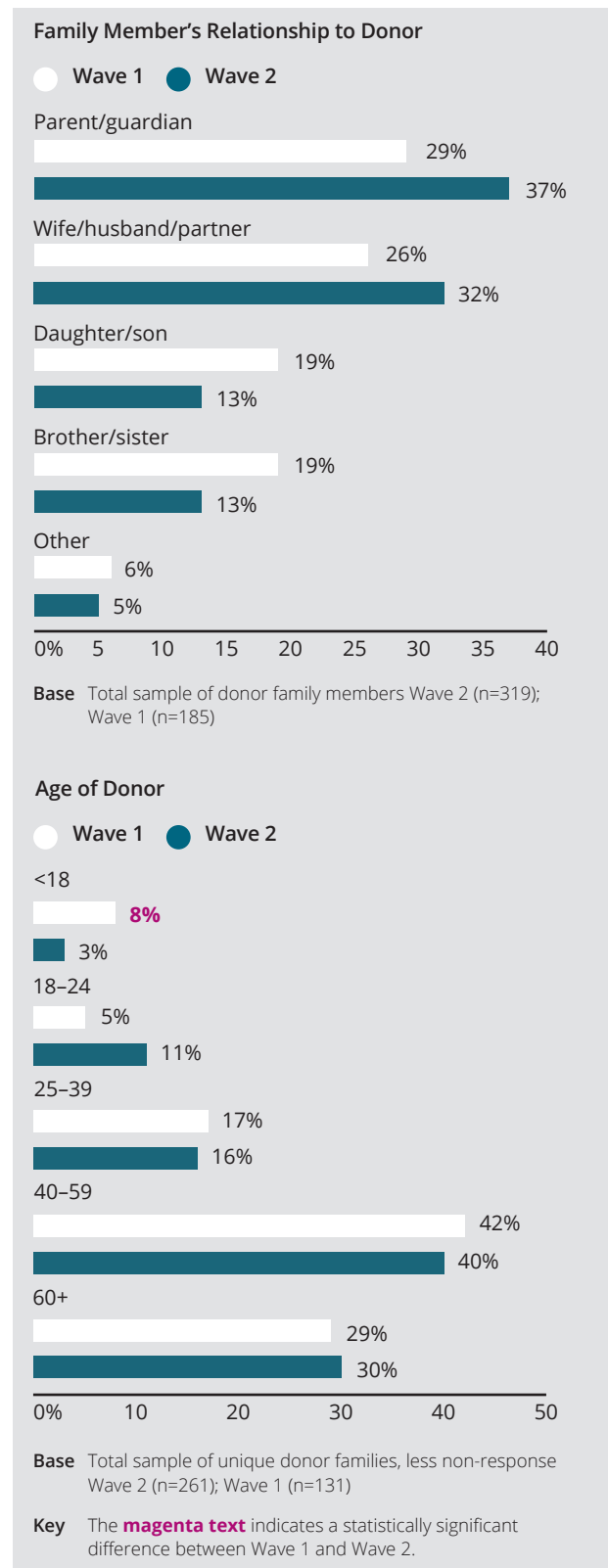
Two percent (2%) of the Wave 2 donor sample are of Aboriginal or Torres Strait Islander descent. Four percent (4%) of the Wave 2 sample of donor families speak a language other than English at home. The languages spoken include:

- Afrikaans
- Dutch
- French
- Hindi
- Hungarian
- Italian
- Polish
- Spanish

Age and Relationship to Donor

The relationship of respondents to donors and the age range of donors for both Wave 1 and Wave 2 of the Donor Family Study are outlined at Figure 2. A wide range of family members are included in the study, with donors ranging in ages from 11 to 83 years.

Figure 2 Relationship to donor and Age of Donor
(listed as Figure 4 in Wave 2 Research Report)

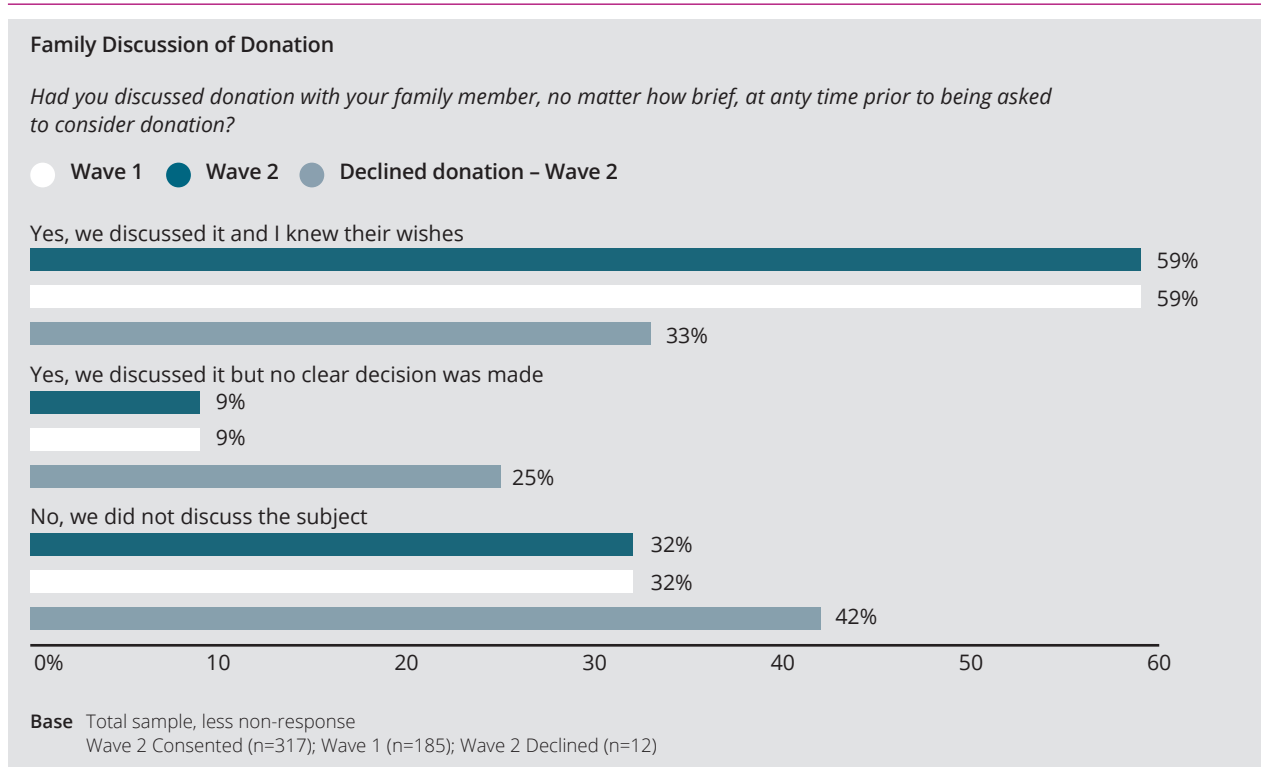


Key Findings

Role of Prior Family Discussion

Knowing the wishes of a loved one makes the donation decision easier for family members. In Wave 2, approximately three in five donor family members (59%) had discussed organ and tissue donation with their loved one prior to consenting to donation, which is consistent with Wave 1 (refer Figure 3 below).

Figure 3 Prior discussion of organ donation (listed at Figure 6 in Wave 2 Research Report)



Families who discussed organ and tissue donation with each other, no matter how brief the conversation, found the donation decision considerably easier than families who never had the discussion. In fact, 80% of these families said that having a prior conversation with their loved one made consenting to donation a lot easier. This is a slight, though not significant, increase since Wave 1 of 4%. The same is found among families who declined donation (67% who discussed donation with their loved one found the decision to decline a lot easier knowing that their loved one did not wish to donate).

Conversely, as shown in Table 1, families who did not have the discussion are more likely to find the donation decision a difficult one (11% compared with less than 1% of those who discussed donation and knew their loved one's wishes). This is consistent with Wave 1 findings, where 16% of families who had not discussed donation found the decision a difficult one. This figure rises for families who declined donation - 20% of families who did not discuss donation found the decision to decline a difficult one.

