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NATIONAL STUDY OF FAMILY EXPERIENCES OF ORGAN AND TISSUE DONATION WAVE 2: EXPERIENCES IN 2012 AND 2013 - RESEARCH REPORT -



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Organ and Tissue Authority

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Executive Summary

This report details the findings of Wave 2 of the National Donor Family Study and represents the views and experiences of families who made a donation decision in 2012 and 2013. The research includes families who consented to donation and families who declined donation. The research seeks to understand families' experiences before, during and after donation and to ascertain and monitor how their needs can best be met.

All states and territories are included as are both pathways to donation. Amongst families who consented to donation, 24% opted to participate in the Wave 2 study. This is an improvement on the Wave 1 response rate of 18%, resulting in a significantly larger sample size (n=319 Wave 2; n=185 Wave 1).

Twelve families who declined donation took part in the quantitative component of the research and one family who declined donation consented to a personal interview.

Donor families' experiences begin in the Intensive Care Unit or Emergency Department of hospitals across Australia. Ninety-nine percent of families feel that staff in these departments treated them and their family member with great sensitivity and consideration.

For the DBD pathway donors, brain death testing is required and in 24% of instances, family members were offered to be present. When offered, it is taken up by 73% of family members. Ninety-one percent (91%) of these family members find that being present helps them to accept that their loved one has died.

In 2012 and 2013 (Wave 2), the donation conversation was initiated primarily by health professionals (58% vs. 46% in Wave 1). This conversation, initiated by health professionals, was raised with 48% of families *before* (10%) or at the *same time as* (38%) families were informed of the prognosis for their loved one. Initiating the conversation at this time can be a source of additional distress, with 35% of family members feeling that the timing was inappropriate.

However, 87% of families (including intended donors) feel that discussions about donation are handled with sensitivity and compassion. Donor families are given enough information (88%), opportunities to ask questions (97%, up from Wave 1 of 93%), answers to their questions (98%) and time to discuss donation and make their decision (96%).

Ninety-five percent (95%) of those who had previously discussed donation and knew the wishes of their loved one said that it made their donation decision easier. Thirty-two percent (32%) of families had not discussed donation with their loved one prior to making a decision. These families were much more likely to find the donation decision a difficult one (11% vs. 0.5% for those who had discussed and knew wishes).

Seventy-eight percent (78%) of donor family members see donation as a chance for something positive to come from a tragedy; 76% are motivated to donate because they feel that their loved one would have wanted to help others.

Eighty-nine percent (89%) of families (including intended donor families) feel that they were treated with consideration and sensitivity *after* agreeing to donation. In most instances (79%), they are offered support from a social worker, counsellor or chaplain. The majority of donor family members (89%) feel they are provided with the right type and amount of information about donation surgery. Almost all families (95%) feel that there were given enough time with their family member at this stage.

Forty-seven percent (47%) of families were given an opportunity to be with their loved one after donation surgery; of these, just over half (56%) opted to do so. Overwhelmingly 84%, found the experience to be a positive one. Eleven percent (11%) of family members who were *not* asked if they would like to see their family member post-surgery, would have liked to have been asked.

In Wave 2, 95% of families report being offered ongoing contact following donation from either DonateLife or hospital staff. This is a statistically significant increase on Wave 1 (85%). Ongoing contact from a Donor Family Support Coordinator is regarded as ‘definitely helpful’ by 79% of family members.

The initial phone call informing families of the outcome of the donation is the most helpful resource, with 79% saying that this was *definitely helpful*. Ongoing contact was considered helpful because the DonateLife coordinator understood the person’s situation (20%) and families were able to learn the outcome of the donation, be given updates on the progress of recipients and know the impact of their gift (19%).

Sixty-three percent (63%) of unique donor families have received a letter, via DonateLife, from at least one transplant recipient. In almost all cases (98%), this letter provided an enormous amount of comfort. Despite choosing to receive correspondence, 25% of donor families have not received any (consistent with Wave 1 families at 24%). Fifty percent (50%) of donor family members are not aware that they are welcome to write to recipients.

Just 3% of families are not comfortable with their donation decision in hindsight. The most common reason for this is insufficient or no contact with recipients (15%) and not being sure whether donation was the wish of their loved one (13%). This highlights the importance of encouraging the donation conversation within families.

For donor families who consented to donation, responses to questions on the donation decision included:

- A total of 85% of donor families are very comfortable with their decision;
- For 92% of these family members, donation provided comfort, most frequently at the time of donation (68%), but also over time and especially when receiving contact from DonateLife and recipients (57%); and
- After their donation experience, 89% of donor family members would donate their organs/tissues after death.

All **intended donor families** (i.e. families who consented to donation but the donation did not proceed) were comfortable with their donation decision; 80% very comfortable and 20% somewhat comfortable.

Eighty-three percent (83%) of families who declined donation are today comfortable with their decision to decline; 17% are not. Those families who are not comfortable with their decision declined donation because at the time, their family was not unified in their views; one or more family members was against donation and that being the case, the family declined.

Part A - Research Overview

1.0 RESEARCH BACKGROUND

In 2009, the Organ and Tissue Authority (OTA) was established as part of the Australian Government's National Reform Programme to create a nationally consistent and coordinated approach to organ and tissue donation and transplantation. Since then, a range of measures have been implemented which include enhanced support for donor families, increased capability and capacity within the health system to maximise donation rates and to raise community awareness, and stakeholder engagement across Australia to promote organ and tissue donation.

In addition to increasing community engagement and awareness, understanding the donation process and support needs of families who are asked to make a donation decision is critical. As such, an ongoing program of research known as the Donor Family Study was implemented¹.

The Donor Family Study seeks to understand and learn from families before, during and after the donation process, and monitors changes in donor family support needs over time, which contributes in determining how needs of families can best be met.

In 2013, OTA appointed Proof Research to conduct Wave 1 of the Donor Family Study, representing families who made a donation decision (consented to or declined donation) in 2010 and 2011. The Wave 1 report was published in 2014, and is available at <http://www.donatelife.gov.au/national-wave-1-donor-family-study>. This report details findings of Wave 2 of the study, representing families who made a donation decision in 2012 and 2013, and compares findings with the Wave 1 report.

¹ The OTA's Donor Family Study continues on from research conducted every four years since 1995 by the Australasian Transplant Coordinators Association (ATCA).

2.0 RESEARCH OBJECTIVES

The overall aim of the Donor Family Study is to:

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

This aim is supported by a number of key objectives:

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

3.0 RESEARCH METHODOLOGY

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

The program involved five key stages:

- Stage 1: Inception meeting and project set-up
- Stage 2: Design research instruments and documents
- Stage 3: Human Research Ethics Committee (HREC) and Research Governance (RG) submission and approval process
- Stage 4: Fieldwork - quantitative and qualitative research
- Stage 5: Analysis and reporting

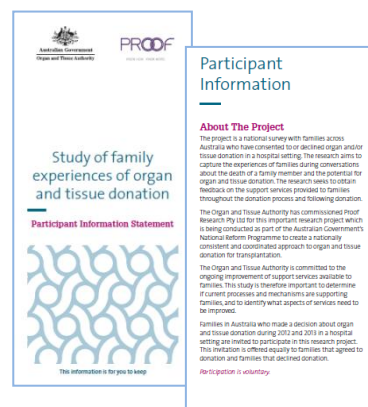
3.1 STAGE 1: INCEPTION MEETING AND PROJECT SET UP

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

3.2 STAGE 2: DESIGN RESEARCH INSTRUMENTS AND DOCUMENTS

The Proof Research team drafted various research instruments for the project. Through a consultative process with OTA and the DFSC, the instruments were amended in light of feedback and finalised once approved. The final set of research instruments includes:

- Covering letter from health services/ hospitals (for families who declined donation)
- Covering letter from the OTA CEO
- Participant Information Statement (PIS)
- Consent Form (for participation in a face to face interview)



- Questionnaire:
 - For families who consented to organ and/or tissue donation.
 - For families who declined organ and/or tissue donation.
- Discussion Guide for use in the in-depth personal interviews:
 - With families who consented to organ and/or tissue donation.
 - With families who declined organ and/or tissue donation.



The Human Research Ethics Committee (HREC) approved survey instruments and consent forms are included in the Appendices (A3).

3.3 STAGE 3: HREC AND RESEARCH GOVERNANCE SUBMISSION PROCESS

Prior to commencing the fieldwork, 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.

For the former stage of research, approval was granted from the Human Research Ethics Committees (HRECs) outlined at Table 1:

Table 1: List of HRECs for Consenting Strand of Research

FAMILIES WHO CONSENTED TO DONATION		
STATE / TERRITORY	HREC	APPROVAL DATE
ACT	▪ ACT Health HREC	▪ 26 May 2015
NSW	▪ South Eastern Sydney Local Health District HREC	▪ 20 May 2016
VIC	▪ Australian Red Cross Blood Service Ethics Committee ▪ Austin Health HREC	▪ 30 December 2014 ▪ 7 April 2016
TAS	▪ University of Tasmania HREC (Tasmania) Network	▪ 10 August 2015
SA	▪ SA Health HREC	▪ 3 February 2015
NT	▪ Menzies School of Health Research ▪ Central Australian HREC	▪ 19 March 2015 ▪ 29 April 2015
WA	▪ Sir Charles Gairdner Group HREC	▪ 9 December 2015
QLD	▪ Townsville Hospital and Health Service HREC	▪ 14 December 2015

A separate ethics approval process was conducted for families who were eligible for donation but who declined (Table 2). This process involved site specific applications to the following 32 Research Governance Offices (RGOs).

Table 2: List of Research Governance Offices for Declined Strand of Research*

FAMILIES WHO DECLINED DONATION		
LOCATION	RGO	APPROVAL DATE
NSW	▪ Northern NSW Local Health District	▪ 22 December 2016
	▪ The Sydney Children's Hospitals Network	▪ 31 January 2017
	▪ Illawarra Shoalhaven Local Health District	▪ 17 March 2017
	▪ Northern Sydney Local Health District	▪ 31 March 2017
	▪ Hunter New England Local Health District	▪ 4 April 2017
	▪ Western Sydney Local Health District	▪ 26 June 2017
	▪ Sydney Local Health District	▪ See Note 1
VIC	▪ Peninsula Health	▪ 6 December 2016
	▪ Ballarat Health Services and St John of God Hospital Ballarat	▪ 14 December 2016
	▪ Northern Health	▪ 18 January 2017
	▪ Austin Health	▪ 17 March 2017
	▪ Eastern Health	▪ 29 March 2017
	▪ Western Health	▪ 30 March 2017
	▪ The Royal Children's Hospital Melbourne	▪ 4 May 2017
	▪ St Vincent's Health	▪ 16 May 2017
	▪ Alfred Health	▪ See Note 1
	▪ Melbourne Health	▪ See Note 2
	▪ Monash Health	▪ 6 June 2017
TAS	▪ Covered by HREC approval	▪ 10 August 2015
SA	▪ Northern Adelaide Local Health Network	▪ 10 March 2016
	▪ Central Adelaide Local Health Network	▪ 16 March 2016
	▪ Southern Adelaide Local Health Network	▪ 27 April 2016
NT	▪ Covered by HREC approval	▪ 19 March 2015 ▪ 29 April 2015
WA	▪ Osborne Park Health Care Group	▪ 23 February 2016
	▪ St John of God Health Care	▪ 4 April 2016
	▪ Child and Adolescent Health Service	▪ 31 March 2016
	▪ Fremantle Hospital and Health Service	▪ 14 September 2016
	▪ South Metropolitan Health Service	▪ 14 September 2016
	▪ East Metropolitan Health Service	▪ 24 October 2016
QLD	▪ Gold Coast Hospital and Health Service	▪ 6 June 2016
	▪ Metro South Hospital and Health Service	▪ 15 June 2016
	▪ Townsville Hospital and Health Service	▪ 7 March 2017
	▪ Metro North Hospital and Health Service	▪ 27 March 2017
	▪ Sunshine Coast Hospital and Health Service	▪ 3 May 2017

- * Families who declined donation in the ACT were unable to participate and provide feedback due to approval not being granted by the ACT Health HREC.

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

Note 2: At the time of closing the survey and writing the report, approval from the RGO was still pending.

3.4 STAGE 4: FIELDWORK

The fieldwork comprised two strands of research activities:

- Quantitative
- Qualitative

Once HREC approvals for the consenting strand of research and site specific approvals for the declined strand of research were granted, fieldwork commenced.

3.4.1 QUANTITATIVE FIELDWORK

In all states and territories with the exception of Western Australia, once databases containing the name and address details of family members were received, survey packs were prepared by Proof Research and distributed direct to families.

The HREC requirements in Western Australia were that survey packs be prepared by Proof Research and then distributed to family members by DonateLife WA (for the consenting strand of research) or hospital (for the declined strand of research).

The survey packs contained:

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

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

Fieldwork was staggered according to HREC and RGO approval dates and receipt of the relevant databases. Survey packs were distributed to families who **consented to donation** between 1 April 2016 and 21 July 2016. Reminder cards were distributed between 11 July 2016 and 21 October 2016. For families who **declined donation**, survey packs were distributed between 15 August 2016 and 13 July 2017.

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

3.4.2 QUALITATIVE FIELDWORK

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

Face-to-face interviews were conducted between 27 July 2016 and 27 February 2017. With the permission of families, the interviews were audio recorded for transcription and analysis purposes.

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

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

3.5 STAGE 5: ANALYSIS AND REPORTING

Quantitative fieldwork for families who consented to donation closed on 7 December 2016. Hard copy questionnaires and online responses were then merged into one central database for statistical analysis. A phase of data cleansing and validation was carried out to address anomalies, missing responses and to confirm the final response rate. Recordings of all personal in-depth interviews were transcribed and full content analysis on each was carried out.

The fieldwork period for families who declined donation closed on 8 August 2017.

3.5.1 ANALYTICAL NOTES

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

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

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

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

4.0 SAMPLING - FAMILIES WHO CONSENTED TO DONATION

4.1 SAMPLE FRAME

All families who consented to organ and/or tissue donation in a hospital setting during 2012 and 2013 were invited to participate in Wave 2 of the Donor Family Study. This includes intended donors (i.e. families who consented to donation but the donation did not proceed).

4.2 RESPONSE RATES

Survey packs were sent to N=1,428 family members who consented to organ and tissue donation. Of these, n=116 were returned to sender due to a change of address or the person being deceased (bringing the total survey population to N=1,312). Of these, n=319 family members who consented to donation in 2012 or 2013 took part in Wave 2 of the Donor Family Study. This equates to an overall response rate of **24.3%**; an improvement on the Wave 1 response rate of 18%. The sample achieved in Wave 2 is significantly higher than that achieved in Wave 1 (n=185 family members).

In terms of the qualitative research strand, 105 consenting donor family members agreed to participate in a personal interview which is a decrease of 21 family members from Wave 1. Of these, 30 personal interviews were conducted face-to-face, with each interview averaging 60 minutes in length.

4.3 SAMPLE COMPOSITION - QUANTITATIVE

4.3.1 GEOGRAPHIC COVERAGE

The distribution of the sample across States and Territories is shown in Table 3. Comparing the research sample with the population of donor families, we see that Victoria is over-represented with a response rate of 33.9% while Western Australia is under-represented with a lower response rate of 15.7%. In total, a quarter of donor family members (24.3%) who were invited to participate in the study did so.

Table 3: Wave 2 - Quantitative sample overview by state/territory (Consenting Strand)

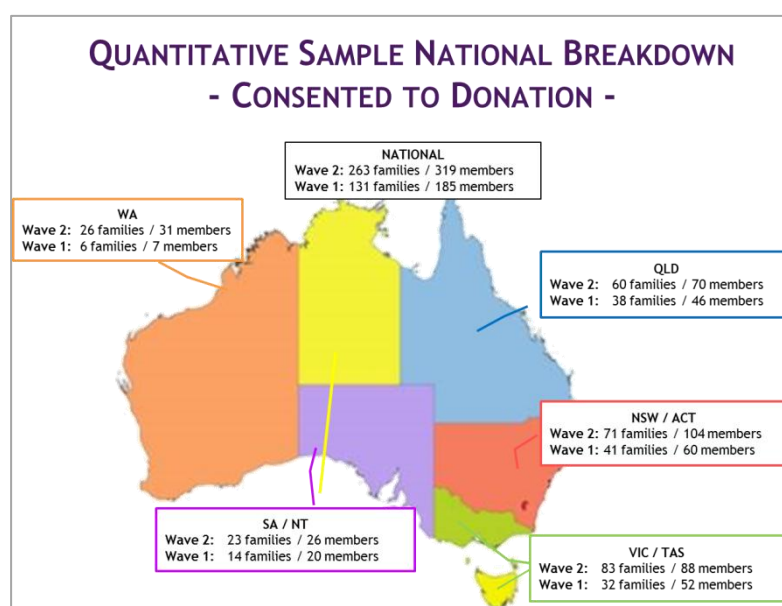
STATE/ TERRITORY	TARGET POPULATION		PARTICIPATING SAMPLE		RESPONSE RATE
	CONSENTING DONOR FAMILY MEMBERS*	% OF NATIONAL TOTAL	NO. QUESTIONNAIRES COMPLETED	% OF NATIONAL TOTAL	
NSW	364	27.7%	86	27.0%	23.6%
ACT	66	5.0%	18	5.6%	27.3%
VIC	224	17.0%	76	23.8%	33.9%
TAS	34	2.6%	12	3.8%	35.3%
QLD	321	24.4%	70	21.9%	21.8%
SA	85	6.5%	21	6.6%	24.7%
NT	21	1.6%	5	1.6%	23.8%
WA	197	15.0%	31	9.7%	15.7%
TOTAL	1,312	100.0%	319	100.0%	24.3%

* Excluding surveys packs that were returned to sender

As stated, a total of 319 individual family members took part in Wave 2 of the Donor Family Study. These individuals represent 263 unique donor families. This is a significant increase in sample size since Wave 1, where 185 family members from 131 unique donor families took part. Including members of the same donor family in the study is important as each individual family member's experience is unique and it ensures that the range of experiences is included.

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

Figure 1: Quantitative sample national breakdown



4.3.2 YEAR OF DONATION

In terms of the year-of-donation breakdown, 47% of families included in the Wave 2 sample consented to donation in 2012; the remaining 53% in 2013 (Table 4).

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

PARTICIPATING SAMPLE OF UNIQUE DONOR FAMILIES - YEAR OF DONATION -				
STATE/ TERRITORY	2010	2011	2012	2013
NSW	13	23	33	29
ACT	2	3	6	3
VIC	9	16	34	39
TAS	4	3	5	5
QLD	14	24	23	37
SA	8	6	7	11
NT	0	0	2	3
WA	4	2	13	13
TOTAL	n=54 41% of Wave 1 sample	n=77 59% of Wave 1 sample	n=123 47% of Wave 2 sample	n=140 53% of Wave 2 sample

4.3.3 DONATION PATHWAY

There are two pathways to deceased donation: donation after brain death (DBD) and donation after circulatory death (DCD). In Australia in 2012 and 2013, the majority of organ donors came from the DBD pathway (78%), while 22% came from the DCD pathway.²

Families who consented to donation after their family member was declared brain dead and those where donation followed circulatory death, were included in the research.

As shown in Figure 2, 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).

² Distribution of Deceased Organ Donors by Donation Pathway, Organ and Tissue Authority Annual Report 2013-14, p31

Figure 2: Wave 2 Sample - Donation Pathway

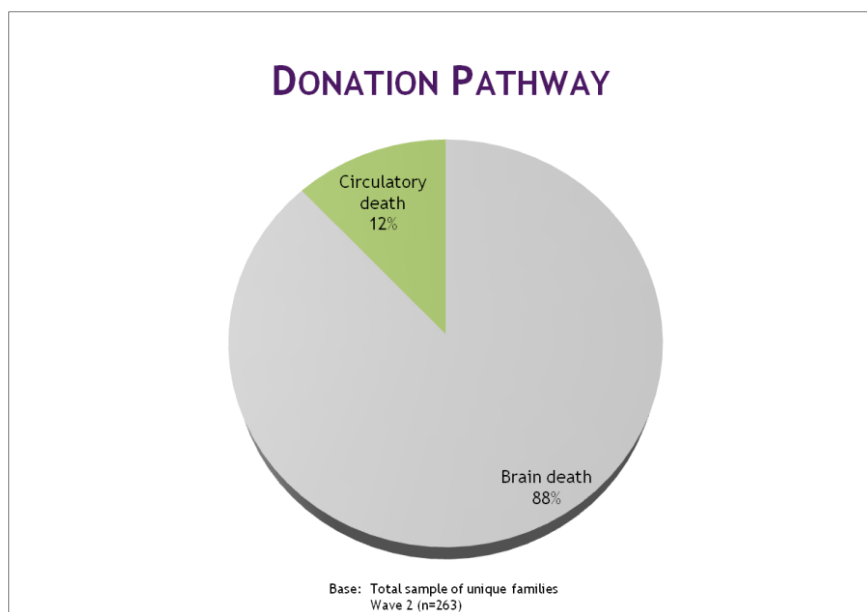


Table 5 shows the donation pathway for Wave 1 and Wave 2 samples, by state/territory.