Table 1 Impact of donation discussion on donation decision (listed as Table 12 in Wave 2 Research Report)

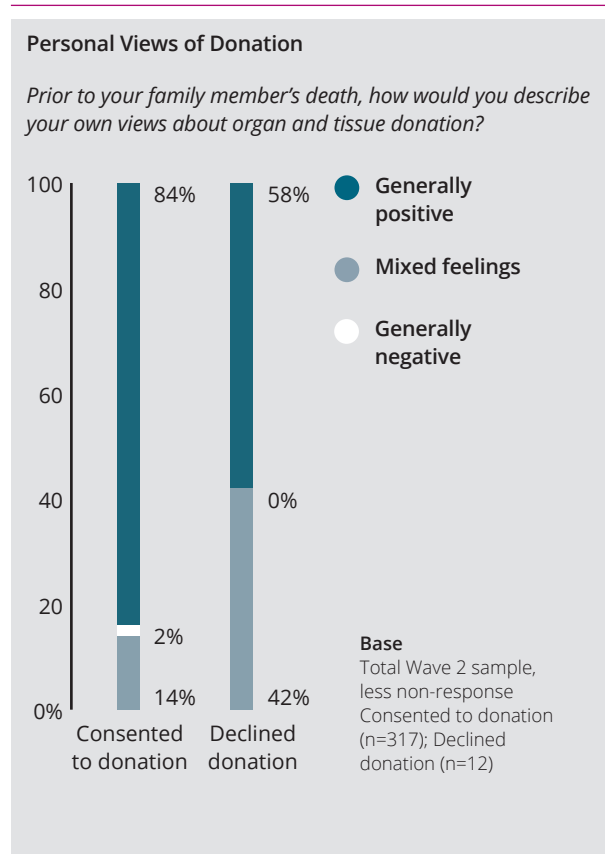
Impact of degree of discussion	Discussed and knew wishes (N=188)	Discussed but no clear decision made (N=28)	Total discussed donation (N=216)	Did not discuss donation (N=100)
Made our decision a lot easier	86%	39%	80%	32%
Made our decision a bit easier	9%	21%	11%	11%
Made decision easier - net	95%	61%	90%	43%
Did not impact on our decision	5%	32%	8%	46%
Made our decision a bit more difficult	0.5%	7%	1%	6%
Made our decision a lot more difficult	-	-	-	5%
Made decision more difficult - net	0.5%	7%	1%	11%

- Significantly higher than total sample
- Significantly lower than total sample

Personal Views about Donation

In Wave 2, 84% of donor family members were supportive of organ donation prior to their family member’s death, compared with 58% of family members who declined donation (refer Figure 4). **This is a statistically significant difference.** Sixteen percent (16%) of donor family members had mixed feelings (14%) or did not support donation (2%), but still consented to donation, compared with 42% of family members who declined donation. **Again, this difference is significant.** A comparison with Wave 1 in this section is not possible as the question was new in the Wave 2 study.

Figure 4 Personal Views of Donation (listed as Figure 7 in Wave 2 Research Report)

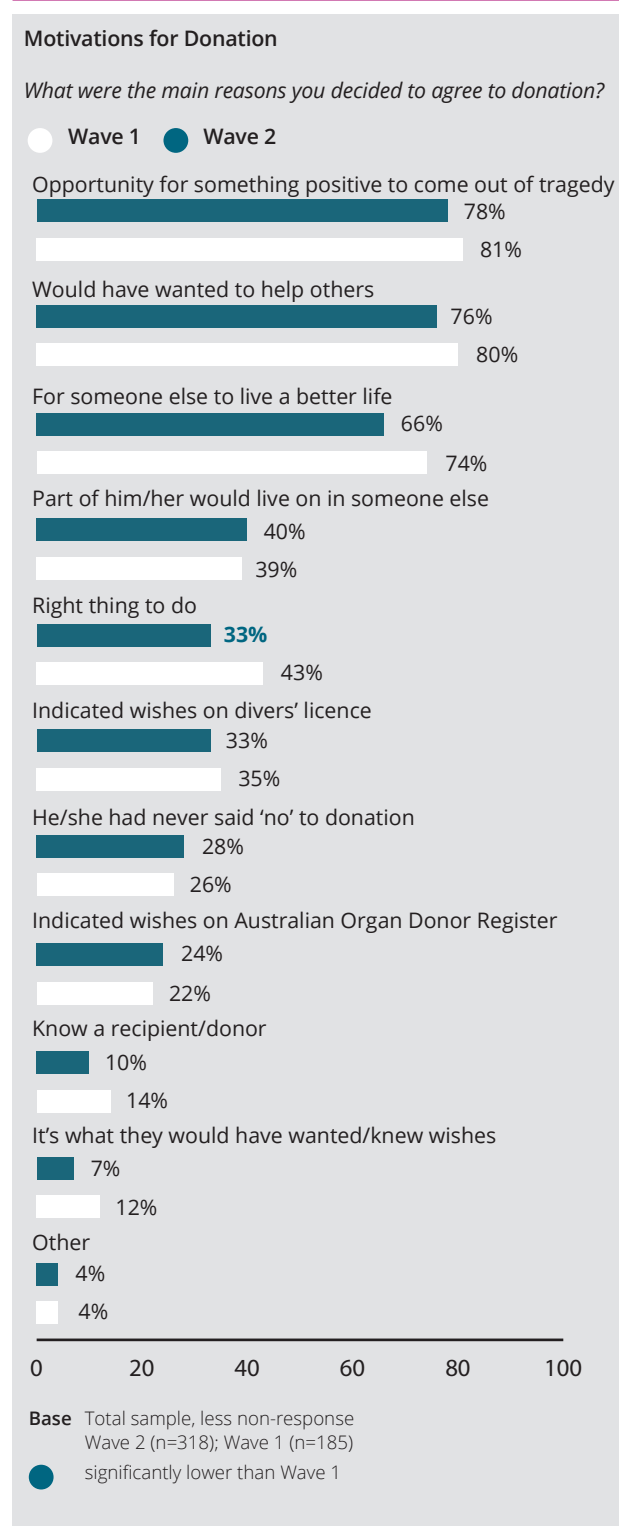


Motivations for Donating

In Wave 2, the majority of donating families (78%) see organ and tissue donation as a chance for something positive to come out of a personal tragedy (Figure 5), which is consistent with Wave 1. Knowing that other people's lives have been changed by the act of donation can help donor families cope with their loss.

In addition, three quarters (76%) of donor family members were motivated to donate because they felt that their loved one would have wanted to help others.

Figure 5 Motivations for Donation (listed as Figure 8 in Wave 2 Research Report)



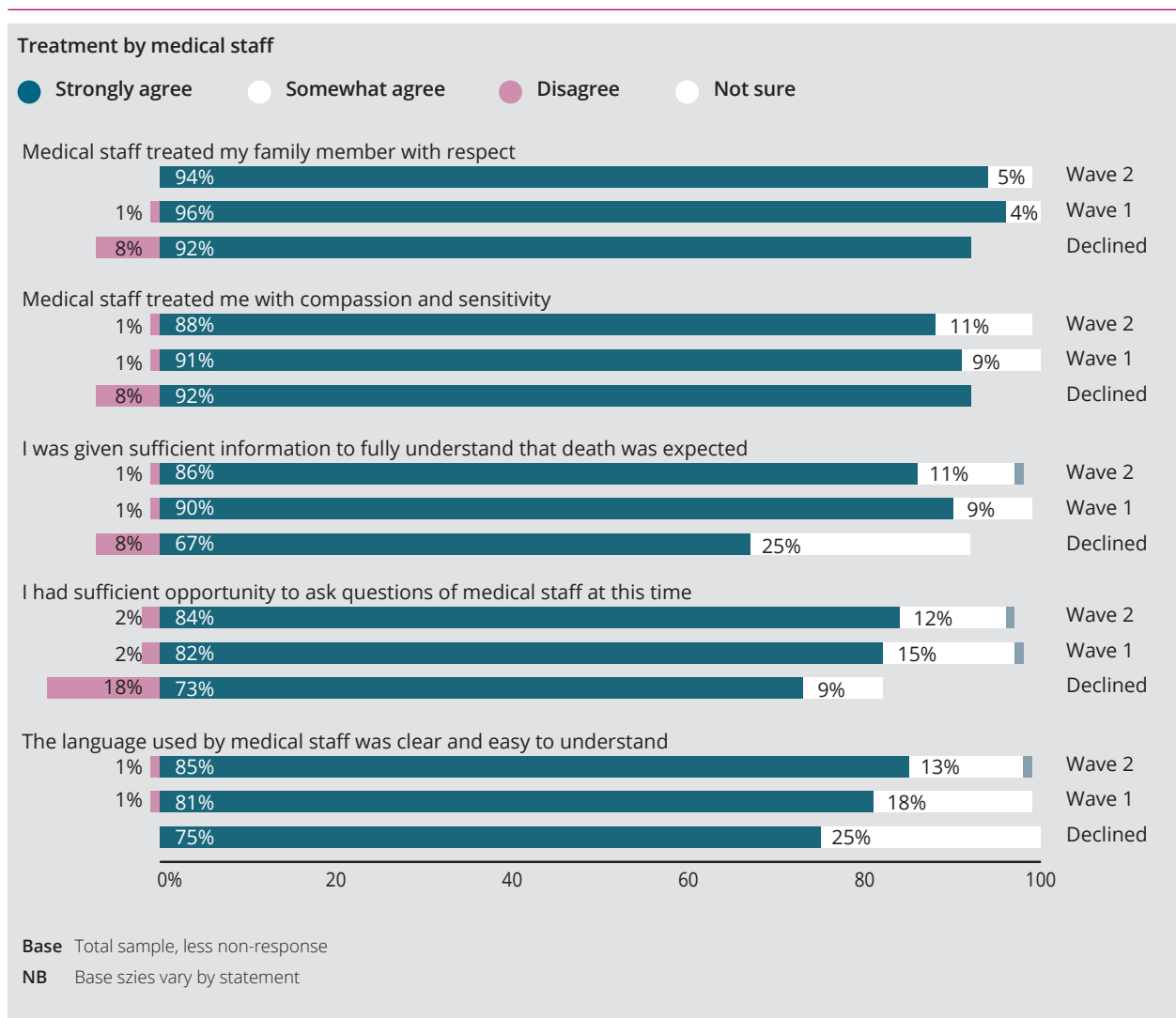
Support provided Before, During and After Donation

Treatment by medical staff

Depending on the individual circumstances of each donor, medical staff may have discussed with family members either testing for brain death or withdrawal of cardio respiratory support. When family members in Wave 2 think back to that time, the vast majority of families who consented to donation (99%) recall medical staff treating their family member with respect and themselves being treated with compassion and sensitivity (Figure 6). This is slightly less so for families who declined donation (8% disagreed that this occurred). This finding is consistent with Wave 1.

There remains some room for improvement around the language used by medical staff (85% strongly agree that the language was clear and easy to understand) and ensuring families have sufficient opportunities to ask questions (84% strongly agree that they had enough opportunities to ask questions of medical staff), which is consistent with Wave 1.

Figure 6 Treatment of families by medical staff (listed as Figure 11 in Wave 2 Research Report)



Raising Donation

In Wave 2, the possibility of donation continued to be primarily mentioned to families by a health professional (58% amongst consenting families; 50% amongst families who declined donation). **This is a significant increase from Wave 1, where 46% of donation conversations with families who later consented to donation, were initially raised by health professionals** (refer Figure 7).

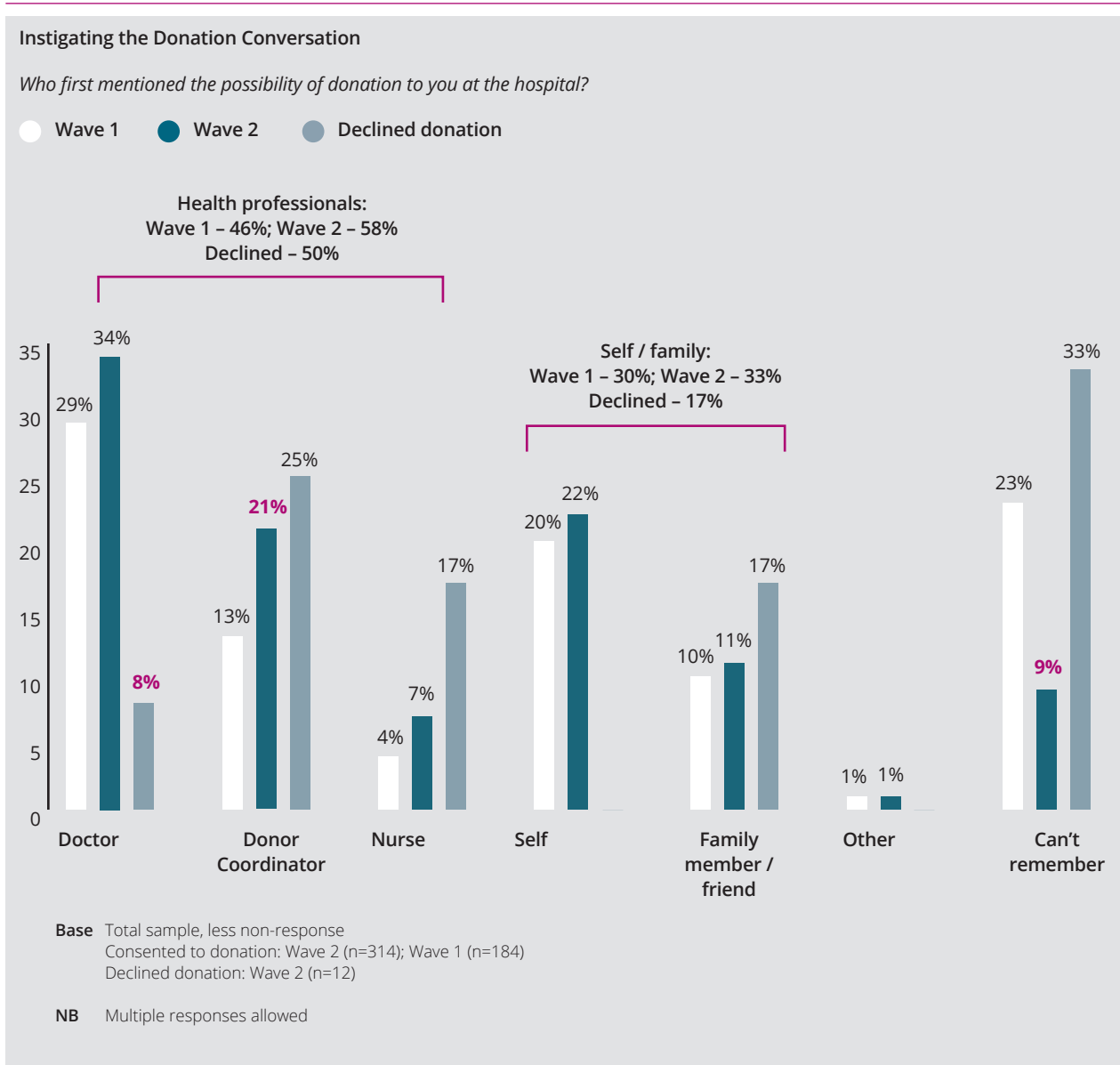
In Wave 2, the donation conversation was instigated by doctors in 34% of cases; Donor Coordinators in 21% of cases and nurses in 7% of cases. **There is a statistically significant increase in the number of donation conversations instigated by Donor Coordinators between Wave 1 and Wave 2, with 13% in Wave 1 and 21% in Wave 2.**

In Wave 2, looking specifically at families who declined donation, a much lower proportion of conversations were instigated by doctors (8%) compared with families who consented to donation (34%).

In Wave 2, one third (33%) of donor conversations were instigated by the next of kin or family members; consistent with Wave 1. Amongst families who declined donation, the conversation was raised by family members in 17% of cases.

Interestingly, far less family members cannot remember who raised the donation conversation in Wave 2 than in Wave 1 (9% down from 23%). This may suggest a more effective and memorable Family Donation Conversation. A total of 33% of families who declined donation are more likely to not recall who raised the conversation.

Figure 7 Reaction to donation being raised by hospital staff member (listed as Figure 14 in Wave 2 Research Report)

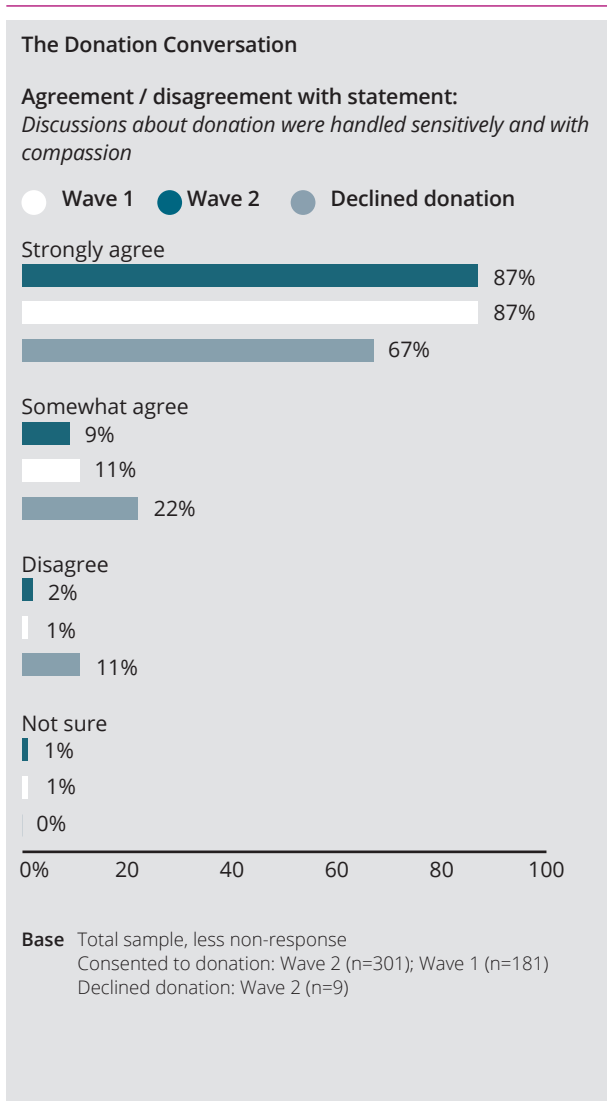


Family Donation Conversation

Discussions about donation

In Wave 2, the vast majority of family members (96%) strongly agree (87%) and somewhat agree (9%) that discussions about donation were handled sensitively and with compassion; slightly less so amongst families who declined donation (89%) with 67% strongly agreeing and 22% somewhat agreeing (refer Figure 7). Findings are consistent with Wave 1.