Table 5: Number of donor families, split by DCD and DBD, by state/territory

STATE/TERRITORY	WAVE 1 2010/2011		WAVE 2 2012/2013	
	DCD	DBD	DCD	DBD
NSW/ACT	4	37	4	67
VIC/TAS	2	30	17	66
QLD	7	31	7	53
SA/NT	1	13	2	21
WA	-	6	2	24
TOTAL NO. UNIQUE FAMILIES	14 (11%)	117 (89%)	32 (12%)	231 (88%)

4.3.4 WHAT WAS DONATED

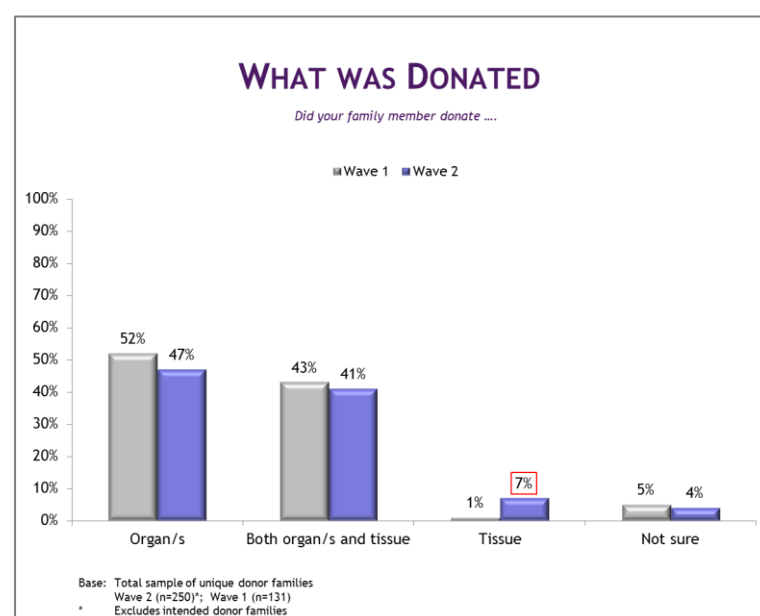
As shown in Table 6, intended donors represent 5% of the Wave 2 sample; families of those who donated organs only represent 45% and families of those who donated both tissue and organs 39%. There are no significant differences between 2012 and 2013 donors.

Table 6: Donation by year of donation

WHAT WAS DONATED	YEAR OF DONATION (UNIQUE DONOR FAMILIES)		
	WAVE 2	WAVE 2 - BY YEAR OF DONATION	
	TOTAL (N=263)	2012 (N=123)	2013 (N=140)
Organs only	45%	49%	41%
Organs & tissue	39%	38%	40%
Tissue only	7%	7%	6%
Not sure	4%	2%	6%
Donation did not proceed	5%	3%	6%

Comparing Wave 1 and Wave 2 and re-percentaging the data to exclude intended donors, the Wave 2 sample includes a greater proportion of tissue only donor families than the Wave 1 sample (Figure 3).

Figure 3: Sample profile - what was donated, Wave 1 vs. Wave 2



4.3.5 RELATIONSHIP AND AGE

Figure 4 shows the relationship of respondents to donors and the age range of donors, for both Wave 1 and Wave 2 of the Donor Family Study. A wide range of family members are included in the study, with donors ranging in age from 11 to 83 years.

Figure 4: Relationship to donor and age of donor

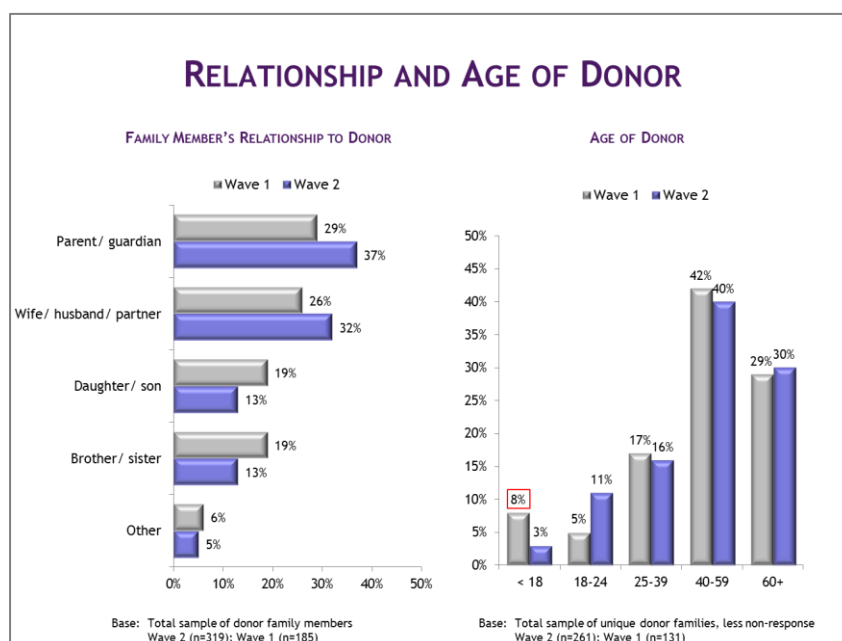


Table 7 shows the relationship of the respondent to the donor, together with the average donor age and age range. As shown, parents of donors represent 37% of the Wave 2 sample and the average age of their donor children is 32 years.

Table7: Relationship of respondent to donor and age of donor

RELATIONSHIP OF RESPONDENT TO DONOR "I AM HIS/ HER"	AVERAGE AGE OF DONOR	AGE RANGE OF DONOR
Parent/ guardian	32 years	11 to 64
Spouse/ partner	58 years	25 to 83
Daughter/ son	62 years	41 to 81
Brother/ sister	49 years	22 to 71
Other (e.g. uncle, aunt, grandparent)	51 years	20 to 79

4.3.6 ETHNICITY

Two percent (2%) of the Wave 2 donor sample are of Aboriginal or Torres Strait Islander (ATSI) descent. According to the latest available Census data (Australian Bureau of Statistics, 2011), 3% of Australia's population identify as Aboriginal or Torres Strait Islander.

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

As the ethnicity of donors was not measured in Wave 1, a comparison with Wave 2 data is not possible.

4.4 SAMPLE COMPOSITION - QUALITATIVE

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

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

STATE/ TERRITORY	NO. OF DONOR FAMILY MEMBERS AGREED TO IN- DEPTH INTERVIEW	NO. OF FACE-TO-FACE INTERVIEWS CONDUCTED		YEAR OF DONATION		TOTAL PERSONAL INTERVIEWS FOR EACH STATE/TERRITORY - CONSENTED TO DONATION
		DBD	DCD	2012	2013	
NSW	19	7	-	3	4	7
ACT	8	2	-	2	-	2
VIC	39	5	1	3	3	6
TAS	5	2	-	-	2	2
QLD	16	5	-	-	5	5
SA	6	2	-	1	1	2
NT	4	2	-	1	1	2
WA	8	4	-	1	3	4
NATIONAL	105	29	1	11	19	30

5.0 SAMPLING - FAMILIES WHO DECLINED DONATION

5.1 SAMPLE FRAME

All families who declined organ and/or tissue donation in a hospital setting during 2012 and 2013, at a participating hospital, were invited to take part in Wave 2 of the Donor Family Study, with the exception of:

- Families in the ACT, as the ACT Health HREC did not grant approval.
- NSW families who participated in the COMFORT study.
- VIC families who declined donation between 1 April 2012 and 30 September 2013 at participating sites:
 - ✚ Royal Melbourne Hospital
 - ✚ St Vincent's Hospital
 - ✚ Austin Hospital
 - ✚ Footscray Hospital

These families were previously contacted as part of a separate research study undertaken by Dr Sandra Neate et al³.

The participating Wave 2 hospitals are detailed in Table 9. As shown, six states and one territory took part in this strand of research, whereas in Wave 1, two states and two territories took part. Wave 2 therefore offered many more families an opportunity to provide their feedback.

5.2 RESPONSE RATES

Survey packs were sent to N=323 family members who declined organ and tissue donation. Of these, n=44 were returned to sender due to a change of address or the person being deceased (bringing the total survey population to N=279). Of these, n=12 families took part in Wave 2 of the Donor Family Study. This equates to an overall response rate of 4.3% (Table 9). It should also be noted that there were no complaints received from family members who declined organ and tissue donation about being invited to participate in the study.

³ Understanding Australian families' organ donation decisions; <http://www.aaic.net.au/document/?D=20140415>

Whilst the response rate in Wave 2 is similar to that achieved in Wave 1, the sample achieved in the declined strand for Wave 2 is higher than that achieved in Wave 1, where just one family member who declined donation took part in the research. This demonstrates the importance of inviting all families who declined donation to take part in the study.

Table 9: Wave 2 - Quantitative sample overview by state/territory (Declined Strand)

STATE/ TERRITORY AND HOSPITAL	TARGET POPULATION	PARTICIPATING SAMPLE	
	FAMILY MEMBERS WHO DECLINED DONATION*	No. QUESTIONNAIRES COMPLETED	RESPONSE RATE
NSW:			
▪ Wollongong	7	0	
▪ Tweed Heads	0	0	
▪ Lismore Base	1	0	
▪ Royal North Shore	7	0	
▪ Westmead	14	0	
▪ John Hunter	16	1	
▪ Royal Prince Alfred ³	-	-	
▪ Children's Hospital at Westmead	13	0	
Wave 2 - Total NSW - Declined	58	1	1.7%
Wave 1 - Total NSW - Declined	Did not participate		
ACT:			
Wave 2 - Total ACT - Declined	Did not participate		
Wave 1 - Total ACT - Declined	9	0	0.0%
VIC:			
▪ Alfred ³	-	-	
▪ Royal Melbourne ³	-	-	
▪ Frankston	4	0	
▪ Northern	12	0	
▪ Royal Children's	12	1	
▪ Footscray	2	0	
▪ St Vincent's	1	0	
▪ Austin	5	0	
▪ Ballarat Base	4	0	
▪ Box Hill	13	0	
▪ Dandenong	8	0	
▪ Monash Medical Centre	22	1	
▪ Sunshine ²	-	-	
Wave 2 - Total VIC - Declined	83	2	2.4%
Wave 1 - Total VIC - Declined	Did not participate		
TAS:			
▪ Royal Hobart	8	2	
▪ Launceston General	2	0	
▪ North West Regional	2	0	
Wave 2 - Total TAS - Declined	12	2	16.7%
Wave 1 - Total TAS - Declined	6	1	16.7%

STATE/ TERRITORY AND HOSPITAL	TARGET POPULATION	PARTICIPATING SAMPLE	
	FAMILY MEMBERS WHO DECLINED DONATION*	No. QUESTIONNAIRES COMPLETED	RESPONSE RATE
QLD:			
▪ Princess Alexandra	20	3	
▪ Townsville	10	0	
▪ Nambour General	4	1	
▪ Royal Brisbane & Women's	10	0	
▪ Gold Coast University	9	1	
▪ Sunshine Coast University ²	-	-	
Wave 2 - Total QLD - Declined	53	5	9.4%
Wave 1 - Total QLD - Declined	Did not participate		
SA:			
▪ Royal Adelaide	8	0	
▪ Lyell McEwin	3	0	
Wave 2 - Total SA - Declined	11	0	0.0%
Wave 1 - Total SA - Declined	5	0	0.0%
NT:			
▪ Royal Darwin	1	0	
Wave 2 - Total NT - Declined	1	0	0.0%
Wave 1 - Total NT - Declined	6	0	0.0%
WA:			
▪ Sir Charles Gairdner	26	1	
▪ Royal Perth	29	1	
▪ Rockingham ¹	-	-	
▪ Princess Margaret	6	0	
▪ St John of God Murdoch ¹	-	-	
▪ St John of God Subiaco ¹	-	-	
▪ Joondalup ¹	-	-	
Wave 2 - Total WA - Declined	61	2	3.3%
Wave 1 - Total WA - Declined	Did not participate		
TOTAL - WAVE 2	279	12	4.3%
TOTAL - WAVE 1	26	1	3.8%

* Excluding surveys packs that were returned to sender

Note 1: These hospitals agreed to participate in Wave 2 but did not have any family members decline donation during 2012 or 2013.

Note 2: RGO approval was granted to include these hospitals in the Donor Family Study, however as they were not operating in 2012/2013, they did not take part in Wave 2.

Note 3: These hospitals agreed to participate in Wave 2, but RGO approval was not granted in line with the approved HREC method, therefore families were not able to be included.

In terms of the qualitative research strand, one family who declined donation agreed to participate in a personal interview. A face-to-face interview lasting for approximately 60 minutes was conducted with this family member in Perth.

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

5.3 SAMPLE COMPOSITION - QUANTITATIVE

5.3.1 GEOGRAPHIC COVERAGE

As shown in Table 9, 12 families who declined donation took part in the research. Their geographic distribution is:

Queensland	-	n=5
Victoria	-	n=2
Western Australia	-	n=2
Tasmania	-	n=2
New South Wales	-	n=1

5.3.2 YEAR OF DONATION DECISION

In terms of the year-of-donation breakdown, 3 of the 10 families who declined donation did so in 2012; the remaining 9 in 2013 (Table 10).

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

STATE	PARTICIPATING SAMPLE OF UNIQUE DONOR FAMILIES - DECLINED DONATION - YEAR OF DONATION -	
	2012 (NO. OF FAMILIES)	2013 (NO. OF FAMILIES)
NSW	0	1
VIC	0	2
TAS	0	2
QLD	3	2
WA	0	2
TOTAL	n=3	n=9

5.3.3 RELATIONSHIP AND AGE

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

Table11: Relationship of respondent to potential donor and age of potential donor

RELATIONSHIP OF RESPONDENT TO POTENTIAL DONOR “I AM HIS/ HER”	AVERAGE AGE OF POTENTIAL DONOR	AGE RANGE OF POTENTIAL DONOR
Spouse/ partner (n=7)	61 years	48 to 75
Parent/ guardian (n=4)	29 years	14 to 46
Daughter/ son (n=1)	69 years	69

5.3.4 ETHNICITY

All twelve families who declined donation and took part in the research only spoke English at home and none were of Aboriginal or Torres Strait Islander descent.

Part B - Research Findings

6.0 THE DECISION TO DONATE

The research findings highlight the importance of prior knowledge of a loved one's wishes regarding donation in making a donation decision. Those who had discussed donation and knew the wishes of their loved one invariably found the decision much easier than those who hadn't.

"It needs to be discussed with all family members so all know and the donor's wishes can then be respected and not have to have a harrowing discussion because it had not been discussed."

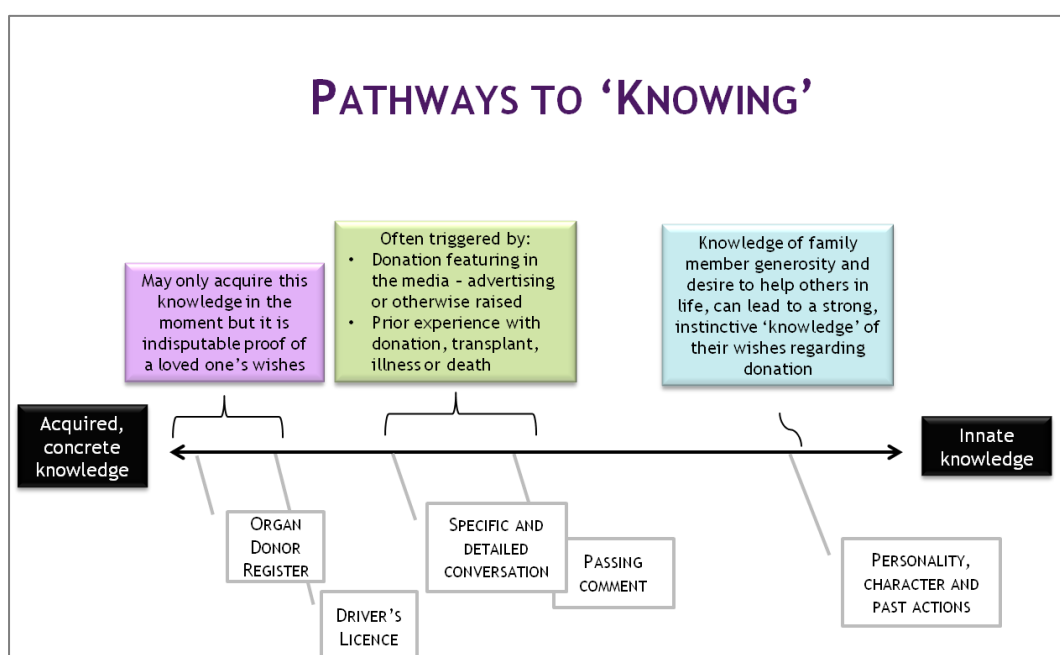
2012 - Declined donation

Many families see donation as something positive that can come from a tragedy and a way to honour the wishes and values of their loved one. Each family's situation is unique and complex and forms the framework in which donation decisions are made.

6.1 IMPACT OF PRIOR KNOWLEDGE

Knowing the wishes of a loved one makes the donation decision easier for family members. There are multiple paths to 'knowing' ranging from solid, acquired knowledge, through to innate knowledge (Figure 5).

Figure 5: Pathways to 'Knowing'



Discussions about donation are often triggered by the media or through personal experience, such as knowing an organ recipient or a donor family. Discussions can range from a passing comment through to a detailed conversation where opinions are strongly expressed.

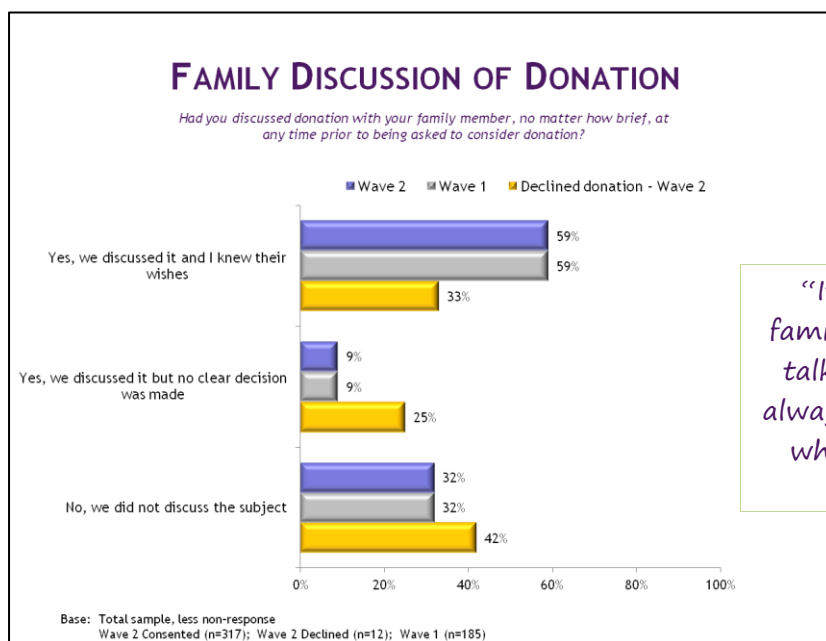
In some cases, despite no recollection of a conversation and no proof of their wishes on the donor register or driver's licence, donor families just know that donation is what their loved one would have wanted because it is in-keeping with the way they have lived their lives.

"Whatever she could do, she would do. If nurses and doctors came in and said 'can we ask you questions', she would go in and she would be one of their test cases for their exams, because her case was just so complicated. Whatever she could do, she would always help because she felt that it was the absolute least she could do."

2012 (Personal Interview)

Consistent with Wave 1 findings, approximately three in five donor family members (59%) in 2012/2013 had discussed organ and tissue donation with their loved one prior to consenting to donation (Figure 6).

Figure 6: Prior discussion of organ donation



"It was something our family had actually always talked about, so we were always aware that that was what he wanted to do."

2013

Whilst 32% of donor families in 2012 and 2013 did not discuss the subject of organ donation with their loved one prior to consenting to donation, this is actually lower than the national incidence of not discussing donation (44% amongst the general population of Australia)⁴. This figure is in line with families who declined donation (42% of families who declined donation in 2012 and 2013 did not discuss donation prior to being asked to consider it), further reinforcing the importance of encouraging people to have the donation conversation with loved ones.

There is evidence in favour of keeping donation top of mind, for continuing to spark conversations and for encouraging people to register their wishes and to make those wishes known to family members.

Continued efforts are needed to encourage more families in Australia to have the donation conversation.

Families who discussed organ and tissue donation with each other, no matter how brief the conversation, find 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).

"It was her choice. My love wanted it."

2013

"At a very difficult time, knowing what we had discussed made a huge difference."

2012

"I knew we were doing the right thing as it is what my husband would have wanted, despite my own personal views."

2013 - Declined donation

Conversely, as shown in Table 12, families who did not have the discussion are more likely to find the donation decision a difficult one (11% in Wave 2, 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.

⁴ Proof Research, 'The Donation Conversation - One Question: national survey' among n=28,206 Australian residents aged 14-100 years, May 2015

This figure rises for families who declined donation - 20% of families who did not discuss donation found the decision to decline a difficult one.

“Not knowing his wish if this situation occurred, gave us all regrets and anxiety.”

2012

Table 12: Impact of donation discussion on donation decision

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

Knowing a loved one's wishes, either formally (being on the Australian Organ Donor Register) or informally (from a conversation or brief chat), helped families in three main ways:

1. It gave some control back to families, in a time when they felt powerless to control the outcome.
2. It was seen as a gesture of love; carrying out their loved one's wishes being the last thing that families felt they could do for their family member.
3. It took the decision out of the hands of individual family members when there was conflict due to not all agreeing about donation; in essence, families felt their loved one was making the decision and the family then united for a common purpose.