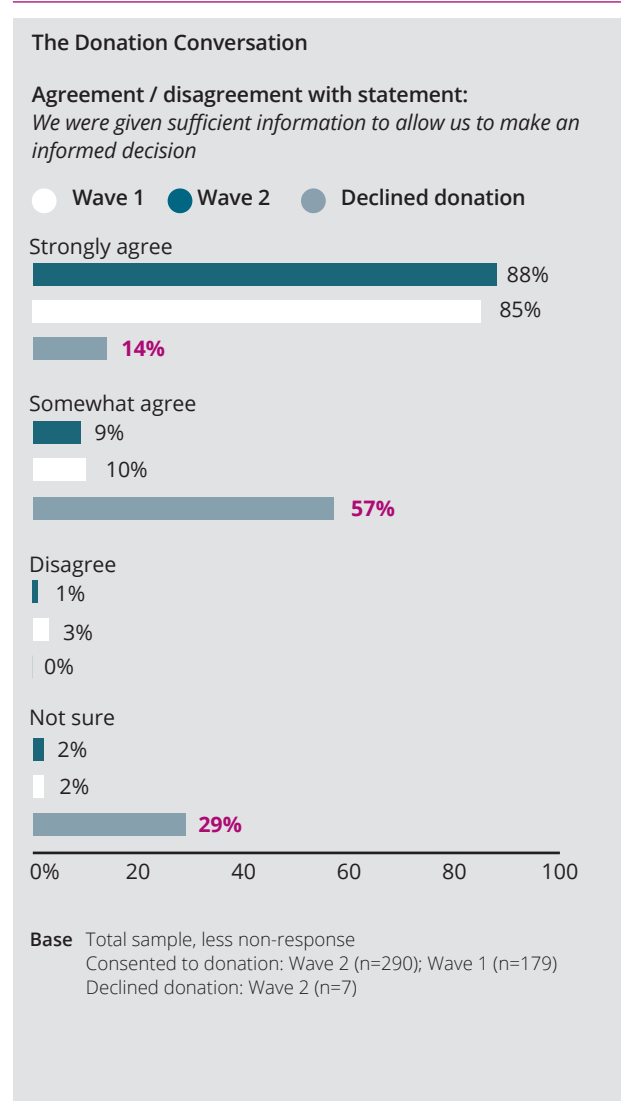
Figure 7 Tone of donation conversation (listed as Figure 19 in Wave 2 Research Report)



Given sufficient information

In Wave 2, in relation to making a decision about donation, the majority of donor family members (88%) strongly agree that they were given sufficient information to allow them to make an informed decision (refer Figure 8). Findings are consistent with Wave 1. Only 14% of families who declined donation strongly agreed, with 57% somewhat agreeing.

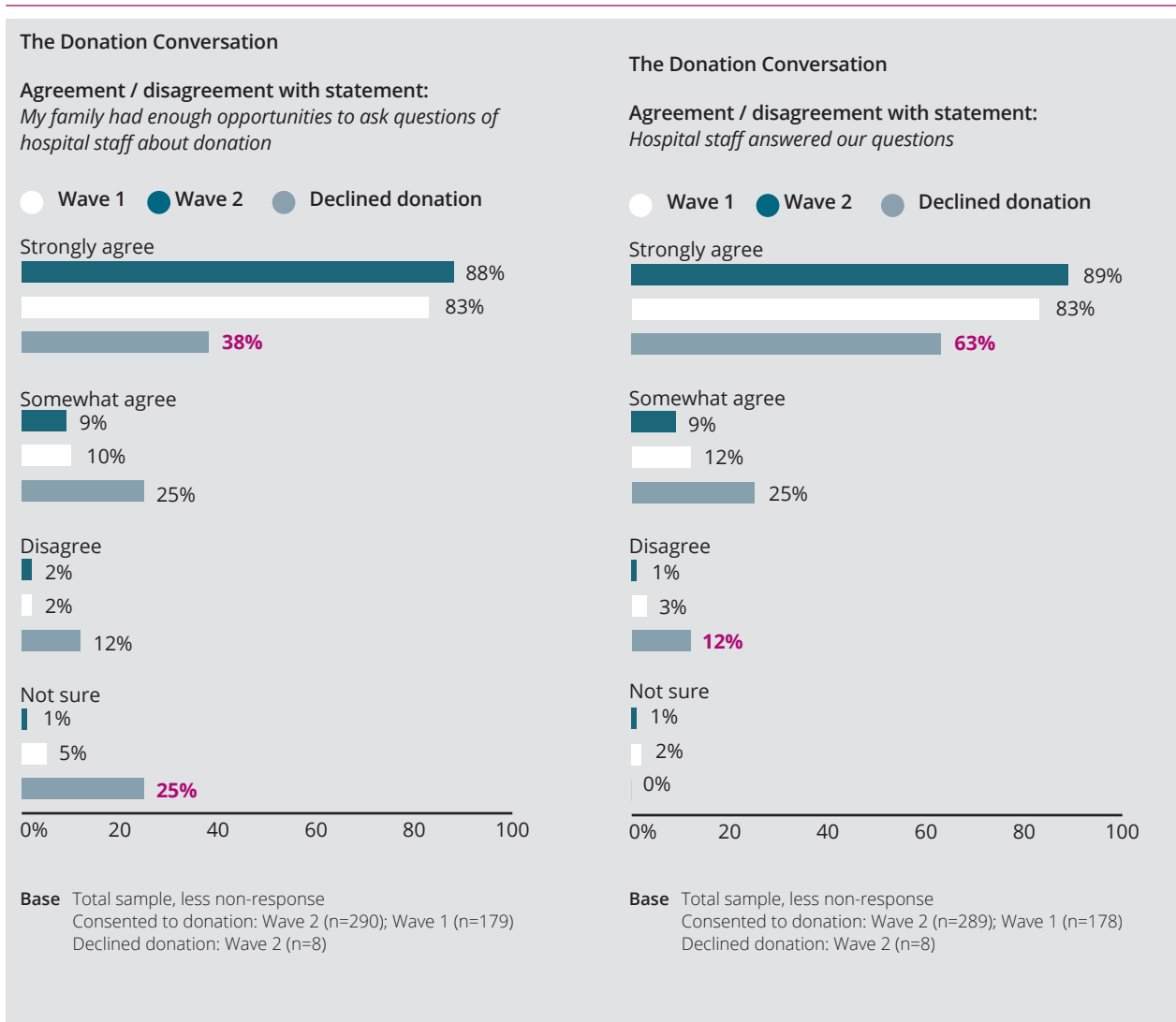
Figure 8 Sufficient information to make an informed decision (listed as Figure 20 in Wave 2 Research Report)



Opportunities to ask questions

In Wave 2, the majority of donor families (97%) agree that their family was provided with enough opportunities to ask questions of hospital staff about donation (refer Figure 9). **This is a significant increase on Wave 1 results, where 93% of families felt this way.** Families who declined donation were significantly less likely to feel they were given sufficient opportunities to ask questions (38% strongly agree). Further, 98% of donor family members agree that hospital staff answered their questions (89% strongly agree). This is consistent with Wave 1. Again, families who declined donation disagreed that hospital staff answered their questions (12%).