“Knowing our son's wishes made the decision to donate his organs simple – it wasn't making a decision but more like doing the right thing.”

2012

“My brother was a registered organ donor, so as a family we united to make the decision between all and that made the decision a bit easier.”

2012

No matter how the knowledge is acquired or how explicit it is, prior awareness of a loved one's donation wishes is undeniably important for families in making the decision to donate.

Family members were asked how knowing or not knowing the wishes of their family member impacted on their decision to donate. As shown in Table 13, half of donor family members (52%) felt that their loved one supported donation, so donating was a way of honouring their wishes.

Table 13: The way in which donation discussion impacts the donation decision

IN WHAT WAY DID KNOWING OR NOT KNOWING THE WISHES OF YOUR FAMILY MEMBER IMPACT ON YOUR DECISION TO DONATE?	TOTAL (N=220)
Wanted to honour his/her wishes / family member supported donation	52%
It made the decision easier at a difficult time	15%
There was no question about what to do/ no doubts/ we were certain	10%
Family member was generous/ giving person/ would have wanted to help others	7%
Positive impact/ felt comfortable with decision/ reassured about decision	6%
All family members were in agreement due to wishes being known	6%
Had no impact on decision to donate	5%
Provided chance for someone else to live/ a positive outcome from our loss	5%
We would have donated anyway/ believe in donation	5%
Seemed like the right thing to do/ no reason to refuse	4%
Made decision more difficult not knowing wishes of family member/ caused regrets and doubts about decision	4%
Family member had prior experience with donation (was a recipient/ knew recipients)	3%
Not an easy process/ very hard to go through	2%
Other reason (< 2% each)	12%

6.2 PERSONAL VIEWS ABOUT DONATION

If donation hasn't been discussed and a loved one's wishes are not known to family members, the donation decision will be influenced by an individual's personal view of donation. They will inevitably ask themselves two key questions:

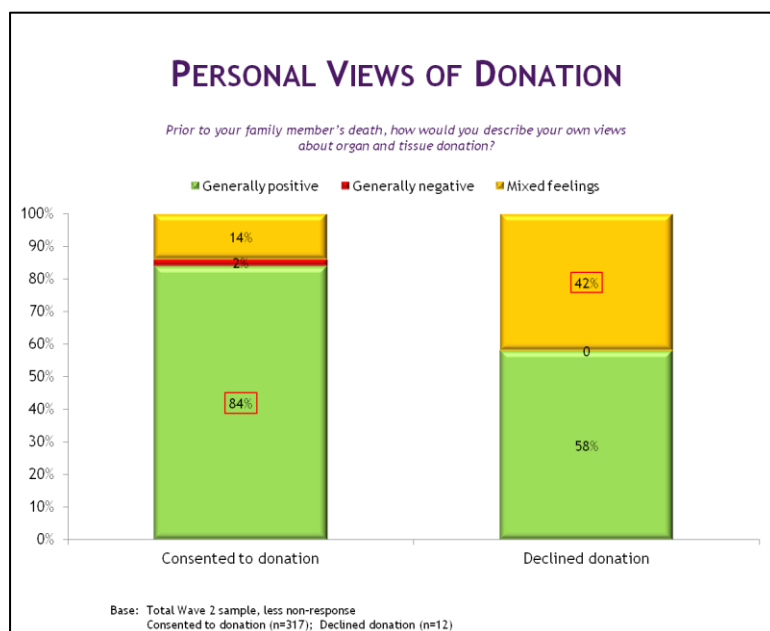
- What would my loved one have wanted?
- Am I comfortable with this/ will the decision sit well with me in the future?

The data shows that the decision to donate is an easier one when donation is supported. When feelings are mixed or not supportive of donation, and if the views of the family member are not known, it becomes a difficult decision. Those who have uncertainty tend to feel uncomfortable about donation surgery. They have questions surrounding the process and how their family member will be treated during surgery. At this time of profound grief, family members are protective of their loved one; maintaining their dignity and not 'putting them through anything else' is of the utmost importance.

Knowing the donation wishes of their loved one becomes even more important when family members are uncertain or hold contrary views of donation. It can help families make a decision with greater confidence and in many instances, feel that they are honouring their family member's wishes.

As shown in Figure 7, 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. 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.

Figure 7: Personal views of donation



Continue to raise awareness of the positive aspects of organ donation.

6.3 MOTIVATIONS FOR DONATION

Consistent with Wave 1, the majority of donor families (78%) see organ and tissue donation as a chance for something positive to come out of a personal tragedy (Figure 8). Knowing that other people's lives have been changed by the act of donation can help donor families cope with their loss.

"Donation has made the loss of our son more bearable."

2012

"It was a sad time which had a happier ending knowing that two other people had their lives saved."

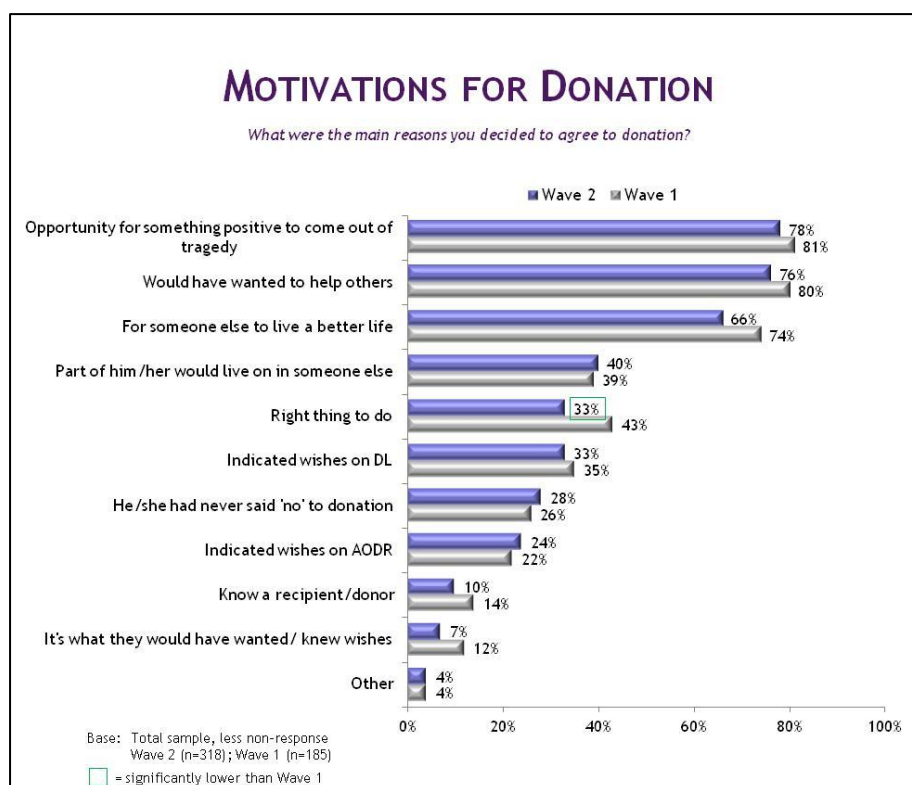
2012

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. This gives donor families a strong sense of pride in their loved one and is something that they cherish and hold on to.

"Knowing that we were following the wishes of our granddaughter made me very proud of her at such a young age."

2013

Figure 8: Motivations for donation



6.4 REASON FOR DECLINING DONATION

There are many reasons why families choose to decline donation (refer Table 14). Of the 12 families who took part in the research, six (50% net figure) declined because they felt that their loved one had been through enough and/or they didn't want him/her to go through donation surgery.

As demonstrated in the following comment, there can also be some confusion around death/ impending death, and a family member's desire to 'protect' their loved one.

"Even though my daughter was on a machine, her heart was still beating and you have hope that she is still with us. Knowing that she would have been taken away while alive [for donation surgery], there is no closure."

2013 - Declined donation

Not knowing the wishes of their loved one was reason to decline donation for 25% of families, while 17% of families were honouring the wishes of their loved one by declining. Two of the 12 families who declined donation (17%), felt that they did not have sufficient information to allow them to make an informed donation decision.

Table 14: Reasons for declining donation

WHAT WERE THE MAIN REASONS YOU DECIDED TO DECLINE DONATION?	TOTAL (N=12)	
He/she had been through enough	33%	(n=4)
I didn't want him/her to have surgery for donation	25%	(n=3)
I didn't know what he/she would have wanted	25%	(n=3)
He/she didn't want to donate	17%	(n=2)
I didn't accept his/her death and couldn't agree to donation	17%	(n=2)
I didn't have enough information about what was involved with donation	17%	(n=2)
Other family members declined (but I would have consented)	17%	(n=2)
Donation was going to take too long and I couldn't wait	8%	(n=1)
I don't like the idea of donation	8%	(n=1)
Other ("we were not asked; the doctors decided" and "sudden death")	17%	(n=2)

"Organ donation was discussed by the nurse but he had already been on life support for days and we did not want it to go on for any longer."
 2012 - Declined donation

6.5 WHY IT MATTERS

While some of the preceding factors are outside the direct control of the OTA, it is nevertheless important to have an appreciation for the complexity of the donation decision for family members, including the interplay of various elements. Of course, additional to these factors are the aspects that can be controlled, such as the timing, delivery and content of the donation conversation and the care and respect provided to families. These are the subject of later sections of this report.

Behind every potential donor there is a complex web of beliefs, feelings, family dynamics and circumstances, combining to create a unique situation for that family. This becomes the framework or context in which families make their donation decision. Great skill is required on the part of health professionals to unravel this web and stay attuned to the needs of each family unit and to each family member.

"It was not my decision to say no. About a year later, Dad's partner asked me why we hadn't been asked about donating. I said we were asked and she had said no - she didn't remember this happening."
 2012 - Declined donation

7.0 AT THE HOSPITAL

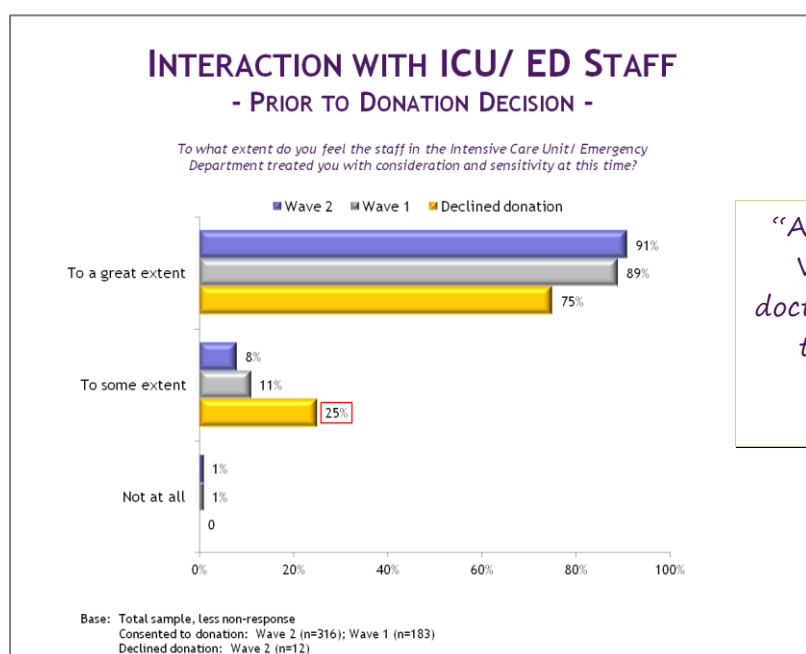
7.1 INTERACTION WITH ICU/ ED STAFF

Almost all donor families (99%) feel that staff in the Intensive Care Unit (ICU) or Emergency Department (ED) treated them with consideration and sensitivity (91% feel this occurred to a great extent; 8% to some extent) prior to any discussions about donation (Figure 9). These findings are consistent with Wave 1.

Whilst families who declined donation feel they were treated with consideration and sensitivity prior to making their donation decision, the strength of feeling is less so than for families who consented to donation (25% felt this way ‘to some extent’ compared with 8% of donor families).

“They were magnificent. Very caring and sensitive doctors and nurses.”
2012 - Declined donation

Figure 9: Interaction with ICU/ED staff prior to donation decision



“All staff were wonderful. Very considerate. The doctors were incredible with their information and compassion.”
2012

“I cannot speak highly enough of the care and understanding the hospital staff showed to us during that horrible time.”
2012

“ICU staff were just amazingly good (at their job and relating to family).”
2013

Families generally experience staff as respectful, caring, compassionate and considerate. They appreciate their gift for finding the right words, for explaining the situation carefully, for their willingness to bend the rules (e.g. by allowing more than 2 family members at the ICU bedside at a time) and for the tender and caring way in which they treat their loved ones. Small gestures like brushing their hair with care and talking to them are vitally important.

"The nursing and medical staff treated our family with dignity, respect and compassion."

2013

As shown in Figure 9 above, just 1% of donor family members feel that ICU/ED medical staff did not demonstrate sufficient sensitivity towards them. As demonstrated in the comments below, often this was just one doctor or nurse out of the whole medical team, but unfortunately the smallest unwelcome comment or gesture makes a lasting impression and the negative experiences tend to remain with family members for years.

"I felt all the hospital staff were very sensitive. The only person who seemed insensitive was the doctor who first told us the news my daughter was brain dead. It was like he had done it 100 times before and he may as well have been ordering a meal at McDonalds."

2013

"We encountered issues with one male nurse over misunderstandings and he was very rude in a time when we all were very stressed."

2012

"The first doctor we saw when arriving was very rude. His exact words were, 'he only has 2% brain function, nothing we can do'. But after him everyone was amazing."

2013

"Unfortunately when my husband was first taken to Emergency, I was ushered into a side room. It was very cold, I was upset, shaking and in shock. Nobody came to tell me what was going on, or how my husband was. I thought he might have died then. It was 2 or more hours before anyone came and then said my husband was up in ICU."

2013 - Declined donation

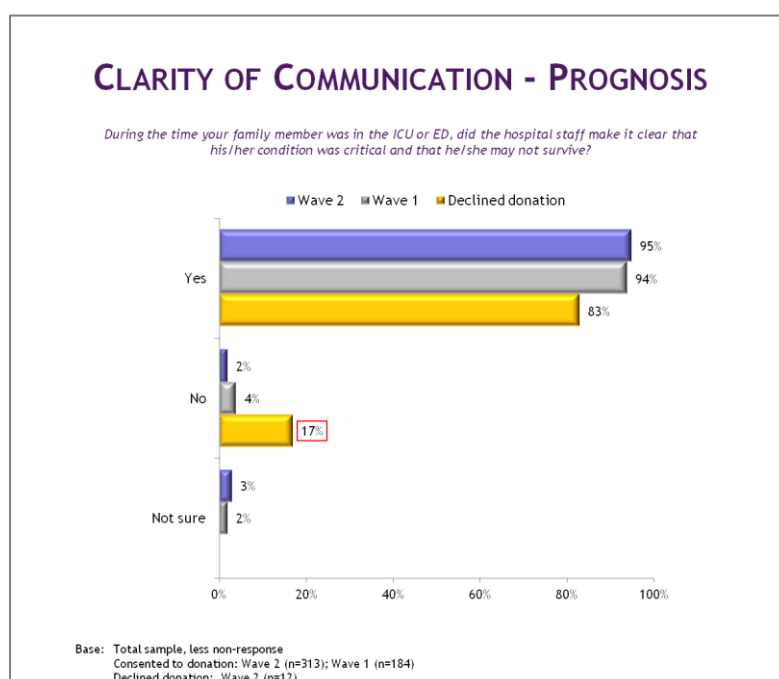
Negative experiences up to the point of delivering bad news, seem mainly to be driven by inconsistent messages from the medical team regarding the condition of the family member, or comments made that the family feels are inappropriate and unnecessary.

7.2 DELIVERING BAD NEWS

7.2.1 CLARITY OF COMMUNICATION

In the vast majority of cases (95%) in 2012 and 2013, ICU and ED staff have been skilled at ensuring family members fully realise the gravity of the situation and that their loved one is not likely to survive. This appears to be less so for families who declined donation, with 17% of these families feeling that the prognosis was not made clear to them (Figure 10).

Figure 10: Clarity of Communication - Prognosis



“To me it was surreal. I believed he'd be okay.”

2013 - Declined donation

Families who were shown brain scans of their family member alongside scans of a healthy brain, felt this helped them to realise that their family member had died. They appreciated the doctor's willingness to share and interpret the scans.

“On his move to ICU, I asked to see the brain scan and I could see a large cloud in that area. I was then satisfied of his condition.”

2012

“What was important to me was being shown the brain scan result of my sister, compared to a normal brain. That was enough for me to understand that she was dead.”

2012

The prognosis was not adequately explained to 2% of donor families and unfortunately this can lead to families having false hope. In these cases, the subsequent donation conversation may feel inappropriate.

“I think they need to be more straight forward, as my brother thought Mum would wake and I knew she wouldn't but they wouldn't say.”

2013

Supporting families and providing information to help them understand that their loved one will not recover requires clear, concise and consistent communication from medical staff.

For these families, the approach taken by ICU doctors in delivering the prognosis was considered to be somewhat cold and clinical. At all times, the tone of communication used should be sensitive. The right balance, in every situation, needs to be struck between providing clarity and delivering the news with sensitivity and compassion.

“It was all very cold and clinical and not taking into consideration the fact that this is our child that you're talking about. You're telling us that our child is dying and you know she would just go into the facts and say ‘well no you can't do that because the fact that the brain is swelling so much means it's already been so damaged that he probably won't survive anyway, or he'll be a vegetable for the rest of his life’. But now that I think about that conversation with the next doctor and how it was completely different, there definitely must have been a better way that she could have broken the news.... because at that stage we still had hope.”

2013 (Personal Interview)

Furthermore, special care should be taken when the prognosis needs to be delivered by telephone. Some families feel that while they don't want to be kept in the dark, they would rather the news be softened over the phone if a face-to-face conversation can be had soon afterwards.

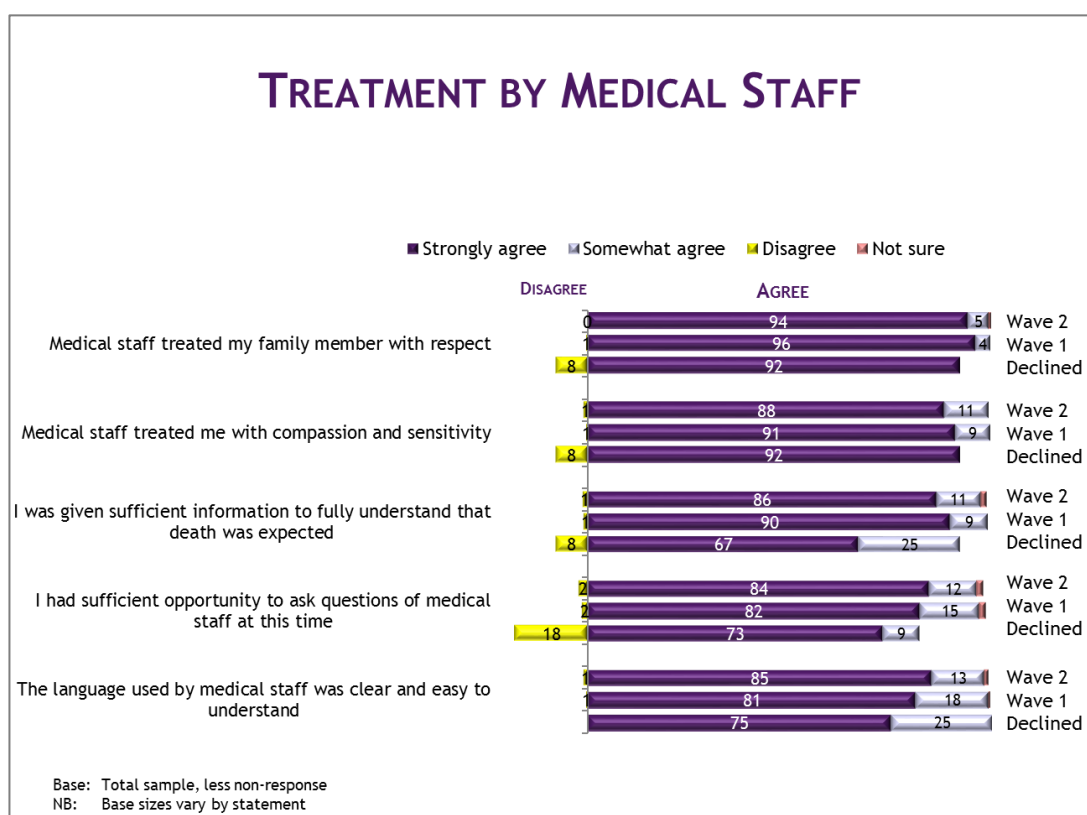
“They said ‘yeah, no, she’s brain dead, so you better come up and say your goodbyes’. And there wasn’t ever any talk of her getting better, that was just how it was. That could have been handled better...looking back he was quite jovial about it like it was just odd... I mean I know that we’re driving up from Melbourne and you probably want to tell people that before they get there, but then again over the phone is probably not the best way to be breaking that sort of news.”

2012 (Personal Interview)

7.2.2 TREATMENT OF FAMILIES

Depending on the individual circumstances of each donor, medical staff may have discussed with family members either testing for brain death or withdrawal of cardio respiratory support. When family members think back to that time, the vast majority of families who consented to donation (99%) recall medical staff treating their family member with respect and themselves being treated with compassion and sensitivity (Figure 11). This is slightly less so for families who declined donation (8% disagreed that this occurred).

Figure 11: Treatment of families by medical staff



“The staff were fantastic and very supportive. The Doctor even cried when he told us that Mum was brain dead.”

2013

“Couldn't have asked for better staff. The dignity and respect they gave and showed to my daughter was very special and I will never forget it.”

2013

Consistent with Wave 1 findings, 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).

Some families who declined donation feel that they could have been given more information to fully understand that death was expected (8% disagree that this occurred; 25% somewhat agree).

“At no time were we given information that this was ‘final’, not until I asked the question. We had false hope that once on the ventilator, all would be okay.”

2013 - Declined donation

7.3 BRAIN DEATH TESTING

Of the unique family units who participated in the study, 88% had family members who donated after brain death (DBD). As shown in Figure 12, 24% of DBD donor family members were offered the option to be present during brain death testing. This is consistent with donor families in Wave 1. Whilst not significantly different from donor families, 36% of families who declined donation were given an opportunity to witness the testing.

Of those families who were given a choice, three quarters (73% of consenting donor families and 75% of families who declined donation) opted to be present. Among donor families, this represents a significant increase since Wave 1, where 55% of donor family members asked to be present during testing.

Whilst witnessing brain death testing can be confronting and upsetting for family members, in 91% of cases (67% amongst families who declined donation), family members say that being present helped them to understand that their family member had died. This acceptance is critical to have *prior* to the donation conversation being instigated.

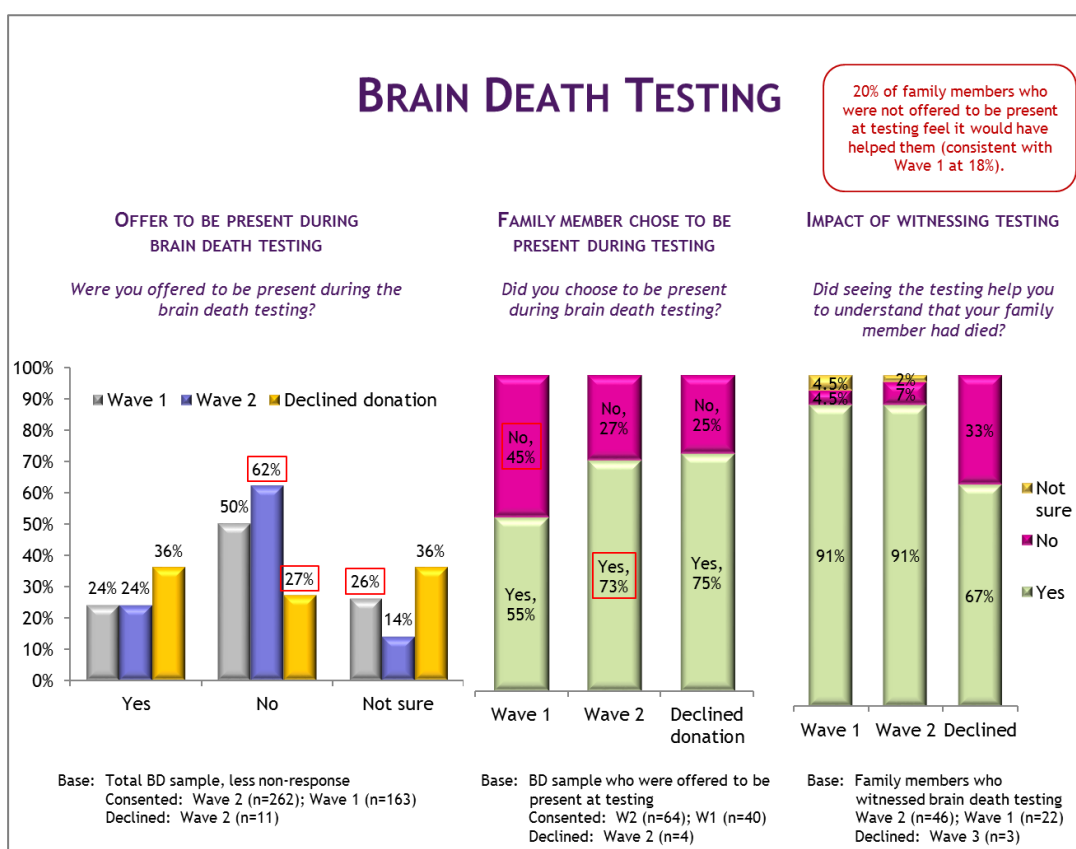
“This was very confronting at the time, but did prove Mum had died, leaving no doubt that everything had been done for her.”

2012

“Witnessing the testing process was a great help in accepting our situation. I was impressed with the professionalism and sensitivity of the staff involved.”

2012

Figure 12: Brain death testing



Some family members who decline to be present for brain death testing simply do not feel strong enough to witness the procedure. They want to hold on to a more positive and vibrant visual image of their loved one. Importantly though, this does not mean that they haven't accepted their loved one's death or the inevitability of it.

Those who choose to be present for brain death testing do so for many reasons. It can be about keeping their loved one company and 'standing guard' to ensure that they are treated respectfully throughout; it can help solidify the decision to take them off life support and it can give families assurance that the brain death testing was conducted properly, that the medical staff 'got it right.'

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

"The testing was done with extreme sensitivity and compassion. The staff could not have done more to make our daughter comfortable and describe the procedures."

2012

"The doctor performing the test was very good, explaining at every step what he was doing and what he was looking for, so that I could understand the process."

2013

Nevertheless, there are opportunities to **improve this process** for family members by better preparing them for the tests. This would involve explaining what tests will be conducted, why the tests are necessary and what doctors are looking for with each test.

"I found it distressing. I assumed that there would have been a machine to see any activity in the brain."

2013 - Declined donation

In 2012 and 2013, 62% of DBD donor family members and 27% of families who declined donation, were not asked if they would like to be present for brain death testing. Among donor families, this is a significantly higher proportion than Wave 1 (50% of families in 2010 and 2011). A total of 20% of donor families and 33% of families who declined donation, today feel that being present for testing would have helped them with their loss.

"It would have stopped the occasional thought, that maybe she hadn't been completely gone. It would have been incredible to have been given that option, as a big part of my grieving process was needing to know and understand as much as I could."

2013

"In hindsight, it would have been appreciated to be offered the opportunity to be present during brain death testing. This is the first time I even knew this was an option."

2012

"Very cross. I asked to go with them but was made to sit outside."

2013 - Declined donation

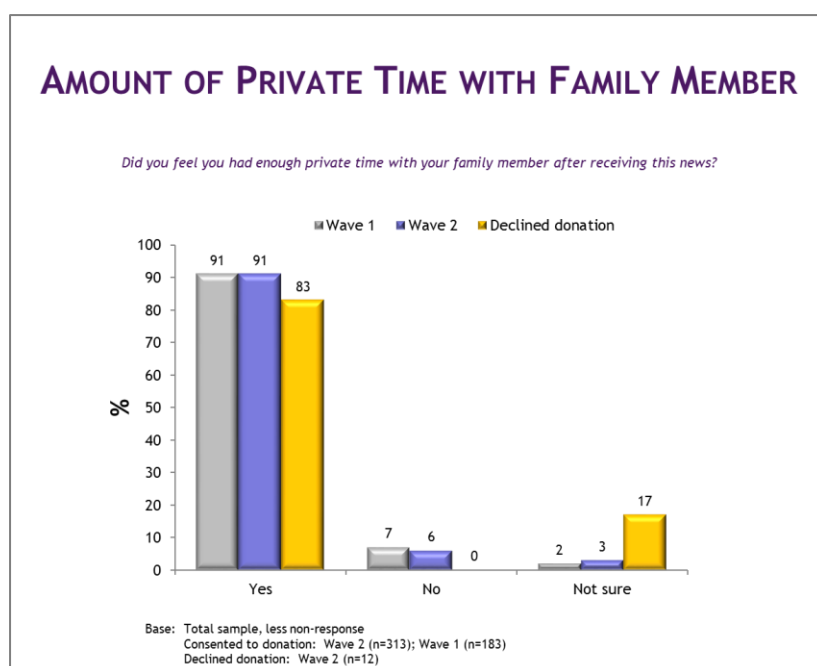
All families should be asked if they would like to be present at brain death testing. To better prepare family members for the experience and allow them to make an informed decision, medical staff should fully explain the nature of the testing and let family members know what to expect.

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

7.4 TIME WITH FAMILY MEMBER POST-PROGNOSIS

In 91% of cases, family members who consented to donation felt they were given enough private time with their family member after receiving the news that their loved one was brain dead or is likely to die. As shown in Figure 13, this has remained consistent since Wave 1. A total of 83% of families who declined donation also felt this way.

Figure 13: Amount of private time with family member



Family members appreciate being able to say their goodbyes in a way that is comfortable and appropriate for them. Some family members recall with gratitude ICU staff allowing large groups of friends into the ICU to say goodbye to their teen. In other cases, offers are made to sit quietly together or to embrace their loved one. These gestures are very much appreciated by family members.

A total of 6% of family members feel that they did not have enough private time with their family member after receiving the catastrophic news. This feeling of a lack of time can sometimes be more about the *quality* of time and the environment, rather than the *amount* of time. As shown in the following comments, these family members were hoping for one last period of true ‘alone’ time with their loved one, to say goodbye properly.

“I would have liked a little time before my son died and after he died, completely alone with him, in privacy. Not a long time, just a little. Just him and me.”
2012

“More private rooms. We were told that her life support was going to be turned off after brain testing the day before, so it would have been a little better more private.”
2013 - Declined donation

The four key things families need from hospital health professionals when being informed of the likely outcome for their loved one are:

- *Clarity* - of information and of the situation
 - *Compassion* and understanding
 - *Time* - to absorb the information
 - *Privacy* - private time to have with their loved one.
-

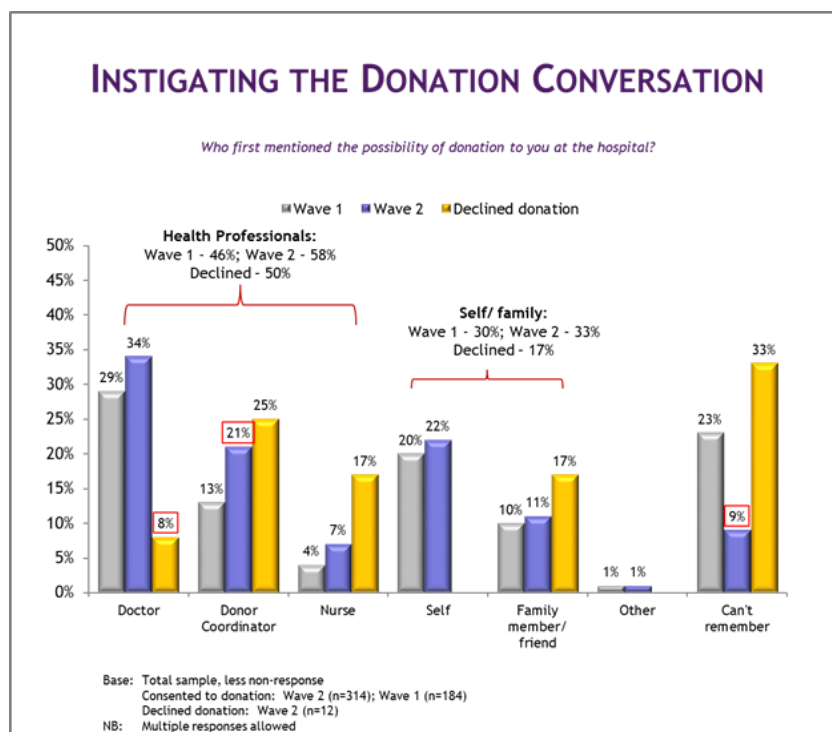
8.0 THE DONATION CONVERSATION

8.1 APPROACHING THE FAMILY

The possibility of donation continues 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 since Wave 1, where 46% of donation conversations with families who later consented to donation, were initially raised by health professionals (Figure 14). In 2012 and 2013, the donation conversation was instigated by doctors in 34% of cases; Donor Coordinators in 21% of cases and nurses (7%). There is a statistically significant increase in the number of donation conversations instigated by Donor Coordinators between Wave 1 and Wave 2. In Wave 1 (2010/ 2011 donor families), 13% of conversations were instigated by a Donor Coordinator, compared to 21% of conversations in Wave 2 (2012/2013 families).

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%).

Figure 14: Who initiates the donation conversation



During 2012/2013, 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.

There are no significant differences in terms of who initially raised donation between 2012 and 2013 donor families.

Table 15 shows that there are no significant differences in who instigates the donation conversation between the two donation pathways. There has been a significant increase, however, in donor coordinators instigating the conversation for DBD families, up from 12% in Wave 1 to 21% in Wave 2.

Table 15: Donation instigator by donation pathway (over time)

WHO FIRST MENTIONED THE POSSIBILITY OF DONATION TO YOU AT THE HOSPITAL?	YEAR OF STUDY			
	WAVE 1 - DBD (N=164)	WAVE 1 - DCD (N=20)	WAVE 2 - DBD (N=276)	WAVE 2 - DCD (N=38)
Doctor	31%	10%	34%	37% ↑
Nurse	4%	5%	6%	13%
Donor coordinator	12%	20%	21% ↑	18%
Total health professional	47%	35%	57% ↑	61%
Family member/ friend	10%	10%	12%	8%
Self	19%	30%	22%	24%
Other	1%	-	1%	-
Total family/self	30%	40%	33%	32%
Can't recall	23%	25%	9% ↓	8%

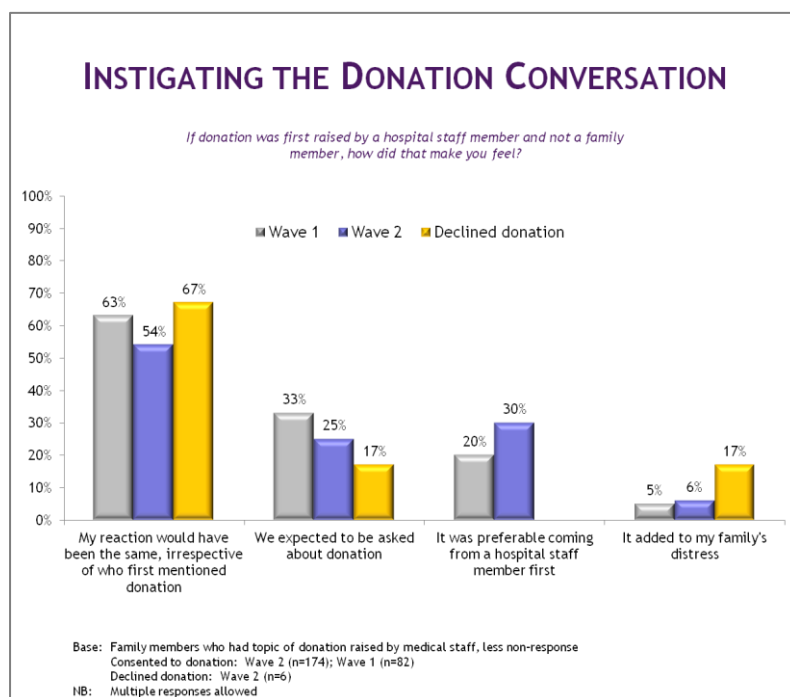
NB: Data in table represents the views of all family members who consented to donation, rather than individual families (to be consistent with the way the question was measured in 2004 and 2008).

Just 6% of donor family members feel that being asked about donation by a hospital staff member added to their family's distress (Figure 15). For two-thirds of these family members (62%), the donation request came either *before* (15%) or at the *same time as* (46%) the news of their family member's expected death. They felt that they did not have sufficient time to digest the information and fully understand the situation prior to being asked to consider donation.

“The conversation re organ donation should be a separate conversation – after being able to absorb the news.”

2012

Figure 15: Reaction to donation being raised by hospital staff member



The qualitative research uncovered some themes surrounding who initially raised the subject of donation with the family. It was found that when the Donor Coordinator was present at the time of donation first being raised, there were mixed reactions. The presence of a Donor Coordinator at this stage was not a problem for most families, but for some, it caused confusion.

When the Donor Coordinator was not introduced to the family at the outset of the meeting, it felt disrespectful. In these instances, when the Donor Coordinator's role was disclosed, for some families, the initial omission felt deliberate and even a little deceitful. In situations where their role and reason for being in the meeting was made clear to families from the outset, some families indicated that they felt pressured or rushed by the presence of the Donor Coordinator, if donation had not been raised earlier.

“I was a little confused about who/what role in a medical sense the DonateLife staff had.”

2012

8.2 TIMING OF THE DONATION CONVERSATION

In 2012 and 2013, 48% of consenting family members were asked about donation by a health professional *before* (10%) or *at the same time as* (38%) being told of their family member's brain death or expected death; 36% were asked *after* the grave news was delivered (Figure 16). Findings are consistent with Wave 1 and do not vary significantly by state/ territory. For 44% of families who declined donation, the timing of the conversation cannot be recalled.

Figure 16: Timing of the donation conversation

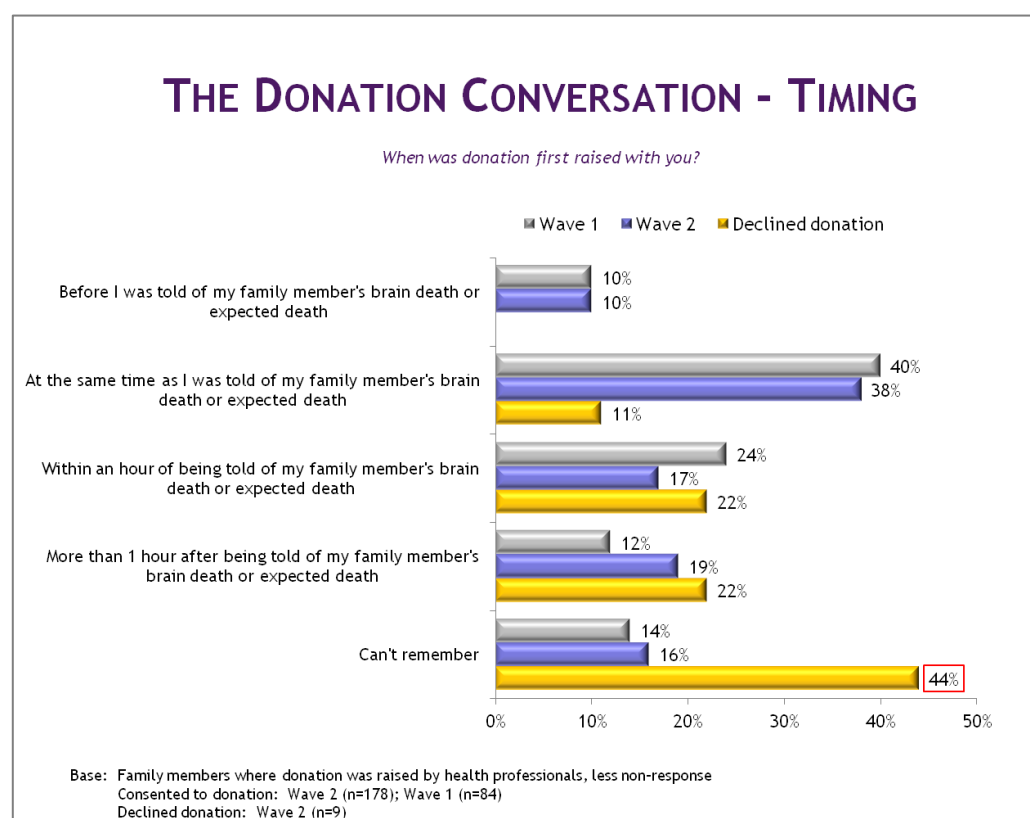


Table 16 shows that there are no significant differences in the timing of the donation conversation when raised by health professionals between donation pathways. Similarly, there are no statistically significant changes since Wave 1.

Table 16: Timing of donation (by donation pathway)

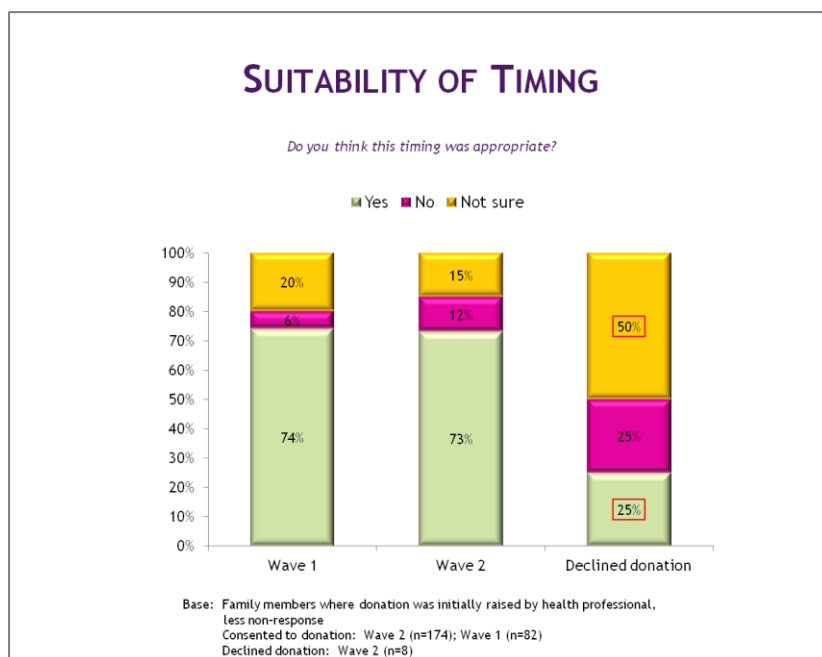
TIME OF INSTIGATING DONATION CONVERSATION	WAVE 1 - 2010/2011		WAVE 2 - 2012/2013	
	DBD (N=77)	DCD (N=7)*	DBD (N=155)	DCD (N=23)
Before	10%	-	11%	4%
At same time	38%	71%	39%	30%
Within an hour	26%	-	17%	17%
More than an hour	12%	14%	17%	30%
Can't recall	14%	14%	15%	17%

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

* Caution: small base

In total, three quarters (73%) of donor family members feel that the timing of the approach by health professionals was appropriate; 15% are not sure and 12% feel the timing was inappropriate (Figure 17). These findings are consistent with Wave 1. Perceptions vary amongst families who declined donation, with half (50%) being unsure of the appropriateness of the timing and 25% feeling that the timing was suitable.