Figure 9 Opportunities to ask questions (listed as Figure 21 in Wave 2 Research Report)

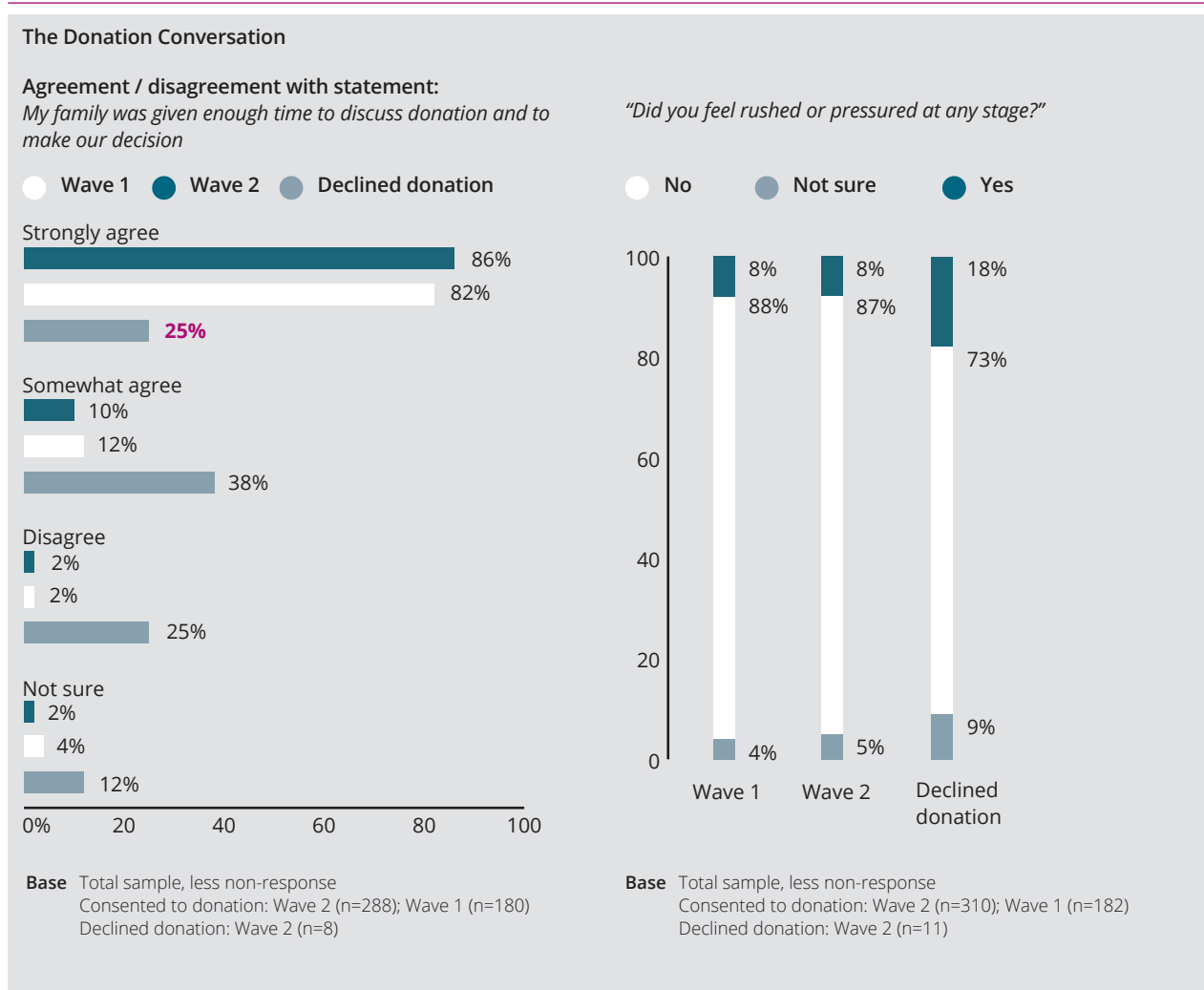


Time to make a decision

In Wave 2, the majority of families (96%) feel they were given enough time to discuss donation and to make their decision (refer Figure 10). Findings are consistent with Wave 1. Families appreciate being given a private room or space in which they can regroup, discuss donation as a family and make a decision.

Families who declined donation were less likely to feel that they were given sufficient time to make a decision (25% disagree, with a further 12% being unsure). Eighteen percent (18%) of families who declined donation and 8% of families who consented to donation felt rushed or pressured to some degree, consistent with Wave 1.

Figure 10 Time to make a decision (listed as Figure 22 in Wave 2 Research Report)

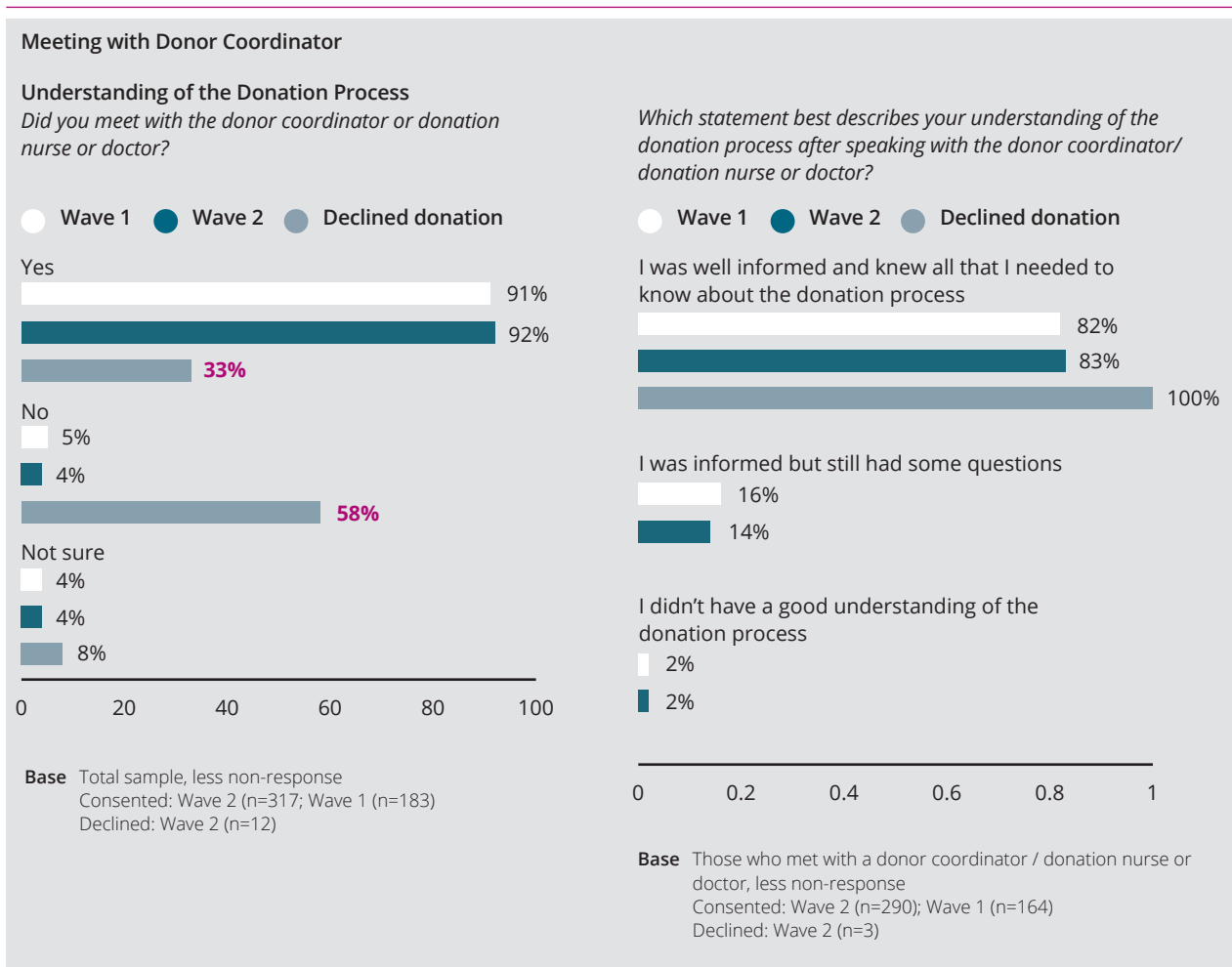


Understanding the Donation Process

In Wave 2, nine in ten donor families (92%) recall meeting with the donor coordinator or donation specialist nurse/doctor (refer Figure 11). After this meeting, 83% of donor family members felt well informed and felt that they knew all they needed to know about the donation process. Some family members (14%) still had unanswered questions, while a further 2% left the meeting with no clear understanding of the donation process. These findings are consistent with Wave 1.

Of the 12 families who declined donation, 4 recall meeting with a DonateLife coordinator, specialist nurse or doctor. These families felt that they were well informed after this meeting.