Figure 17: Appropriateness of donation conversation timing



Looking at the appropriateness of the timing by when donation was raised by a health professional, as shown in Table 17, one third (35%) of family members who were asked about donation *before* being informed of their loved one's death/ impending death, found this timing to be inappropriate. This is significantly higher than every other time period tested in the research.

Further, a considerable proportion of donor family members (15%) felt it was inappropriate for health professionals to discuss donation at the same time as being informed of the prognosis for their loved one.

These findings are consistent with Wave 1 where the data suggested that families found the timing of the donation conversation to be more appropriate when instigated some time *after* being informed of their family member's brain death or impending death.

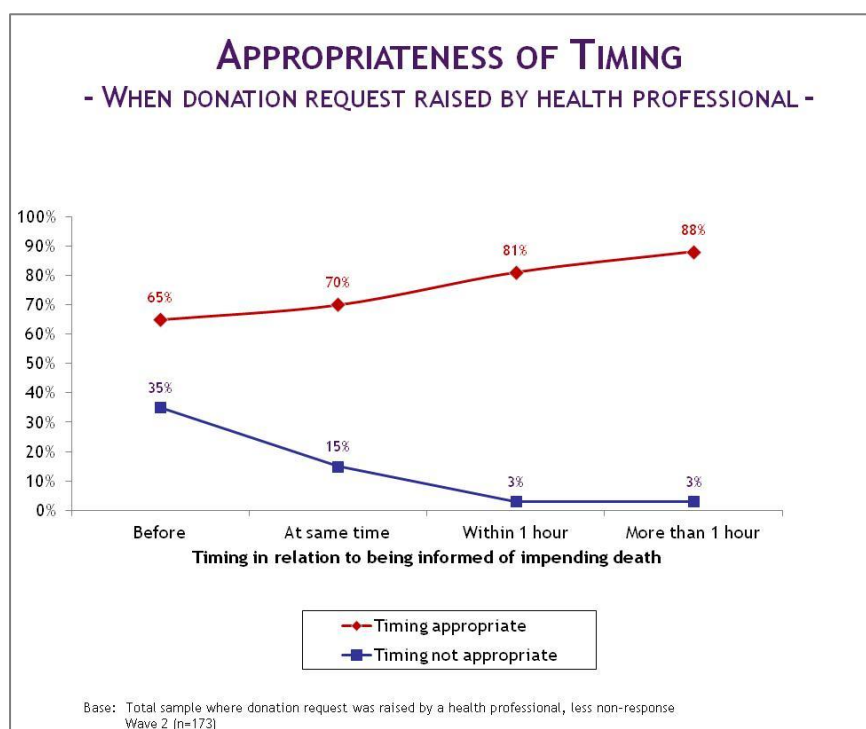
Reinforcing this, the only time that family members who declined donation felt the timing was appropriate, was when the conversation was raised *after* being informed of their loved one's death/ impending death.

Table 17: Raising donation - appropriateness of timing

TIMING APPROPRIATE?	DONATION RAISED BY HEALTH PROFESSIONAL TIMING IN RELATION TO BEING TOLD OF FAMILY MEMBER'S BRAIN DEATH OR EXPECTED DEATH				
	BEFORE (N=17)	AT SAME TIME (N=66)	WITHIN 1 HOUR (N=31)	MORE THAN 1 HOUR (N=33)	CAN'T RECALL (N=26)
Yes	65%	70%	81%	88%	62%
No	35%	15%	3%	3%	12%
Not sure	-	15%	16%	9%	27%

Figure 18 shows that, when donation is raised by a health professional, the appropriateness of the timing increases when families are given a sufficient amount of time to process the news of impending death or brain death of their family member.

Figure 18: Appropriateness of timing when donation raised by health professional



Raising donation *before* or at the *same time* as delivering grave news can, at a minimum, take families by surprise and at most, offend and upset families. Families have to know that their loved one has or will soon die, before they can open themselves up to receiving new information about donation as an end of life possibility.

"I think we would have benefited from more time between hearing about her death and the discussion about organ donation. There was not enough time to process that she was going to die before the organ donation discussion. Some of us still held hope for her – the window was not closed to us."

2013

"I was asked whether we would consider organ donation by phone before I had even seen my husband or fully understood what had happened. This was very distressing and a very cruel way to learn that he would likely not survive."

2012

The 'bad news' conversation and donation conversation are two very important conversations that each deserve to be given time. Care must be taken with each conversation so that the key pieces of information are absorbed and understood by family members. The most effective way of doing this is to separate the conversations and allow each to stand on its own.

“Even though you know it goes hand in hand, you have to process that devastating information and then, I guess, approach the organ donation subject.”

2013 (Personal interview)

“I understand the question needs to be asked but time is needed to digest the fact that they are going to die before you have to think about donations.”

2013 - Declined donation

In essence, there is a clear purpose for both conversations (1. informing family members of the impending death of their loved one and 2. requesting consideration of donation). Information provided in the first conversation needs to be fully understood before asking families to consider and process new information about donation.

The findings indicate that the following needs to be undertaken by health professionals before starting the donation conversation:

- Ensure the family is ready for the donation conversation
- Treat the family with respect by seeking permission to introduce a new person - the Donor Coordinator.

Families are unique and health professionals need to be attuned to the nuances of each family and able to adapt their approach to meet individual family needs.

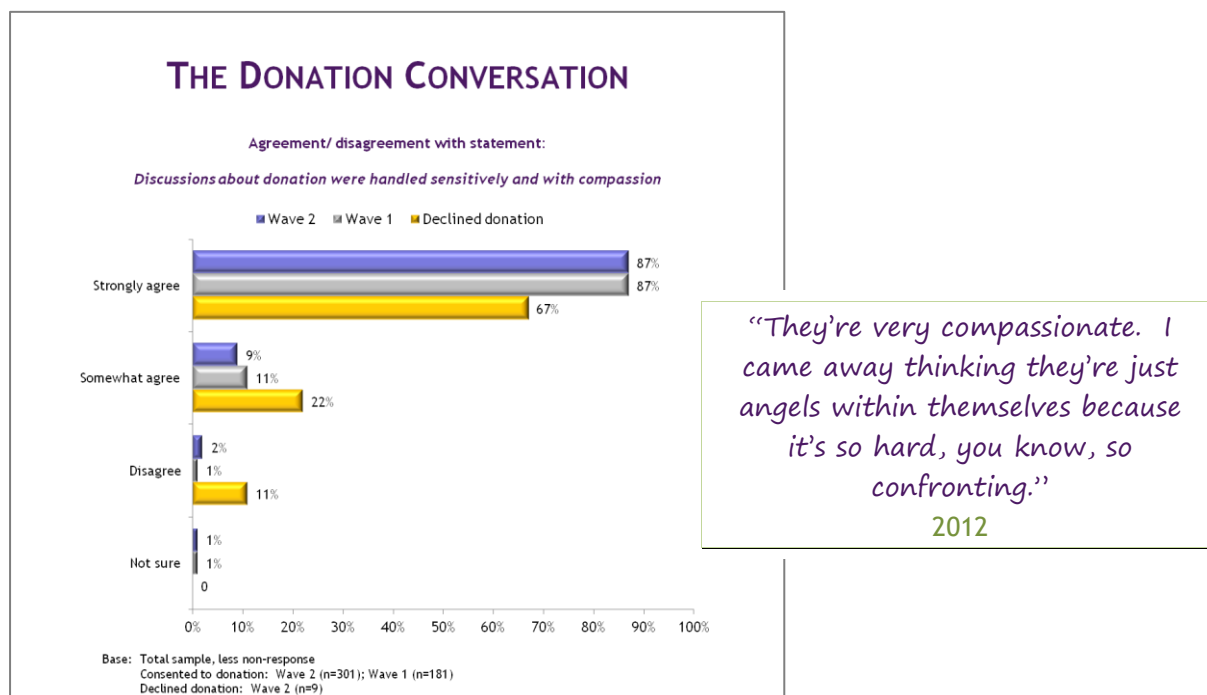
*The research findings indicate that the donation conversation should not be initiated before or at the same time as delivering the bad news to families; rather the timing is considered to be **more appropriate** when the **conversations are separated and paced** in line with the family's needs.*

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

8.3 TONE OF CONVERSATION

In the vast majority of cases, family members feel that discussions about donation were handled sensitively and with compassion; slightly less so amongst families who declined donation (Figure 19). Findings are consistent with Wave 1.

Figure 19: Tone of donation conversation

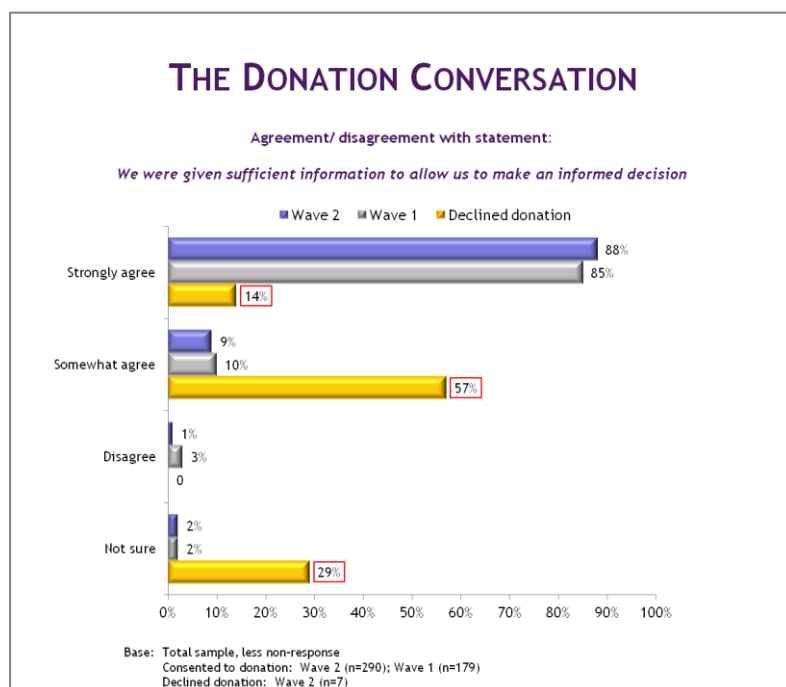


When recalling discussions about donation in more detail during the personal interviews, family members focused on discussions they had with Donor Coordinators. Feedback about coordinators is overwhelmingly positive; they are frequently described as having a wonderful manner, being genuine, compassionate and able to say the right things at the right time. Family members feel that Donor Coordinators deliver information in a sensitive way.

8.4 INFORMATION

With regards 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 (Figure 20). Only 14% of families who declined donation strongly agreed, with 57% somewhat agreeing.

Figure 20: Sufficient information to make an informed decision



All families are different and will respond to information in different ways, so being sensitive to each individual person's needs and checking in with them on what they need, is required.

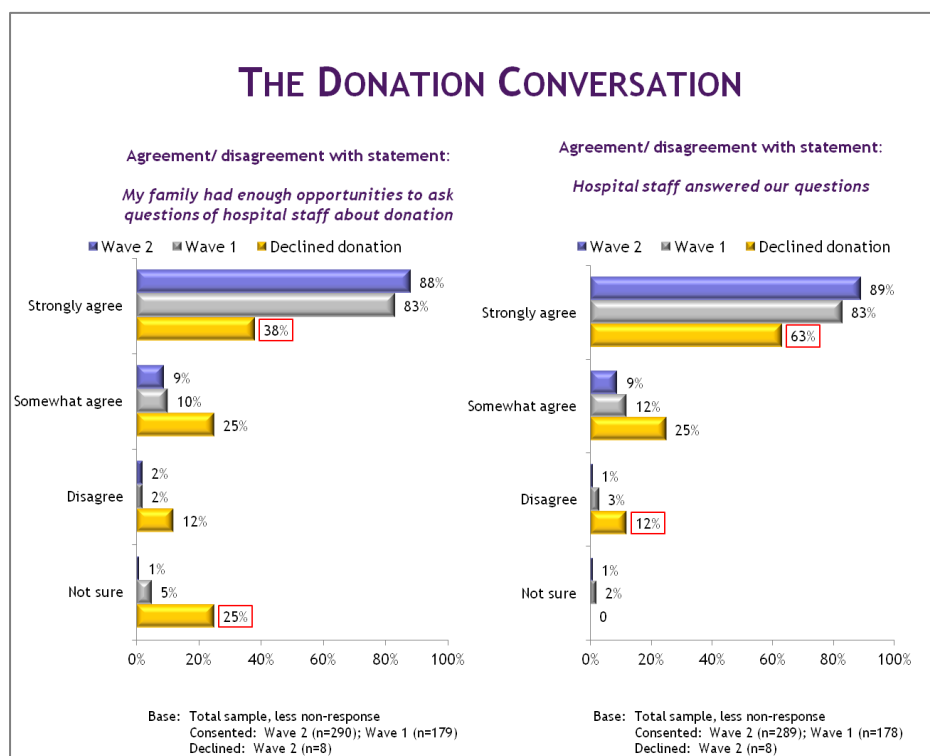
"We asked many questions about the whole process including medical decisions, so sought out information- many may not want that detail but it's important to be able to gain it. We wanted a high level of information about all aspects."

2013

The majority of donor families (97%) in 2012 and 2013 agree that their family was provided with enough opportunities to ask questions of hospital staff about donation (Figure 21). 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 21: Opportunities to ask questions



"All questions were answered in a manner we could understand, so everything was clear."

2012

"I don't think there is an easier way to donate and grieve. Everyone was supportive and answered our questions."

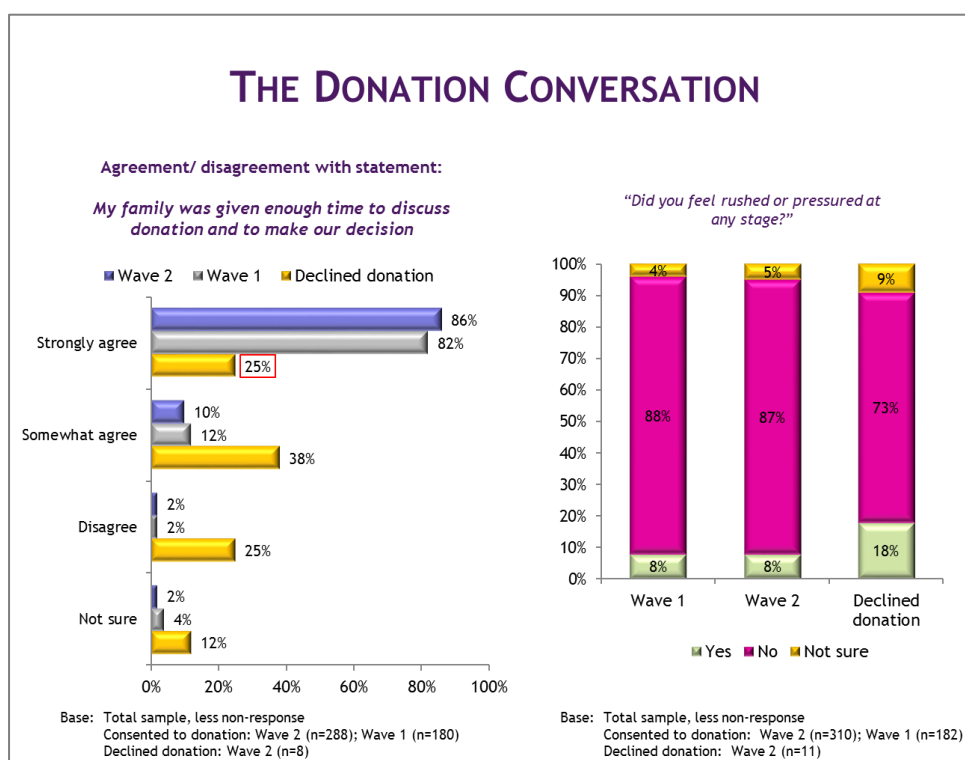
2012

8.5 TIME TO CONSIDER DONATION

Families mostly feel that they were given enough time to discuss donation and to make their decision (96% of consenting family members agree in total; 86% strongly agree) (Figure 22). 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 22: Time to make a decision



"When we did get there I felt very rushed. To me this had just happened, but I could see that staff were eager to organise donation by this point. And I really did not like the way that I was told 'he's only on the machines so we could contact you and ask about donation', or something to that effect."

2013

Whilst families understand that there are time pressures for donation from a medical point of view, it is important to *not* impart that sense of urgency to family members and to allow families sufficient time to:

1. Process the news
2. Digest the request for donation
3. Absorb the information about donation
4. Discuss the way forward with family members

If possible, family members should be provided with a private room to discuss donation. This is a sign of consideration; for grieving families, this simple act translates into a sense of respect.

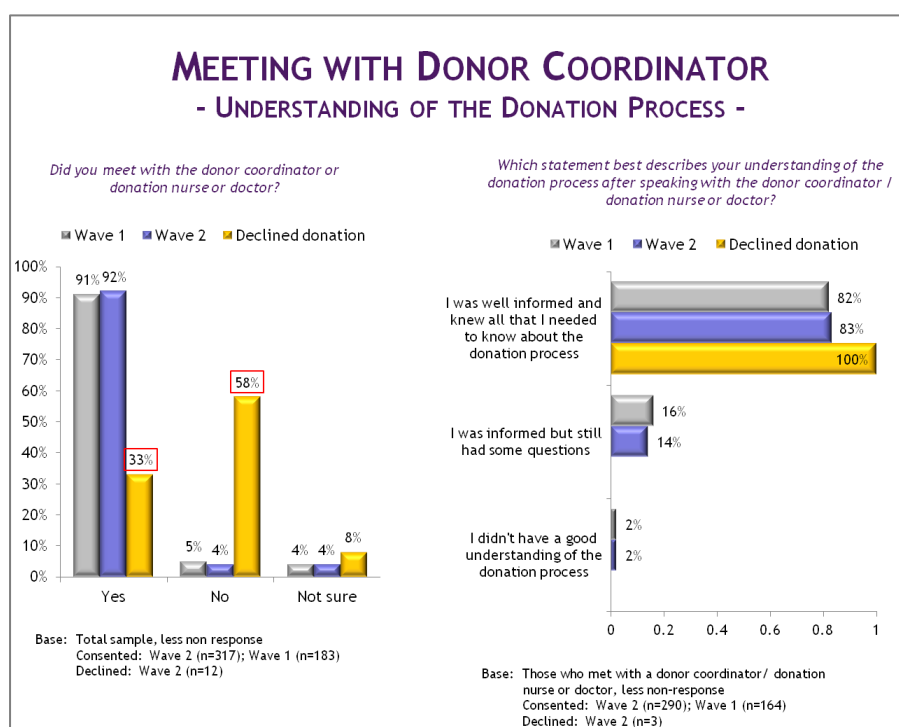
9.0 MOVING TOWARDS DONATION

9.1 UNDERSTANDING OF THE DONATION PROCESS

Nine in ten donor families in 2012 and 2013 (92%) recall meeting with the donor coordinator or donation nurse/ doctor (Figure 23). 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, four recall meeting with a DonateliLife coordinator, nurse or doctor. These families felt that they were well informed after this meeting.

Figure 23: Meeting donation staff



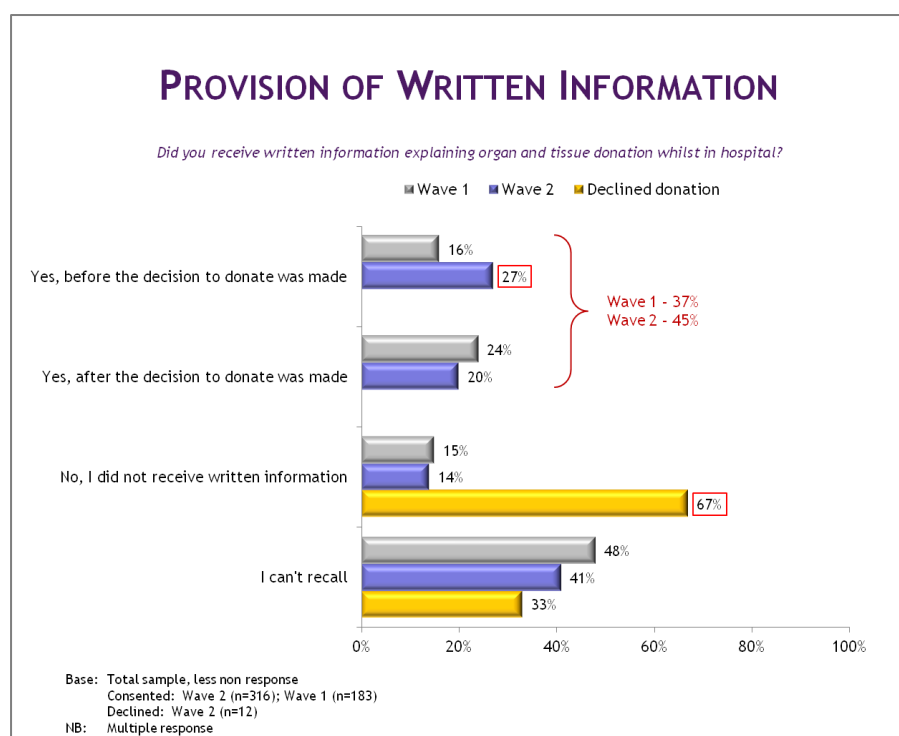
Nine in ten donor family members (88%) were made aware that even if donation was agreed to, the donation may not happen for any number of reasons. This is consistent with Wave 1 (90%). Four percent (4%) of family members were not made aware of this.

9.2 PROVISION OF WRITTEN INFORMATION

In 2012 and 2013, 45% (net) of family members recall being provided with written information explaining organ and tissue donation (Figure 24). This is higher than reported in 2010/ 2011 (37%). A significantly greater proportion of family members were provided with written information *prior* to the donation decision being made (27% in Wave 2 compared with 16% in Wave 1).

Of families who declined donation, 67% were not provided with written information. Fourteen percent (14%) of donor family members stated that they did not receive written information explaining organ and tissue donation whilst in hospital, whilst a substantial proportion (41%) do not recall.

Figure 24: Receipt of written information



"Because it was such an emotional time, it was difficult to take in all of the information and the options. I would have liked a one page flowchart showing the options so I could go away and think about it and be clear about what would happen."

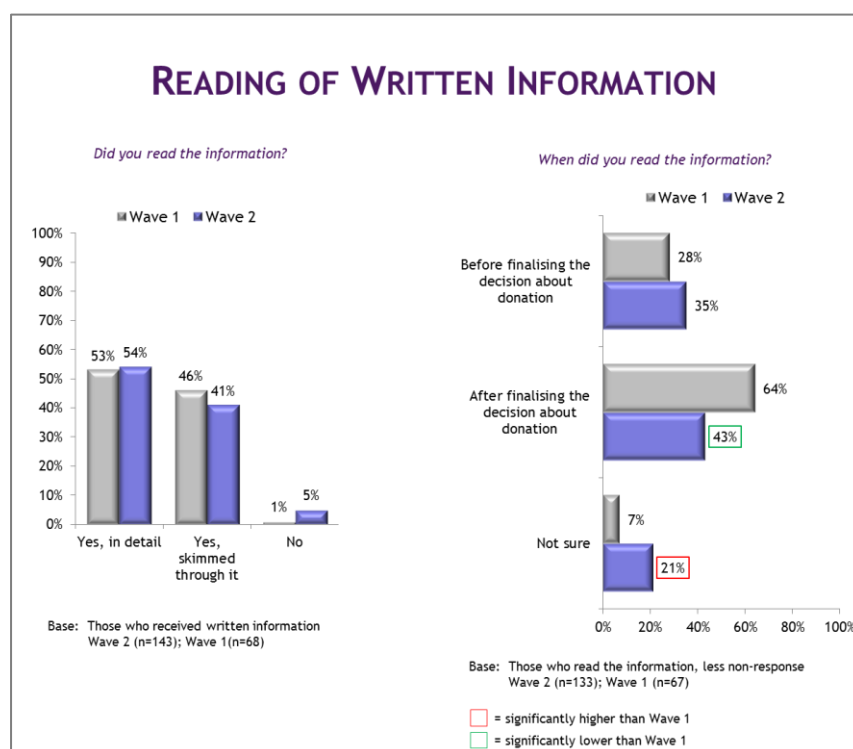
2013

“We were dazed, shocked and somewhat fragile. We were treated well. The really important thing is for medical staff to provide prompt and honest information.”

2012

For those who did receive information, just over half (54%) **read the information** in detail, while two in five (41%) skimmed through it. Five percent (5%) of families who were given information decided not to read it (Figure 25). Again, this is consistent with Wave 1. The information is mostly read before and after families have made the decision to donate, although in Wave 2, a greater proportion of families don’t recall when they read the information (21% compared with 7% of families in Wave 1).

Figure 25: Reading of written information



As shown in Table 18, almost all (96%) family members who received and read the written information explaining organ and tissue donation whilst in hospital, found it to be useful (52% 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), therefore reiterating the importance of encouraging readership of the information, in their own time. This is consistent with Wave 1 findings.

Table 18: Usefulness of information by readership

USEFULNESS OF WRITTEN INFORMATION	WAVE 1 TOTAL WHO RECEIVED AND READ INFORMATION (N=66)	WAVE 2 TOTAL WHO RECEIVED AND READ INFORMATION (N=136)	READ IT IN DETAIL (N=77)	SKIMMED THROUGH (N=59)
Very useful	54.5%	52%	64%	37%
Quite useful	41.0%	44%	35%	56%
Not useful	4.5%	2%	-	5%
Can't recall	-	1%	1%	2%

"Even though I may not have fully processed written info 100% at the time, it is good to have."

2013

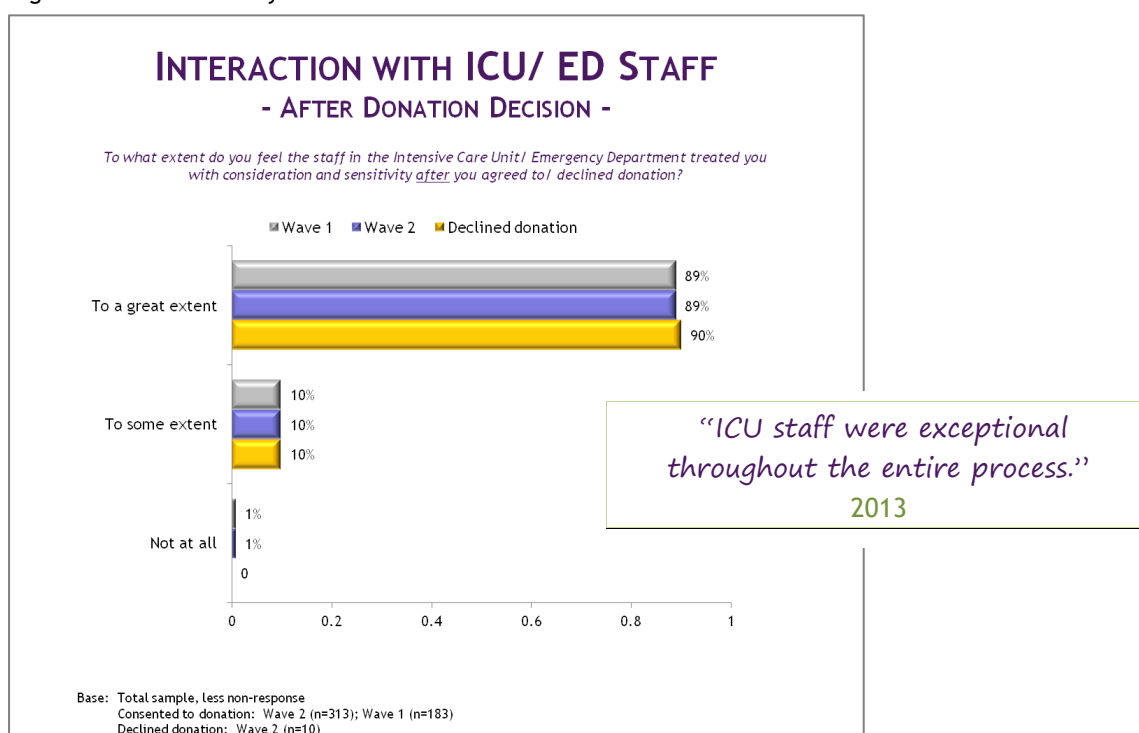
Written information is important for donor families to receive whilst in hospital, however it should not replace verbal communication from the health professional. Verbal information should be succinct and delivered in layman's terms for ease of processing.

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

9.3 SUPPORT FROM HEALTH PROFESSIONALS - AFTER CONSENTING TO DONATION

Nine in ten families feel that staff in the ICU or ED treated them with consideration and sensitivity *after* they made their donation decision, irrespective of whether that decision was to decline or consent (Figure 26). This is consistent with Wave 1.

Figure 26: Treatment by staff after donation decision



“The staff remained the same with us after we had declined organ donation, as they had been before.”

2013 - Declined donation

In explaining the quality of care they continued to receive post the decision to donate, families emphasise gestures made by hospital staff, such as the offer to come and go from ICU as they please, to lie on the bed with their loved one or to have groups of friends and relatives in ICU at the same time. Families also recall health professionals suggesting and arranging keepsakes such as locks of hair or handprints to be taken. Actions like bringing in a recliner for a mother of a teenage boy and speaking directly to the patient, thanking them for the gift they are giving, all contribute to the perception of ongoing care. Likewise, hospital staff showing genuine, emotional reactions to the situation helps reassure families that their loved one is still important to health professionals, even though they have died or will soon die.

Whilst the overwhelming majority of family members feel the care given to them post-consent was consistent with that received pre-consent, there are some family members where for them, this was not the case.

“After the decision was made to donate, it felt unusual and like we were being treated differently. Communication seemed to drop and we felt quite in the dark and unsure about what was happening next and expected timeframes.

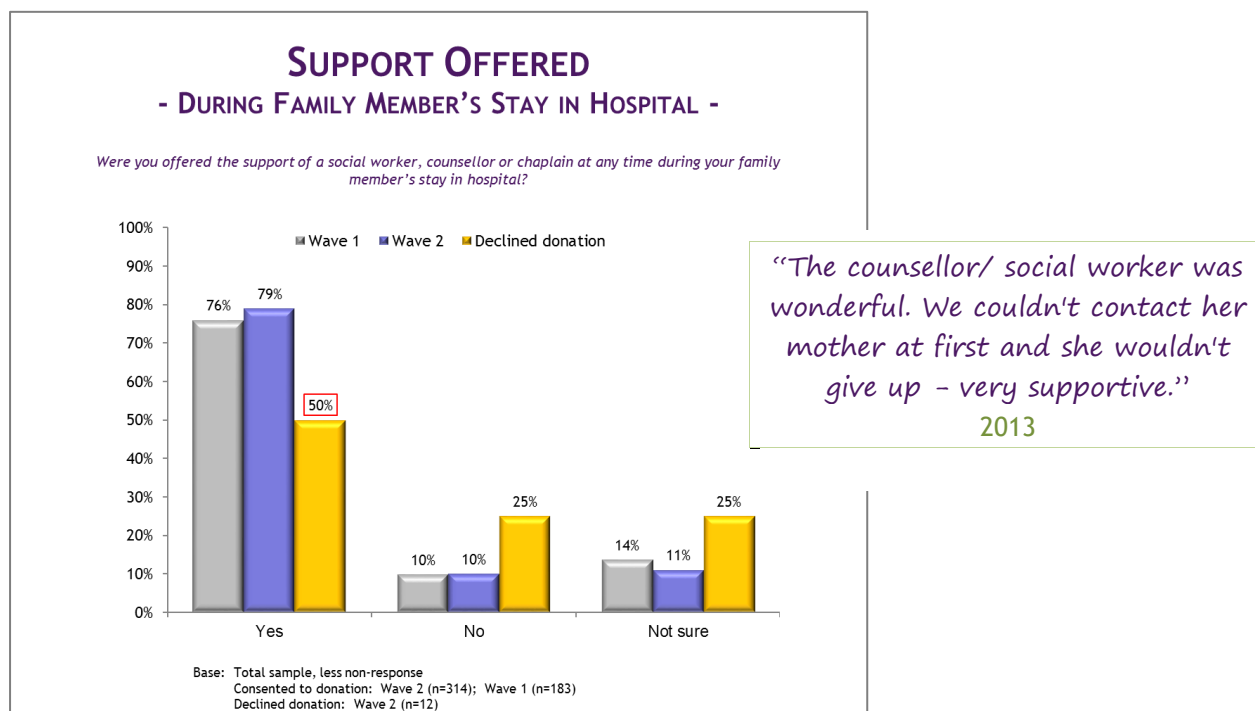
2013

Consistent with Wave 1 findings, when treatment of families (and especially the donor) post-consent is inconsistent with that received pre-consent, families begin to doubt their donation decision. They can feel abandoned and used by health professionals and this is a feeling that is likely to stay with them for years to come, often causing them to regret their donation decision.

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

In 2012 and 2013, 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 (Figure 27), 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 27: Support offered during stay in hospital



"The coordinator and hospital social worker were supportive and I was able to contact them when I was upset and needed someone to speak with."
2012

Table 19 shows findings across Waves 1 and 2, split by donation pathway. During 2012/2013, 78% of family members of DBD donors were offered the support of a social worker, counsellor or chaplain during their family member's stay in hospital. Approximately 8 in 10 family members of DCD donors were offered this service.

Table 19: Support of social worker, counsellor or chaplain, by pathway to donation

OFFERED SUPPORT OF SOCIAL WORKER, COUNSELLOR OR CHAPLAIN	2010/2011 FAMILY MEMBERS		2012/2013 FAMILY MEMBERS	
	DBD (N=163)	DCD (N=20)	DBD (N=277)	DCD (N=37)
Yes	74%	95%	78%	84%
No	11%	-	10%	8%
Not sure	15%	5%	11%	8%

9.4 THE DONATION PROCESS

As found during the Wave 1 research, the time between consenting to donation and when donation surgery takes place can be very distressing for family members. Whilst the decision to donate has already been made, when it comes to the practical tasks leading to surgery, reality sets in about the finality of their decision and this is where doubts can arise and families can begin to second guess their own decision.

“I just felt very alone afterwards. I was aware that it was time sensitive and I just kept worrying about ‘time’. From his passing to donation was a bit unsettling.”

2013

As this is a critical time in the process, families must be managed with care. At no time should health professionals say or do anything that will contribute to family members building a mental picture of the actual act of donation surgery. This includes talking in detail about what will happen during the procedure and making equipment and materials visible to families.

“It was quite confronting to see packages being prepared around his bed for the organs while we were still saying our goodbyes.”

2012

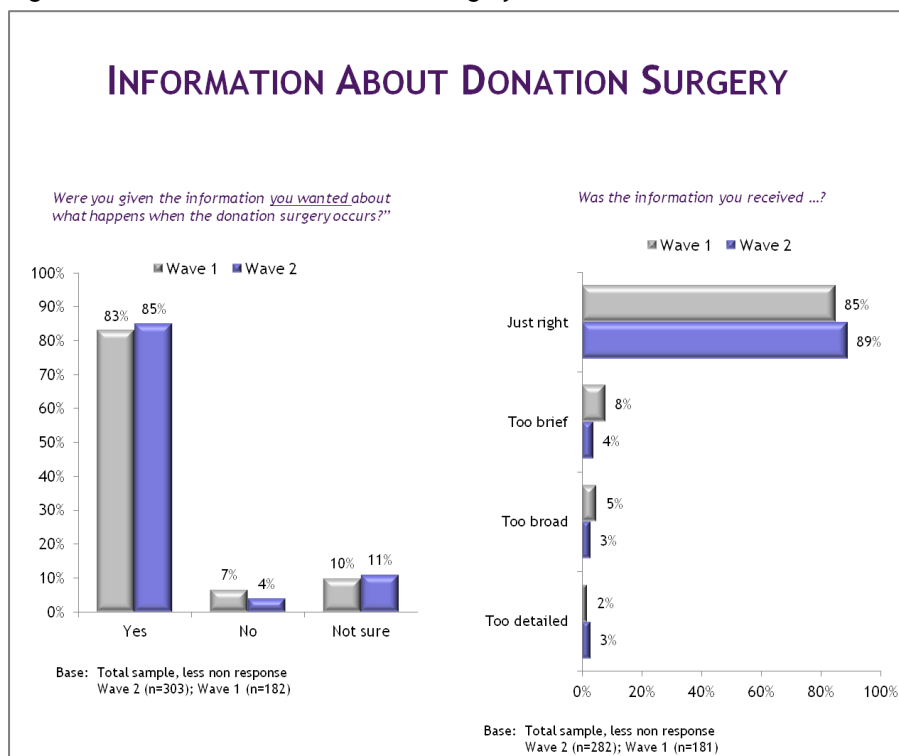
“They walked past with their donor boxes. Mum had to say ‘please don’t do that again’ and ‘don’t wheel him out in front of us’. They said ‘oh, ok, we’ll take him out back.’”

2013

9.4.1 INFORMATION PROVIDED TO FAMILIES

In terms of the information provided, 85% of donor family members feel they were given the information *they wanted* about the donation surgery and 89% felt that the *amount of information* they received was just right (Figure 28). This is a slight, but not significant improvement on Wave 1.

Figure 28: Information about donation surgery



9.4.2 INFORMATION SOUGHT FROM FAMILIES - INFORMED CONSENT

As part of the consent process, family members are asked to nominate which organs and tissues they consent to being donated. One of the findings to emerge strongly from the research in Wave 1 was the difficulty faced by families when asked to make these decisions. This finding is again prevalent in Wave 2 with 2012 and 2013 families, but to a much lesser extent.

POSITIVES

Many family members acknowledge the positive aspects of this process. They feel that it ensures that families are entirely comfortable with the donation. It can give them an opportunity to understand the potential impact of the donation, not just in general terms, but specific to each organ or tissue to be donated.

Families appreciate the non-judgemental approach adopted by DonateLife throughout this process. They state that DonateLife staff were extremely patient, often checking that they were okay and providing ample time to consider consent.

Most donor families are readily able to understand the impact of donation of vital organs. The donation of other things such as skin and eye tissue was harder to grasp. They not only feel uncomfortable with how this may impact the appearance of their loved one, they don't fully understand what a difference this type of donation could make to someone else.

NEGATIVES

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

Some family members also raise the difficulty of answering personal and sometimes intimate questions about their loved one, especially in front of other family members. Consideration should be exercised here and the next-of-kin told about the nature of the questions and the purpose of this line of questioning, so that the discussion can be moved to a private room if required, away from children and extended family.

"It was fine the way it was discussed, however I do recall that members of our extended family were present for support. There were VERY personal questions put to Dad in front of us all. Not really appropriate."

2013

Family members also need to know how long the meeting with DonateLife is likely to take so they can mentally prepare. During the meeting, family members should be made to feel as comfortable as possible. The room should be private and free from interruptions and family members should be offered a break if they need one.

At this stage, of utmost importance for the donor family experience is their comfort and understanding of the situation. Typically, donor staff excel in this area. They have a reputation for being sympathetic, kind and efficient. However, on some occasions, family members can feel let down by this process.

“Answering the list of endless questions we had to go through on no sleep late into the night was just harrowing.”

2013

“We were interviewed by the donor team for about 5 hours. Not offered even a cup of tea. Then asked by the donor team ‘what do you want us to do with the parts we don't use? Put back in the body; put in the coffin with him, or do you want us to just dispose of them?’ He was my son and my remaining family member's brother. To them it appeared to us he was just a lot of usable organs. We almost withdrew our consent. I would have preferred them not to ask that question.”

2013

9.4.3 TIME WITH FAMILY MEMBER PRIOR TO DONATION SURGERY

During the period between donation consent and donation surgery, families strive to reconcile their loved one's death in their own minds. They have made the decision to donate their family member's organs and/or tissue and are now waiting for surgery. This is a crucial period of time for families. If not handled with sensitivity, care and efficiency, the donation process can add considerably to a family member's grief and distress.

Being provided with an opportunity to be with their family member for some quiet time and reflection, as well as allowing family and friends to say their goodbyes privately, is an important part of the reconciliation process for families.

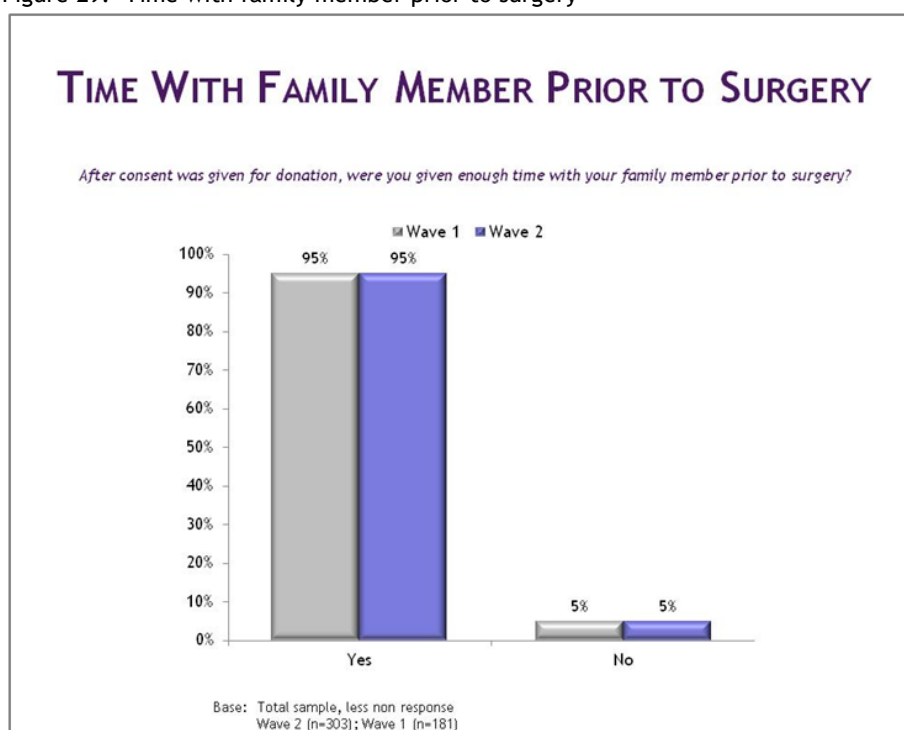
“After we have agreed to donation, it needs to be understood that the person is still our very dear loved one and what happens to them is very much our concern. The family needs to be respected and informed at this time. The important thing is actually our opportunity to say goodbye and the hospital process should not impede that in any way.”