Figure 11 Meeting donation staff (listed as Figure 23 in Wave 2 Research Report)

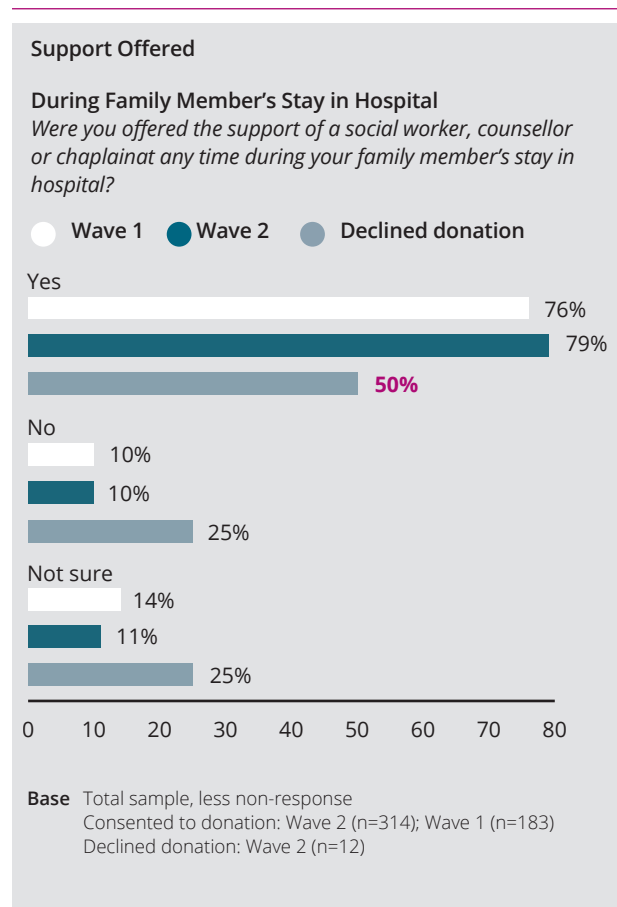


Family Support

Support Services offered to families during family member's stay in hospital

In Wave 2, four in five donor family members (79%) were offered the support of a social worker, counsellor or chaplain at some time during their family member's stay in hospital (refer Figure 12), which is consistent with Wave 1. Families who declined donation were less likely to be offered this type of support (50% were offered), and on reflection, 67% of these families would have liked this support to be made available to them.

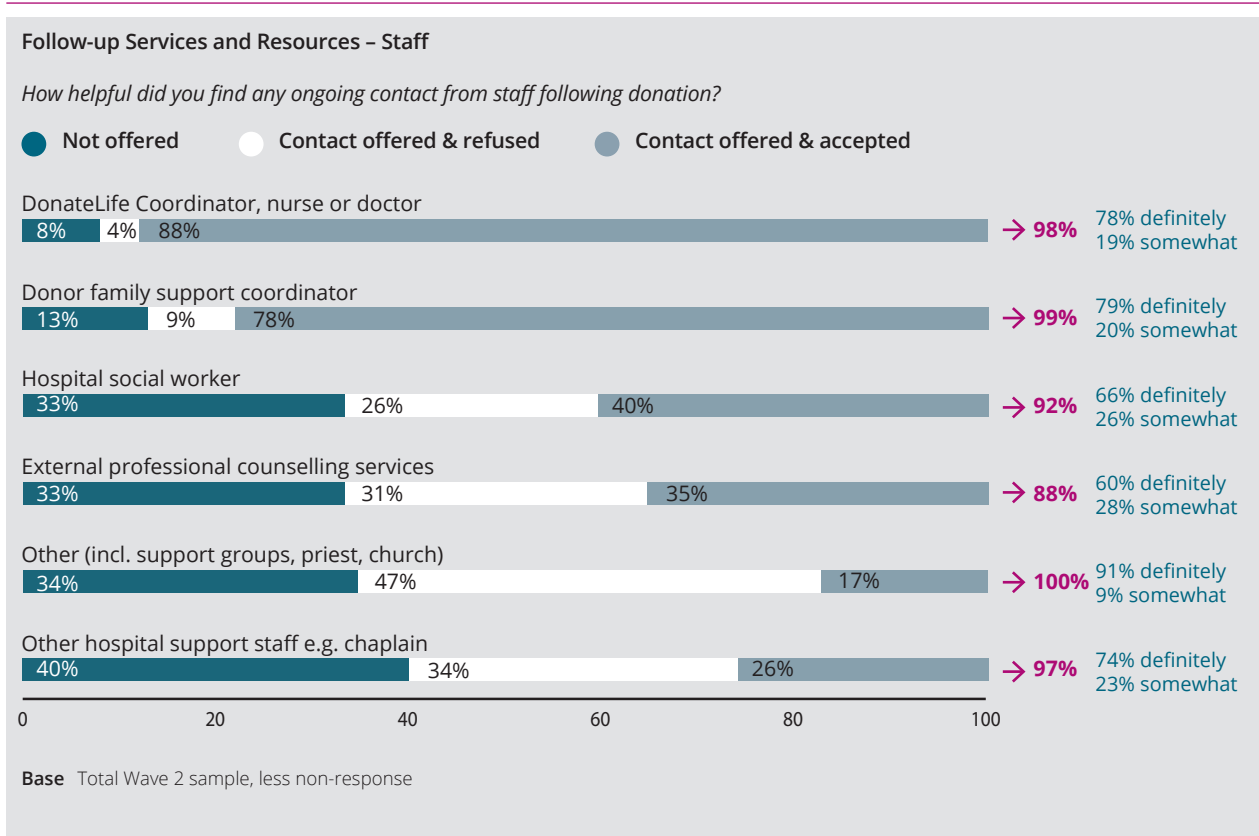
Figure 12 Support offered during stay in hospital (listed as Figure 27 in Wave 2 Research Report)



Following Donation – Ongoing contact

In Australia, the National DonateLife Family Support Service has been established to provide support to families of organ and tissue donors after donation. Support is provided in a number of ways and will differ depending on needs at the time and into the future. In Wave 1, 85% of donor family members were offered ongoing contact following donation from a DonateLife coordinator, nurse or doctor, a Donor Family Support Coordinator, hospital social worker or hospital chaplain (refer Figure 13). **In Wave 2, this support was offered to 95% of donor family members, a statistically significant increase.**

Figure 13 Follow-up Services and Resources (listed as Figure 32 in Wave 2 Research Report)



Services received / Would Like to have received

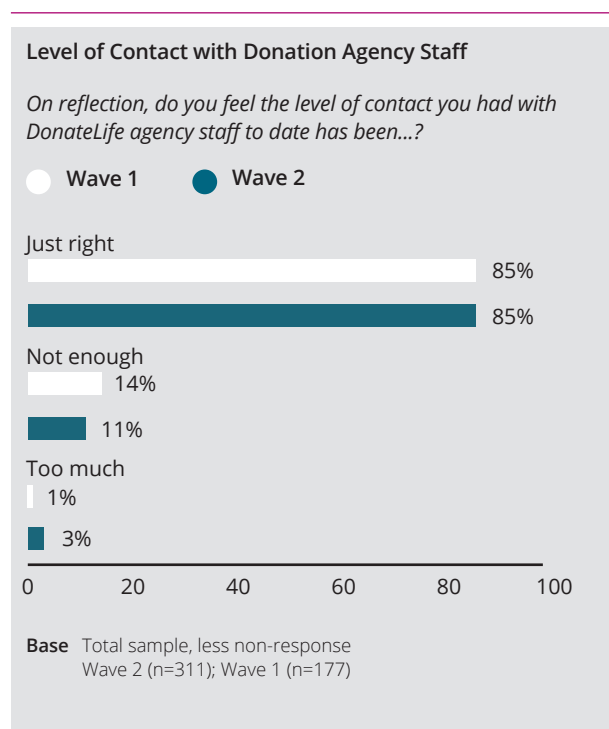
In Wave 2, services that were received by donor family members and whether they found those services helpful were reported. It also reported whether the family members who did not receive each service but would have liked to, as outlined below

	Wave 2	Wave 1
A follow up phone call from the donor coordinator / donor nurse or doctor		
Received	87%	78%
Not received	13%	22%
Helpfulness	99%	94%
Basic information about the transplant recipients		
Received	85%	82%
Not received	-	-
Helpfulness	99%	94%
Follow up support from the donor family coordinator		
Received	78%	59%
Not received	22%	-
Helpfulness	99%	92%
Annual Service of Remembrance		
Invitation to attend the service sent to donor family members	84%	-
Helpfulness even if they chose not to attend	83%	82%

Level of Contact with DonateLife staff

In Wave 2, most donor family members (85%) felt that the contact they had with DonateLife had been at the right level (refer Figure 14). One in nine (11%) family members felt that contact with donation agency staff had been lacking. These findings are consistent with Wave 1.

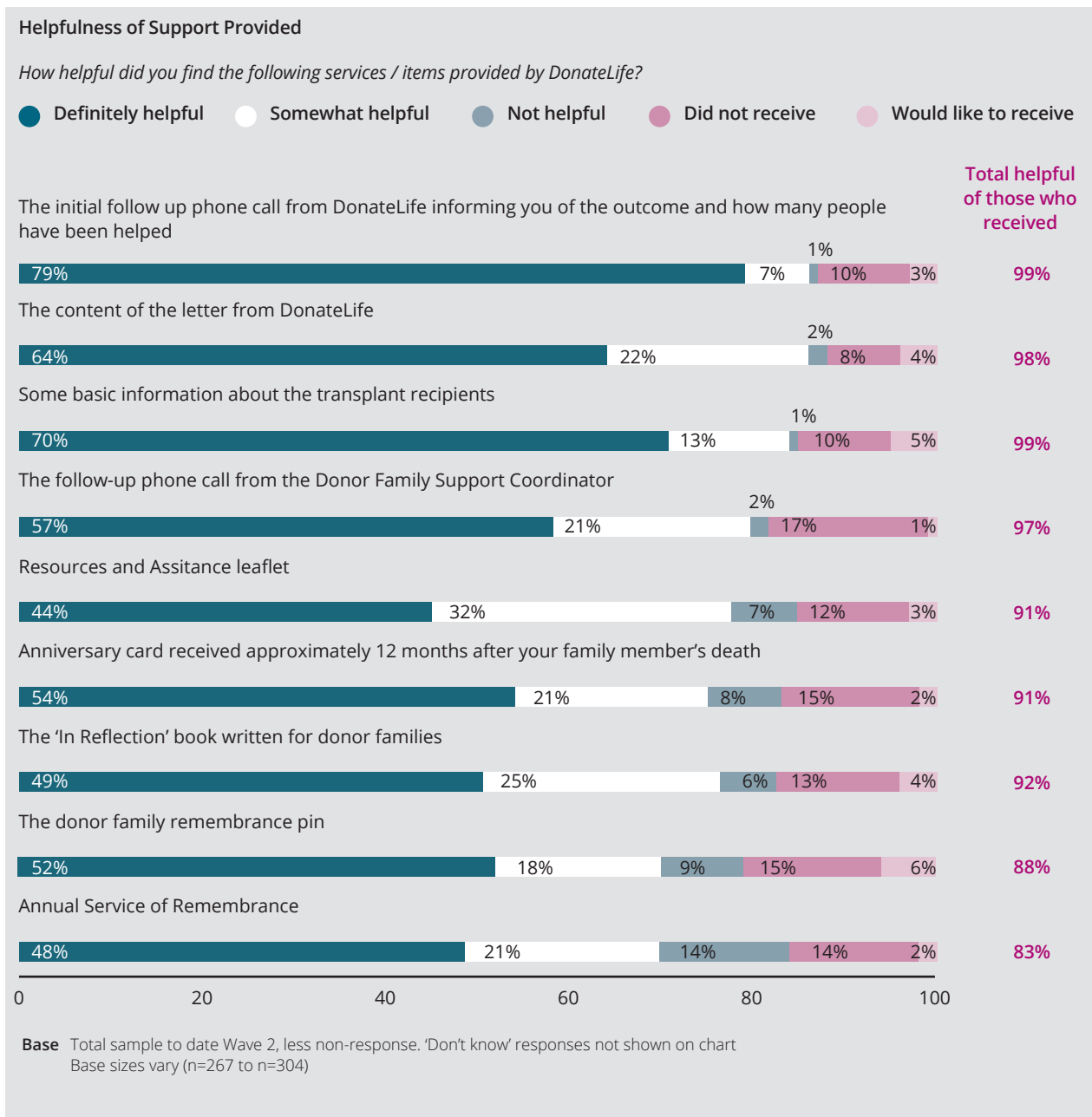
Figure 14 Contact with DonateLife agency staff (listed as Figure 35 in Wave 2 Research Report)



Helpfulness of support provided by DonateLife

In Wave 2, donor family members were asked to rate the level of helpfulness of nine support services / items provided by DonateLife, that they may or may not have received. Findings are shown in Figure 15 below, and compared where possible with Wave 1 findings at Table 2 further below. The vast majority of families who received these services found them to be helpful, suggesting that all families should be offered them. More families in Wave 2 found the follow-up phone call from the Donor Family Support Coordinator to be helpful than for families in Wave 1. All other findings are consistent across waves.

Figure 15 Helpfulness of support provided to donor families (listed as Figure 34 in Wave 2 Research Report)



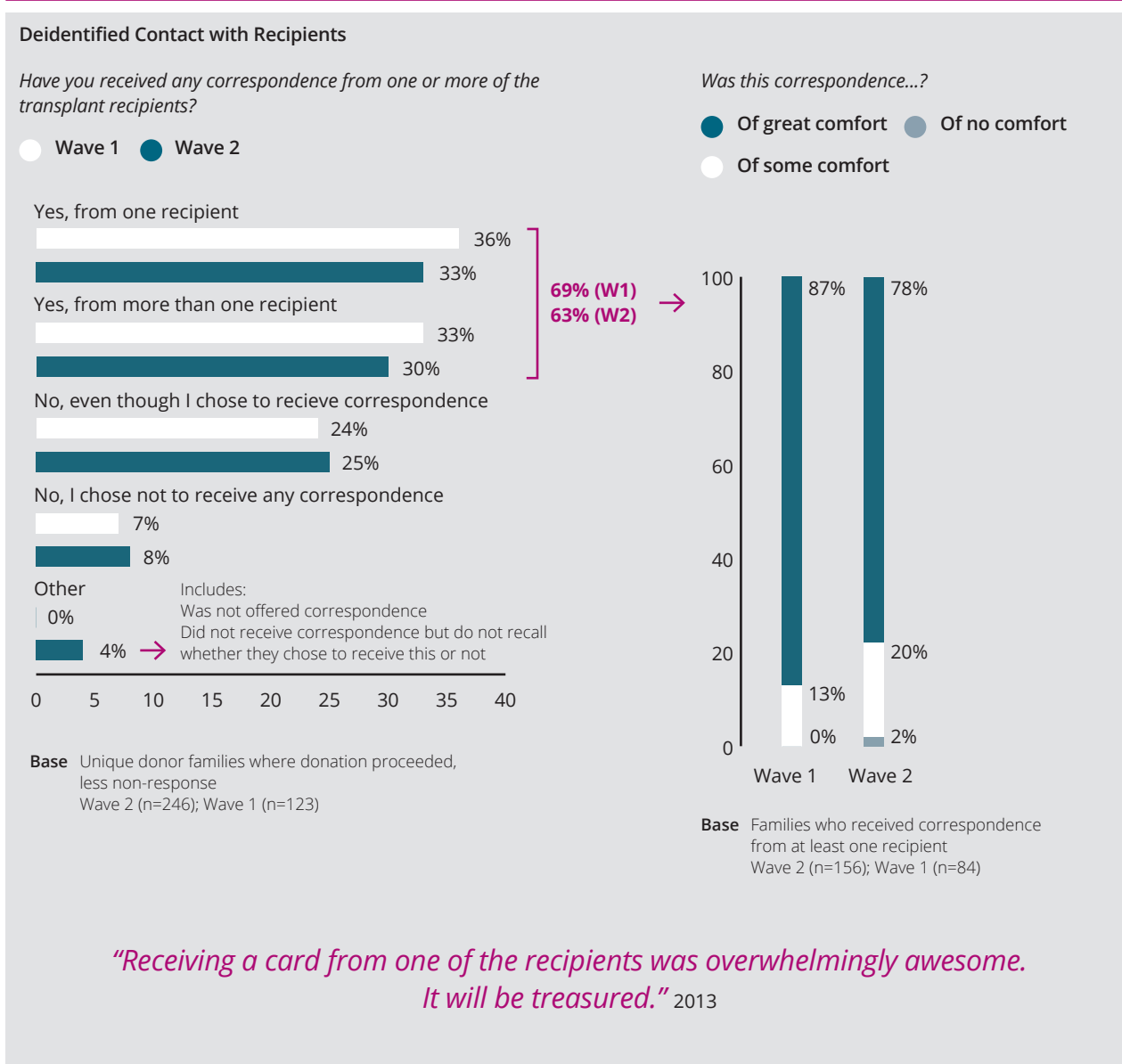
De-identified Contact with Recipients

In Wave 2, two thirds (63%) of donor families received a letter from at least one transplant recipient (refer Figure 16). This is consistent with Wave 1 at 69%. The letter provided comfort to 98% of these families, again consistent with Wave 1 (refer Figure 16).