2013

While many family members feel that no amount of time with their loved one will feel like enough, others in this situation want the process to go as quickly as possible. Aside from being painful to bear personally, they can also experience feelings of guilt. Families often find this limbo period between consent and surgery very intense. Keeping them fully informed and updated at regular intervals during the wait can help reduce some of the tension during this time.

Just over nine in ten donor family members (95%) feel they were given enough time with their family member prior to donation surgery; 5% feel they were not (Figure 29). This is consistent with Wave 1.

Figure 29: Time with family member prior to surgery



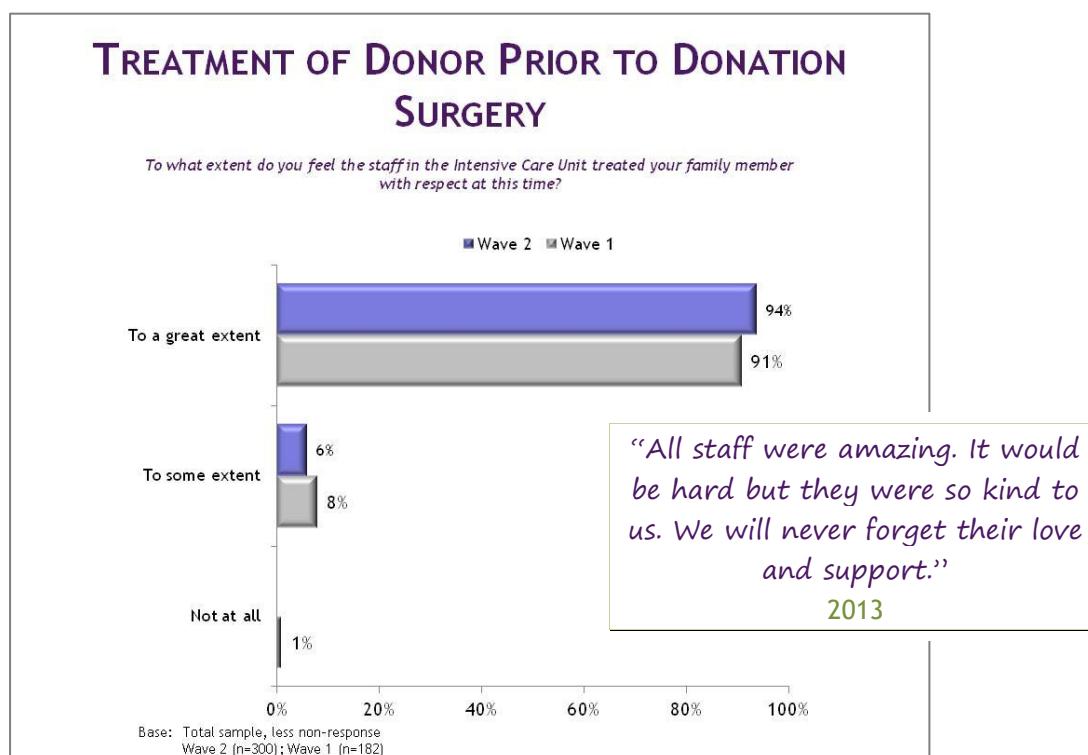
The difficult time between consent and donation surgery must be efficient and informed. Families must be kept up-to-date with accurate information regarding the likely time of donation surgery. If there are delays, family members must be informed and provided with an explanation for the delays.

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

9.4.4 ICU STAFF

In 2012 and 2013, all donor family members who took part in the research felt their loved one was treated with respect by Intensive Care Unit staff during the donation process (94% to a great extent) as outlined in Figure 30.

Figure 30: Treatment by staff prior to surgery



Some hospital staff naturally connect with family members and leave a lasting impression. The little things that are said and done and the small acts of kindness are remembered by families with gratitude.

"I thought it was beautiful and comforting how a nurse told me that she would be with my son until the end."
2012

The research found that the following can reduce the distress of family members between the critical time of consenting to donation and donation surgery:

- ➔ Being kept informed about timeframes
- ➔ Allowing private time with their loved one, ideally in a private room
- ➔ Health professionals continuing to care for the donor with diligence and respect
- ➔ Health professionals not discussing the process of donation with family members/ in front of family members, unless asked to by a family member
- ➔ Health professionals not overtly preparing for donation in front of family members

9.5 IMPROVING THE DONATION DISCUSSION - THE VIEW OF FAMILIES

As part of the Donor Family Study, family members were asked how the way in which **donation was discussed** with them at the hospital could have been improved after they consented to donation. Findings were collected verbatim and have been grouped together at Table 20. Findings from Wave 2 are shown, together with results from Wave 1 where comparisons can be made.

Table 20: Improving the donation conversation

<i>How could the way in which donation was discussed with you at the hospital have been improved after you agreed to donation?</i>	WAVE 1 % OF RESPONSES (N=97)	WAVE 2 % OF RESPONSES (N=128)
No improvements necessary/ discussions handled very well	49%	49% ✓
Staff were compassionate and supportive/ kept family members informed	-	16% ✓
Provide more information regarding timing/ process took too long	4%	5%
Difficult to say due to highly emotional state at the time	-	4%
Personal details about the donor should not be discussed in front of the whole family/questions not tailored to young person, therefore inappropriate line of questioning	1%	4%
A debriefing process would be appreciated/ make sure the family understands what's happening at all times/ keep family better informed about the process	2%	3%
Nothing could make it easier/ difficult and confronting decision to make	3%	2%
Provide more feedback after donation/ more prompt follow-up with families post-donation	-	2%
Provide a private room for discussions and meeting with staff/ provide a larger room for families to gather	-	2%

<i>How could the way in which donation was discussed with you at the hospital have been improved after you agreed to donation?</i>	WAVE 1 % OF RESPONSES (N=97)	WAVE 2 % OF RESPONSES (N=128)
More compassion/ understanding/ empathy	1%	2%
More discussion/ don't feel it was discussed with hospital staff	-	2%
Ensure all family members are able to say goodbye to donor/ not all family members had opportunity to say goodbye due to timing and poor communication	-	2%
The timing - we felt rushed	3%	1%
Provide a better explanation of why some organs cannot be used	2%	1%
Do not provide details of <i>how</i> donation surgery will be conducted	-	1%
Improve timing of discussion with DonateLife staff/ had to wait a long time to talk with DonateLife staff member	2%	1%
Don't know/ can't think of anything specific	6%	11%

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

"It is a very emotional time and like many situations you think of things later. But that is not the DonateLife team's fault in any way. They are the most caring and dedicated people you are ever likely to meet."

2013

There is, however, room to improve communication with family members after consent is provided:

- Ensure family members are kept informed of the expected timing and reasons for any delay.
- Ensure family members are contacted after donation surgery (even if there is limited news on the recipient's state of health).

"I expected the coordinator to call after the surgery. After not receiving a call, I ended up calling to find out how the surgery went."

2012

"I was disappointed that it all took so long. I had agreed to it and was told that it would happen that day. They kept on saying 'soon'. It just took too long to happen."

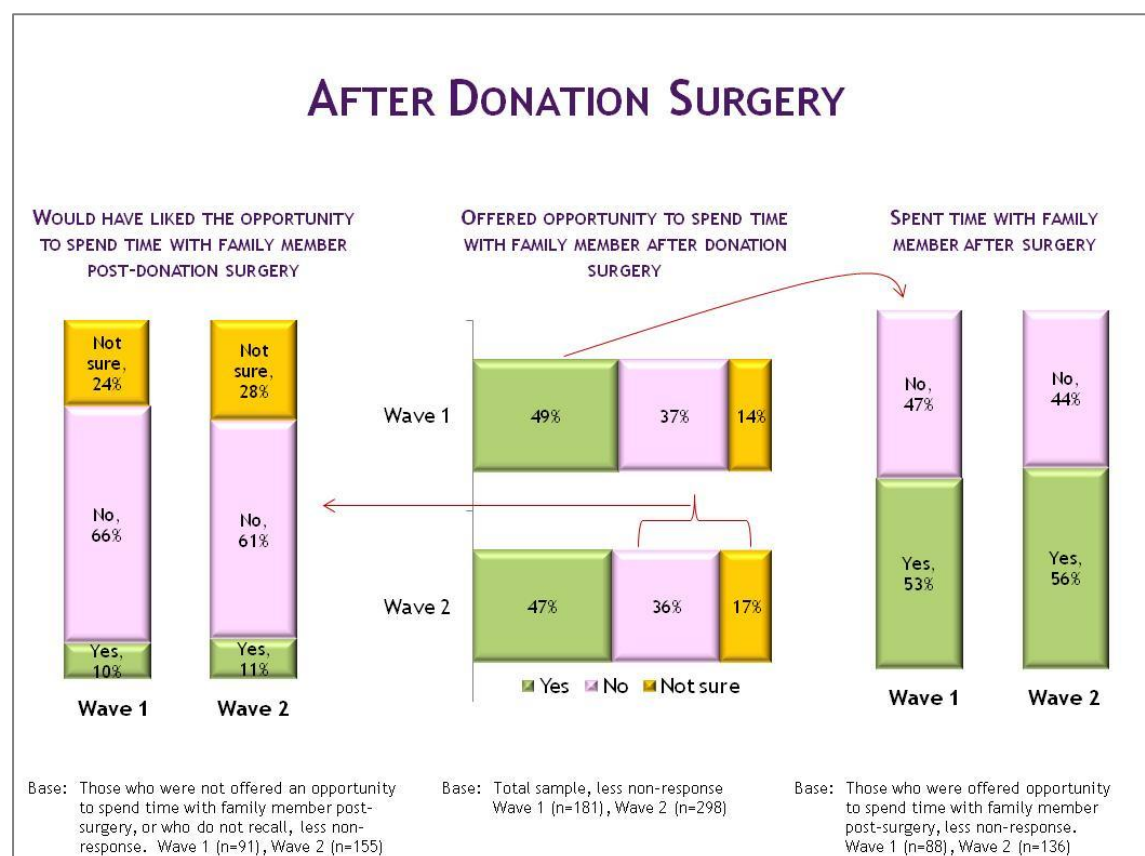
2013

10.0 AFTER DONATION SURGERY

As shown in Figure 31, half (47%) of donor family members in 2012 and 2013 (Wave 2) were offered an opportunity to spend time with their family member after donation surgery. This is consistent with Wave 1.

Of those who were offered, just over half (56%) opted to see their family member after surgery (again, consistent with Wave 1). The majority of these family members (84%), describe the experience as a positive one; 5% describe the experience negatively, while 11% are still unsure how they feel about it.

Figure 31: After donation surgery



"Being able to spend time with our son after the donation of his organs gave our family the opportunity to say our last goodbye, final kiss and hugs and to be with him from his birth to his death gave us great comfort during this tragic time."

2012

Those who saw their loved one post-surgery and felt it was a positive experience spoke of them looking good, comfortable and just as they did prior to surgery. Having the opportunity to be with them, without the machines, tubes and noise was appreciated. Gestures like covering the donor's body with a special blanket that the family could later keep (a patchwork blanket was mentioned by several) were gratefully noted by family members.

One in nine family members (11%) who were not asked if they would like to see their family member post-surgery, would have liked to do so (consistent with Wave 1, as shown in Figure 31).

"It has only now occurred to me that it would have helped being with him after the surgery - I don't think that was suggested and I did not think about it. It would have helped, as at the time of death, you are shell shocked and numb and not able to grieve properly."

2012

Qualitative research has helped us to understand some of the reasons why people decline to see their loved one after donation surgery. The most common explanation was that family members were fearful of what they would see and how their loved one would look. They were conscious of protecting their lasting image of their loved one.

*Seeing their loved one after donation surgery is a personal decision to be made by individual family members, and the opportunity should be offered to all.
It is important to let family members know about any physical changes that may take place in their loved one post-surgery, so that a fully informed decision can be made.*

As part of the research, family members were asked if they wished to share anything additional about their experience at the hospital after donation surgery took place. Responses have been coded into like themes and these are detailed in Table 21.

Table 21: Experience at the hospital after donation

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD ABOUT YOUR EXPERIENCE AT THE HOSPITAL AFTER THE DONATION TOOK PLACE?	WAVE 1 % (N=61)	WAVE 2 % (N=98)
Didn't stay/ was not present/ didn't return to hospital	21%	33%
Already said goodbye before surgery/ didn't want to see family member after surgery/ wanted to remember them as they were	15%	12%
Hospital staff compassionate/ respectful/ supportive/ kind/ wonderful/ professional/ made us comfortable	11%	11%
Agonising/ felt lost/ too stressful/ too upset	5%	9%
Was not given opportunity to see family member after surgery/ had to say goodbye before/ felt rushed	-	7%
Regret not seeing family member after donation/ would have liked to see family member after donation	2%	6%
Gave us more time to spend with them/ opportunity to say final goodbye/ provided comfort	8%	6%
DonateLife team wonderful/ kind/ compassionate/ respectful/ professional	5%	6%
No support after surgery/ didn't know where to go/ nobody to support us after surgery	-	6%
Took a long time/ wish it was faster/ process dragged on	2%	5%
Body was sent straight to coroner after surgery	-	5%
Experience was surreal/ confronting/ strange	10%	4%
Hospital staff were not compassionate/ were insensitive	3%	4%
Received results of surgery by phone/ received phone call when surgery had taken place	2%	4%
Good experience/ moving experience/ tastefully handled	2%	4%
Need to provide a quieter room in ICU for family to gather and grieve, without being told to leave because room is needed	3%	3%
Regret seeing family member after surgery	-	2%
We knew our loved one would be cared for and respected	5%	2%
Had minimal time as surgery needed to commence/ no time to spend with them	3%	2%
Other comments (each totalling < 1% of responses)	23%	5%

Consideration should be given to the environment in which the donor is placed post-surgery. This is another way in which the hospital and DonateLife staff can demonstrate respect for the donor and the donor's family.

11.0 FOLLOW-UP SERVICES

In Australia, donor families are provided with support through the National Donor Family Support Service, providing resources and counselling to support the donor's nominated next-of-kin. Extended family members who were not the nominated next-of-kin have taken part in the research and may not initially have been offered this service.

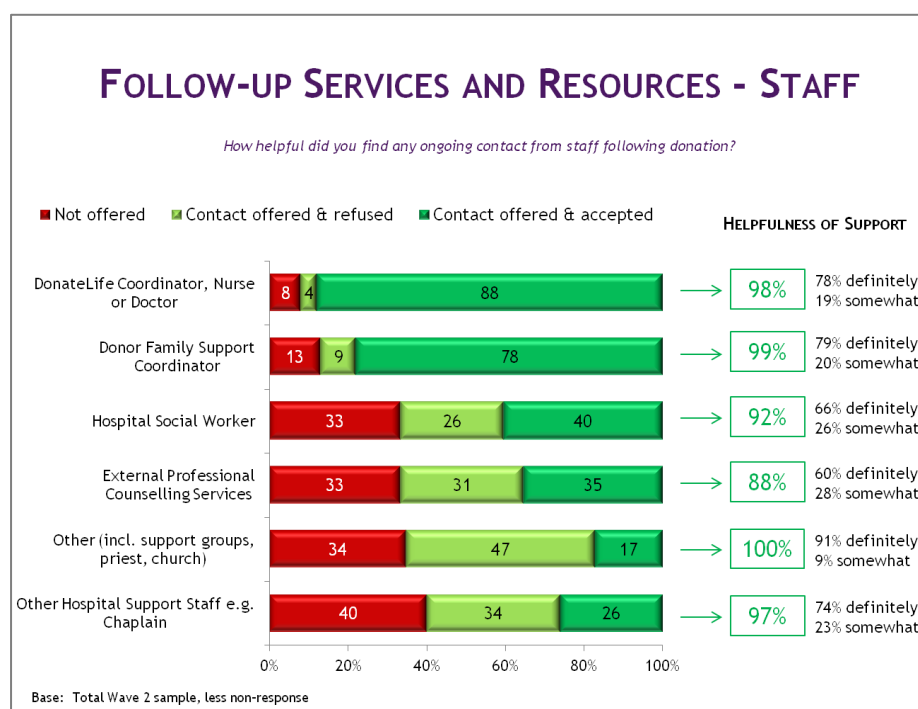
In Wave 1, 85% of donor family members were offered ongoing contact following donation from a DonateLife coordinator, nurse or doctor, a Donor Family Support Coordinator, hospital social worker or hospital chaplain. During 2012 and 2013, this kind of support was offered to 95% of donor family members, a statistically significant increase. Further, ongoing support was offered to 25% of families who declined donation.

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

11.1 SUPPORT OFFERED

Donor family members were asked if they were offered any ongoing contact from DonateLife or hospital staff or from external services. Findings are shown in Figure 32 below and discussed in more detail in this section.

Figure 32: Follow-up Services and Resources offered to Donor Families - Staff



DONATELIFE COORDINATOR, NURSE OR DOCTOR

During 2012 and 2013, 92% of donor family members were offered ongoing contact from the DonateLife Coordinator, nurse or doctor; 88% accepted and received support (up from 52% in Wave 1). This type of support was found to be helpful by 98% of donor families who accepted the offer of contact.

DONOR FAMILY SUPPORT COORDINATOR

Ongoing contact with a Donor Family Support Coordinator (DFSC) was offered to 87% of family members in 2012 and 2013; 78% accepted and received support (up from 59% in Wave 1). Of those families who chose to be in touch with a DFSC, 99% found the contact helpful, 79% very much so.

“The DonateLife person continued to contact me for some months after. I found this very helpful. It felt like someone outside said out loud, they still cared and I could say things to her that I would not necessarily say to my family for fear of them worrying about me.”

2013

For 2012/2013 family members, the support provided by DonateLife staff was greatly appreciated. Their availability, manner, sincerity, compassion, knowledge and experience enabled them to provide much needed support to families after donation.

Families appreciated being given updates on the progress of recipients, whether that be directly from recipients via a letter or card, or from the DonateLife Coordinator. This ongoing contact can make donor family members feel valued which in turn reinforces their donation decision.

“I didn't find it helpful in a physical way but just knowing that they cared enough to follow up and check on our wellbeing was helpful. It helped to know that we weren't forgotten and our son wasn't forgotten after they had used his organs. It was also helpful to know that someone was only a call away if we needed to talk.”

2012

There were rare instances of negative experiences where DonateLife did not provide helpful support following donation. These instances arose from a lack of communication and promises (of a meeting or telephone call) not being kept.

HOSPITAL SOCIAL WORKERS/ HOSPITAL SUPPORT STAFF

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

For hospital social workers, contact was offered to two thirds (66%) of donor family members. Two in five (40%) donor family members did have ongoing contact with a hospital social worker (a significant increase since Wave 1, where 13% had ongoing contact) and of these, the majority (92%) found it helpful; 8% did not.

Support from other hospital staff such as chaplains, was offered to 60% of donor family members in Wave 2. A much lower proportion of donor family members (26%) chose to have ongoing contact with other hospital support staff, such as a hospital chaplain (an increase from 8% in Wave 1). These family members also found this type of support to be helpful (97%).

Looking at families who declined donation, as stated earlier, 25% of these families recall being offered ongoing contact and support; all of these from a hospital social worker. These families all found the support received from the social worker to be helpful, 33% to a great extent; 67% to some extent).

"It was helpful to know that someone was there if we needed it."

2013 - Declined donation

EXTERNAL PROVIDER

Ongoing contact with an external provider, such as counsellor or psychologist, is offered to two thirds (67%) of donor family members. Of these, approximately half go ahead and use the services of an external professional, and of these, 88% find the service helpful.

Other support services are suggested to approximately two thirds (66%) of donor family members. This tends to be with specific support groups (e.g. suicide support groups), local priests, church members or simply friends and family. This type of contact is considered to be very helpful.

Table 22 details the support distribution by state. Looking at the total support offered to donor families, we see that families in the ACT and Tasmania are less likely to be offered support compared with the national average.

Table 22: Support offered to donor families by state/territory

TYPE OF SUPPORT OFFERED:	QLD (N=53-67)	ACT (N=14-15)*	NSW (N=65-76)	VIC (N=64-70)	TAS (N=8-10)*	SA (N=13-21)*	WA (N=25-31)	NT (N=4-5)*
DonateLife coordinator, nurse or doctor	95%	73%	95%	87%	80%	95%	97%	100%
Donor Family Support Coordinator	93%	73%	92%	81%	75%	76%	88%	100%
Hospital Social worker	76%	64%	67%	69%	44%	50%	63%	80%
Other hospital staff	74%	53%	63%	52%	38%	38%	71%	50%
Total support offered - Wave 2	99% ↑	71%	99%	92% ↑	80%	95% ↑	100%	100%
Total support offered - Wave 1	88%	100%	93%	77%	83%	70%	100%	-

* Caution: small base

There does, however, appear to have been some improvements between Wave 1 and Wave 2 in terms of the number of families who were offered support (significant increases noted in Queensland, Victoria and South Australia).