Families differ in how they react to receiving letters from recipients. For the majority, it is an extremely positive experience. They are pleased to learn that lives have changed as a result of the donation and love to read about recipients' stories in their own words and in their own handwriting. They are often deeply moved by these stories and take great comfort in the knowledge that their loved one has helped others.

For other donor family members, correspondence from recipients is met with mixed emotions. They may not be ready to hear from the recipient, in which case letters are put away safely for another time, or for some, their loss is still raw and they simply have no interest in knowing anything about the recipients. In Wave 2, approximately one quarter (25%) of donor families had not received any correspondence from recipients, even though they chose to, consistent with Wave 1 at 24%.

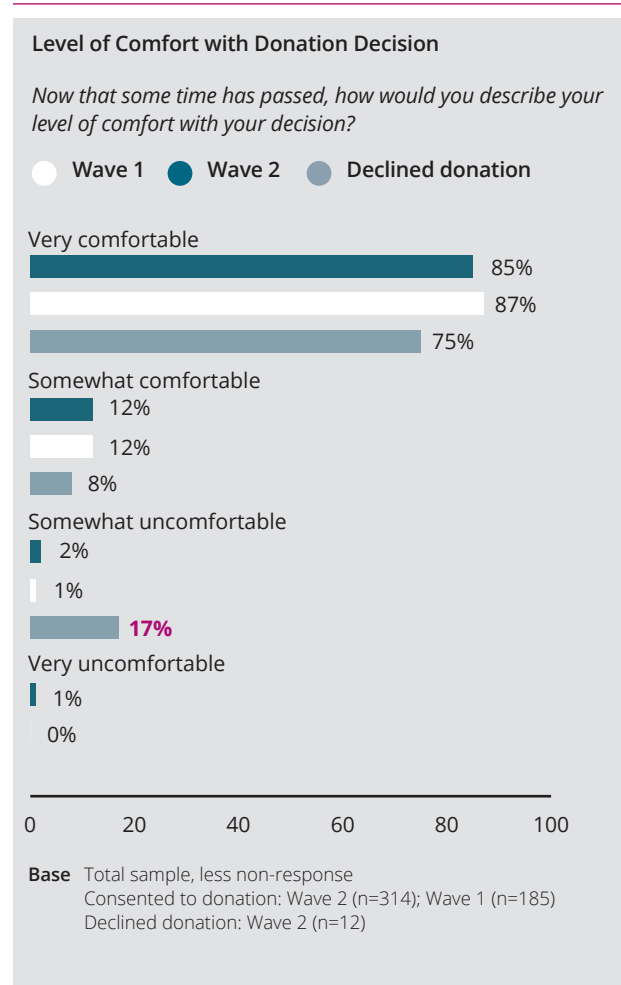
Figure 16 De-identified contact with recipients (listed as Figure 37 in Wave 2 Research Report)



Level of Comfort with Donation Decision

In Wave 2, for 97% of donor families reported that the donation decision they made still sits well with them today; 85% very much so (refer Figure 17), and these findings are consistent with Wave 1. As shown in Figure 17, 17% of families who declined donation are somewhat uncomfortable with their donation decision (for these families, individual family members were not united in their views and donation was therefore declined). **This is significantly higher than families who consented to donation (2% somewhat uncomfortable). In fact, 8% of families who declined donation are not sure if they would make the same decision today.**

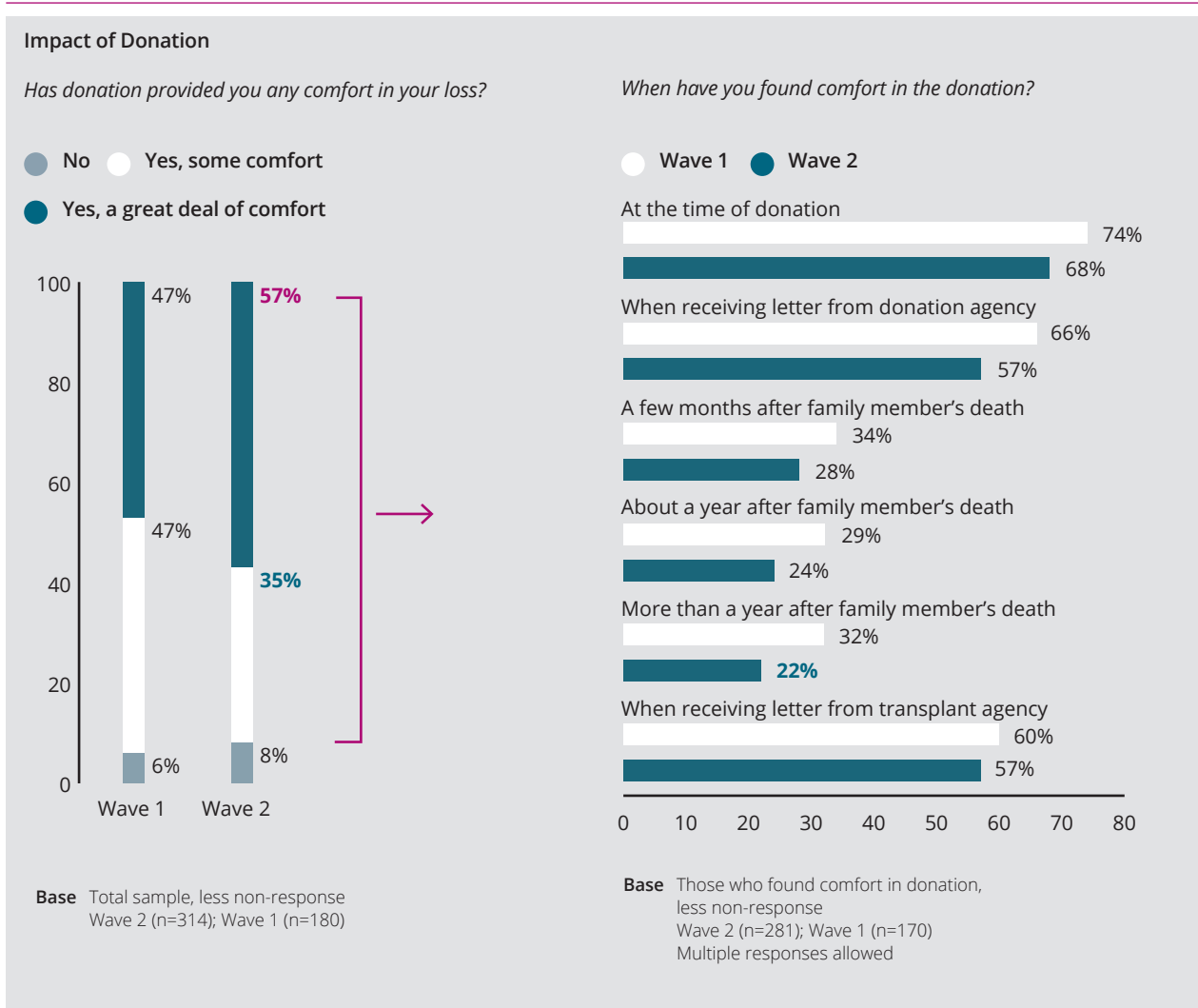
Figure 17 Level of comfort with donation decision (listed as Figure 38 in Wave 2 Research Report)



The Impact of Donation

In Wave 2, 92% of donor families have found comfort in the donation of their loved ones organ (refer Figure 18). At an overall level, this is consistent with Wave 1 families, although a greater number of families in Wave 2 stated that they found 'a great deal of comfort in donation' (57% vs 47% in Wave 1). For many, donation provides comfort in the days, weeks, months and years following a loved one's death. Importantly though, organ donation also provides immediate solace (whilst at the hospital) to family members. In fact 68% of these donor family members found comfort in donation at the time of donation, which is consistent with Wave 1.

Figure 18 The impact of donation (listed as Figure 39 in Wave 2 Research Report)



In Wave 2, in terms of how donation helps, approximately two thirds (64%) of donor family members who found comfort in donation feel that donation provides meaning to them and helps them in their grief (refer Figure 19), consistent with Wave 1.

During the personal interviews, many family members discussed the positive outcomes that donation enabled in an otherwise terrible situation. Donation helped them to know that because of their loved one’s generosity, other lives were saved or improved. It gave their loved one’s life more meaning and their death some greater purpose, and in this way, helped the healing process.

Many families felt positive about being able to honour the wishes of their loved one and enable them to do something that they knew was important to them. This was often felt at the time of donation, but was most keenly felt when they learnt of the outcome of the donation. The ultimate, for many, was to hear from recipients themselves and to hear, in their own words, what a difference the donation has made.

Figure 19 How donation has provided comfort (listed as Figure 40 in Wave 2 Research Report)



*“Thank you for being there when I needed it.
Thank you for making life matter even in death.”*

Donor Family Member, 2013