11.1.1 HELPFULNESS OF SUPPORT

Table 23 outlines ways in which donor family members find ongoing contact helpful. Of importance is the understanding shown to families by the DonateLife Coordinators and being informed of the outcome of donation surgery.

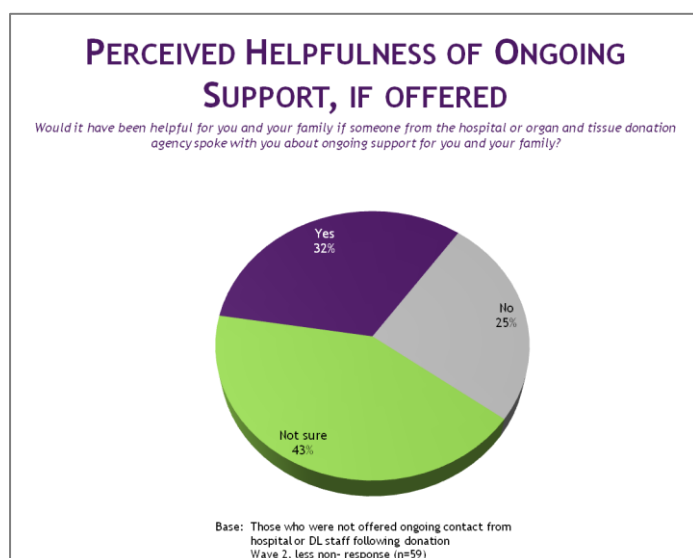
Table 23: Helpfulness of ongoing contact

IN WHAT WAY WAS THE ONGOING CONTACT HELPFUL TO YOU?	WAVE 1 % (N=122)	WAVE 2 % (N=161)
DonateLife Coordinator was helpful and understood my situation	-	20%
Found out the outcome of the donation / gave us progress updates on recipients/ to know our decision was helping others	30%	19%
Felt like we weren't forgotten / felt like we were cared for / nice to be checked up on	20%	13%
Provided comfort / very compassionate / provided positive aspect	17%	11%
Nice to know the support is there if we need it	3%	11%
Counselling / memorial services / DonateLife events were helpful	4%	9%

<i>IN WHAT WAY WAS THE ONGOING CONTACT HELPFUL TO YOU?</i>	WAVE 1 % (N=122)	WAVE 2 % (N=161)
Helped just being able to talk about my family member / someone to talk to / someone external from the family to talk to	7%	8%
Ongoing correspondence with recipients is very helpful	1%	7%
Ongoing contact helped us a lot (no further information)	1%	6%
Private counselling / grief support group was helpful	-	6%
Our family member is recognised and appreciated for their contribution	16%	5%
Helped the grieving process / gave us closure	13%	5%
The support helped validate/ reinforce our decision	2%	4%
Follow-up calls were helpful	1%	3%
It provided useful information / answered our questions	9%	2%
Keepsakes - hair and handprint was lovely / lapel pin helpful	-	2%
Other	6%	2%
Don't know / not sure	1%	1%

Donor family members who were not offered ongoing contact from DonateLife support staff or hospital support staff were asked if it would have been helpful if someone from the hospital or donation agency spoke with them about support. As shown in Figure 33, 32% of donor family members would have found this helpful, while 25% would not. Two in five (43%) were not sure.

Figure 33: Perceived helpfulness of ongoing support if offered



A total of 58% of families who declined donation, were not offered ongoing contact or support, and 17% do not recall being offered ongoing contact or support. One quarter (25%) would have liked someone to contact them while the remaining 75% did not want further contact.

A total of 88% of families who declined donation said that they would have found information about bereavement support services helpful, while 38% said that a follow up phone call from the DonateLife agency would have been helpful.

Some donor family members who live outside of a capital city comment on the lack of support for their area, while others feel that they need more longer term support.

"I was not given ongoing help after my son's operation. I had to seek help myself and in [the area], there is limited help available for grieving parents and others who have experienced losing a loved one to organ donation."

2012

"We received general feedback re transplant success. That was wonderful. Also received various phone calls to offer help. Some were accepted. We were able to access support via the DonateLife network but there possibly should be a more positive longer term (1 month, 2 month, 6 month) follow-up with all immediate family – as there was for me."

2013

"Small gestures of 'gatherings' acknowledgements occur in the city where death occurred. We all live too far away, but the fact that we're still acknowledged has a 'feel good' feeling that you helped contribute to something very special."

2012

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

Particular care should be taken to ensure donor families in regional areas are supported.

Support from a social worker should always be offered to families who declined donation.

11.2 DONATELIFE RESOURCES

Donor family members were asked to rate the level of helpfulness of nine support services/ items provided by DonateLife, that they may or may not have received. Findings are shown in Figure 34 and compared, where possible, with Wave 1 findings, in Table 24.

Figure 34: Helpfulness of support provided to donor families

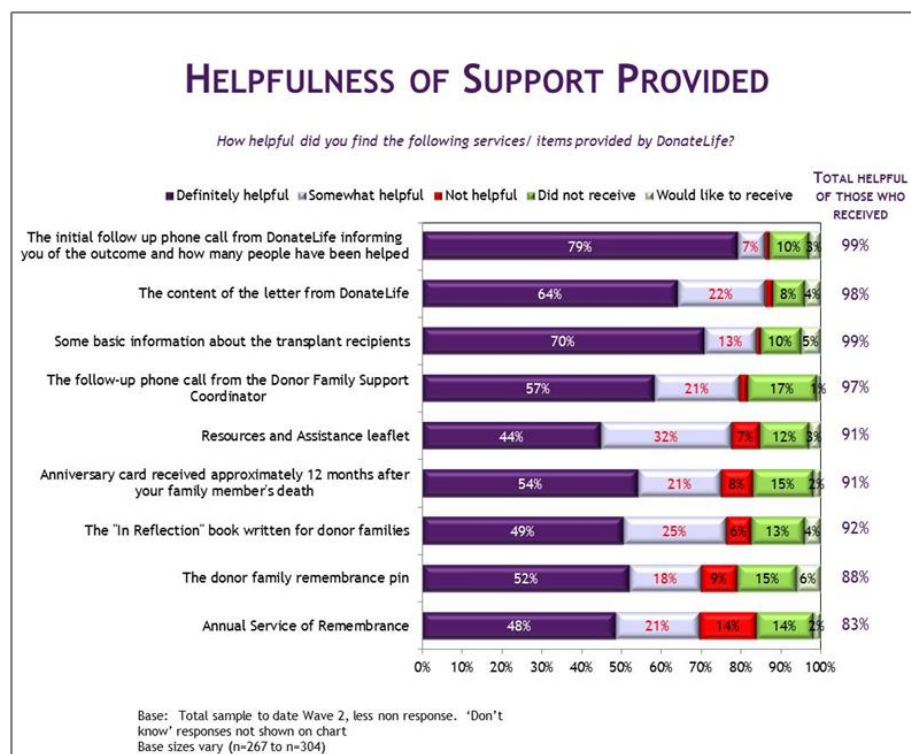


Table 24: Helpfulness of services/ resources

HOW HELPFUL DID YOU FIND THE FOLLOWING SERVICES/ ITEMS PROVIDED BY DONATELIFE? - AMONGST THOSE WHO RECEIVED THE SERVICE/ ITEM -	TOTAL HELPFUL (DEFINITELY + SOMEWHAT)	
	WAVE 1	WAVE 2
Initial phone call from DonateLife informing you of the outcome	99%	99%
The content of the letter from DonateLife	99%	98%
Basic information about the transplant recipients	100%	99%
Follow-up phone call from the Donor Family Support Coordinator	92%	97%
Resources and Assistance leaflet	Not measured	91%
Anniversary card	90%	91%
'In Reflection' book	93%	92%

How helpful did you find the following services/ items provided by DonateLife? - Amongst those who received the service/ item -	TOTAL HELPFUL (DEFINITELY + SOMEWHAT)	
	WAVE 1	WAVE 2
Donor family remembrance pin	Not measured	88%
Annual Service of Remembrance	82%	83%

As shown above, the vast majority of families who receive these services find them to be helpful, suggesting that all families should be offered them. More families in Wave 2 found the follow-up phone call from the Donor Family Support Coordinator to be helpful than in Wave 1. All other findings are consistent across waves.

11.2.1 INITIAL FOLLOW UP PHONE CALL

Of greatest importance to donor family members is the **initial follow up phone call** from DonateLife informing them of the outcome of donation (87% recall receiving this call and of those, 99% found it to be helpful). Having said their good-byes prior to surgery, family members are anxious to know how the surgery went and ideally, if this information was available, whether the transplant/s had been successful. A phone call or conversation with DonateLife as soon as possible afterwards provides a sense of relief to families; *“it was worth it – my loved one was able to help others”*. For some families, there is even a little joy in learning that some good was able to come from an otherwise terrible situation.

“I am personally moved by information directly relevant to my loved one, such as recipients. I tend to find other information not so helpful.”

2012

11.2.2 LETTER FROM DONATELIFE

Similarly, the **letter from DonateLife** is received by 88% of donor family members. Those who receive this letter find the content helpful. This letter is usually sent to the nominated senior next-of-kin (SNOK) whose details are held by the DonateLife agency. As stated earlier, the Donor Family Study is open to all family members, not just the SNOK, so findings regarding correspondence from DonateLife may be under-reported.

11.2.3 INFORMATION ABOUT TRANSPLANT RECIPIENTS

Approximately 85% of donor families report receiving information about transplant recipients from DonateLife and of those, almost all found the information to be helpful, consistent with Wave 1.

Many families have ongoing needs when it comes to information about recipients. While early information is important and appreciated, it isn't always enough.

Since not all families receive contact from recipients, they appreciate that they may still be able to learn about recipients from DonateLife. Letters and phone calls updating them about how recipients are doing provide comfort and further affirmation that they made the right decision. Families appreciate that they can request updates and that DonateLife will do their best to get back to them with that information.

"I would like to receive information about what recipients received which organs and I personally would like to write to recipients."

2012

Consistency of information dissemination is required. Of particular importance is providing basic information about the transplant recipients.

11.2.4 ANNUAL SERVICE OF REMEMBRANCE

An invitation to attend an **Annual Service of Remembrance** was sent to 84% of donor family members in 2012 and 2013. For those who received an invitation, 83% found it helpful, even if they choose not to attend, consistent with Wave 1.

"Aside from the initial letter from DL giving a brief outline of details of who received Mum's organs, nothing else received was of real significance for me. Everything else was neither here nor there. I attended my first Remembrance Service this year (3 years post) and I found it to be a very significant part of my journey though grief. I did not feel that I could attend in the previous years. It gave me peace and interacting with other donor families and recipients in my local area (even though it is 1½ hours drive away) was VERY positive and healing."

2013

“Appreciate it all. Wear my pin. Enjoy receiving info about recipients.”

2013

Almost all participants in the qualitative phase of the research mentioned the Annual Service of Remembrance. Some choose not to go, some would like to go but other commitments and distance are barriers, but almost all are glad that it takes place and that they continue to be invited, even several years on. Families appreciate that their loved one and their gift has not been forgotten. Intended donor family members and families where donation was unsuccessful are especially touched by the way they and their loved ones continue to be acknowledged and included through events such as this.

In terms of the **style** of DonateLife resources, whilst this was not something that was specifically tested as part of the research, donor families provide the following comments:

“Content, style and presentation was easy to read and understand and enough content to not be overwhelming or distressing.”

2012

“I think the content of the resources was clear, concise and easy to read. It was not too detailed or overwhelming and it was easy to understand at that stressful time.”

2013

11.2.5 DONATELIFE COUNSELLING SERVICES

While the helpfulness of counselling services offered by DonateLife was not measured in the quantitative phase of the research, based on the qualitative personal interviews throughout Australia, this service is of great value to many donor family members.

Family members who took up the offer of counselling appreciated being able to talk with someone who had insight into their situation. It was helpful for them to be able to identify the stages they were likely to progress through in their grief, to understand where they were and what was yet to come.

Family members appreciated how accessible and flexible counselling services were; most felt they could call DonateLife at any time and be able to talk about their concerns without time restrictions. Only on rare occasions were DonateLife staff not available when and where needed. Some family members sought outside help from individuals or groups.

While not strictly counselling, donor family members appreciate the follow-up, check-in calls to see how they are coping.

11.3 AMOUNT OF CONTACT WITH DONATELIFE

As shown in Figure 35, most donor family members (85%) feel the contact they have had with DonateLife has been at the right level. One in nine (11%) family members feel that contact with donation agency staff has been lacking. These findings are consistent with Wave 1.

Opting in to receiving correspondence and contact is the key, as there are some donor family members who do not wish to receive phone calls or correspondence from DonateLife, as demonstrated by the following comments.

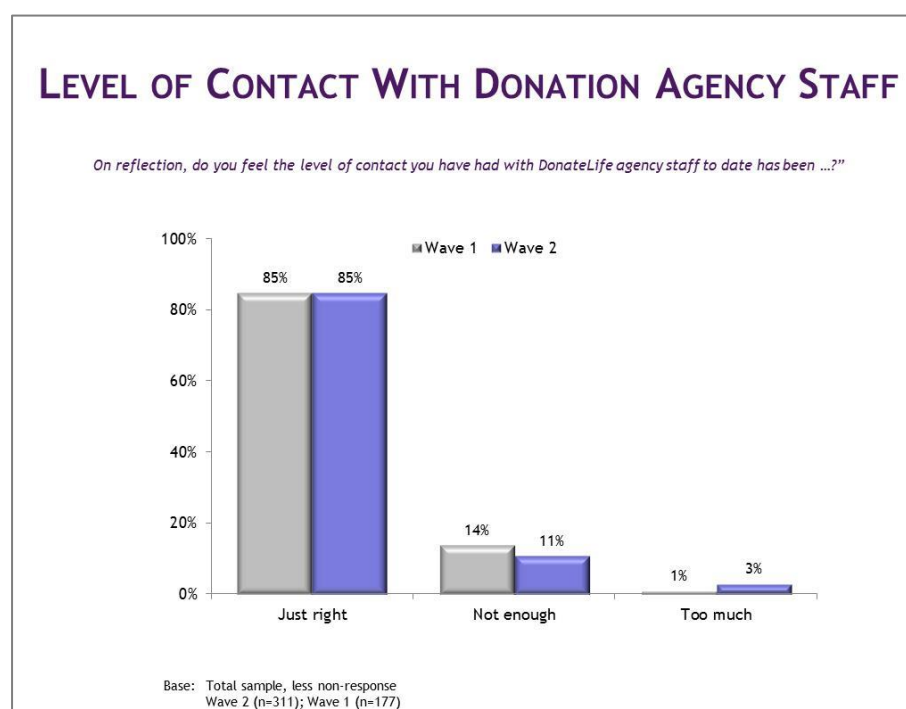
"Not helpful to me because it just reminded me of my loss. I deal with the loss of my daughter my way."

2013

"Given mum didn't end up donating, I don't like being reminded of this every year with the annual service."

2013

Figure 35: Contact with DonateLife agency staff



As shown in Table 25, in 2012 and 2013, donor families in Queensland are significantly more likely to feel that the level of contact with their donation agency staff is just right (94% compared with 85% nationally).

Table 25: Level of contact with donation agency staff, by state/territory

AMOUNT OF INFORMATION	QLD (N=70)	ACT (N=16)*	NSW (N=83)	VIC (N=73)	TAS (N=11)*	SA (N=21)*	WA (N=30)	NT (N=5)*
Just right	94%	63%	90%	75%	91%	90%	83%	80%
Not enough	6%	25%	5%	22%	9%	10%	10%	20%
Too much	-	12%	5%	3%	-	-	7%	-

* Caution: Small base

□ = Higher than the national average - statistically significant

□ = Lower than the national average - statistically significant

Ensure all family members are given the opportunity to opt in or opt out of the process of receiving information and support.

11.4 OTHER SERVICES

Donor family members were asked what other services could be offered to better support family members. As shown in Table 26, approximately 1 in 5 donor family members (19%) would like more updates on recipients (consistent with Wave 1), while a further 6% and 4% respectively feel that more contact with recipients and letters from recipients would be beneficial.

Table 26: Other services to support donor family members

WHAT OTHER SERVICES COULD BE OFFERED TO BETTER SUPPORT FAMILY MEMBERS?	Wave 1 n=114	Wave 2 n=99
None / can't think of any	34%	25%
How the recipients are going / more updates on recipients	15%	19%
More contact in general / check to see how we're going	4%	8%
I got all the support I needed / am happy with the support	20%	8%
More access to social workers / counsellors / ongoing counselling	2%	6%
Would like to meet recipients or have more contact with them	4%	6%
Set up a donate family group in our area/ online support group	3%	5%

WHAT OTHER SERVICES COULD BE OFFERED TO BETTER SUPPORT FAMILY MEMBERS?	Wave 1 n=114	Wave 2 n=99
Better support in regional areas	2%	5%
Disappointed didn't receive letter from recipient	-	4%
Specific support (for children/ young people/ men)	2%	3%
Support in writing letters for both donors and recipients	-	3%
How to cope with grief	4%	3%
Allow more than one relative to be a contact person / provide support for all family members	3%	3%
None/ prefer to source own support/ rely on support from friends	-	3%
More information about the donation process/ raise awareness of donation	-	2%
Would like to be more involved in DonateLife campaigns / events to raise awareness	2%	1%
Other one-off mentions	11%	4%

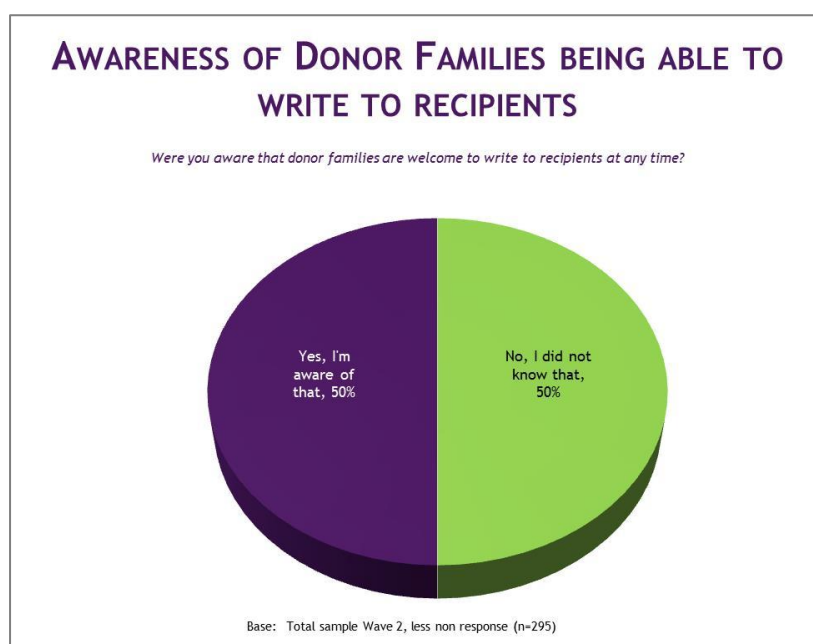
Contact from DonateLife provides family members with much needed support and reassurance of their donation decision. Family members need to feel that their loved one is not forgotten and that their gift is appreciated. One of the greatest gifts for family members is to know how recipients are doing.

12.0 CONTACT WITH RECIPIENTS

12.1 WRITING TO RECIPIENTS

As shown in Figure 36, half of donor family members are not aware that they are welcome to write to recipients. This data was not collected in Wave 1, therefore a comparison is not available.

Figure 36: Writing to recipients



"I was told by staff at the time that this was not permitted, that the recipients were not to be contacted & neither would I be given any information regarding their identity."

2012

From the comments received in the research, donor families are grateful for this opportunity, even though some may choose to never write. Some are of the view that recipients should write to donor families first, while others simply state that they wouldn't know what to say. Either way, they are grateful that the option is available.

Some donor families who are aware that they can write to recipients, spontaneously raise their concerns about the restrictions placed on them regarding what they can and can't write so as not to identify the donor. Whilst they are aware of the laws around anonymity, not being able to refer to their loved one by name or talk about their loved one's personality, is for them, hurtful. Talking about a loved one who has died is one way of keeping that person's memory alive.

"It's hard writing about the donor as a third person with no identity."

2013

"Contact with recipients is too minimised in regards to what I can share about my sister. Not being allowed to use her first name is offensive. She gave the gift of life and deserves to be more than an initial. I felt the DonateLife nurse was overwhelmed by the whole situation - lovely lady but not experienced enough to be dealing with situations like ours."

2013

Ensure that family members are told that they are welcome to write to recipients at any time, should they wish to.

12.2 DEIDENTIFIED CONTACT WITH RECIPIENTS

In 2012 and 2013, two thirds (63%) of donor families received a letter from at least one transplant recipient (Figure 37). This is consistent with Wave 1 at 69%. The letter provided comfort to 98% of these families; again, consistent with Wave 1.

"I received letters from two of the organ recipients saying how grateful they were. This was much appreciated and further proof that I had done the right thing."

2012

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.

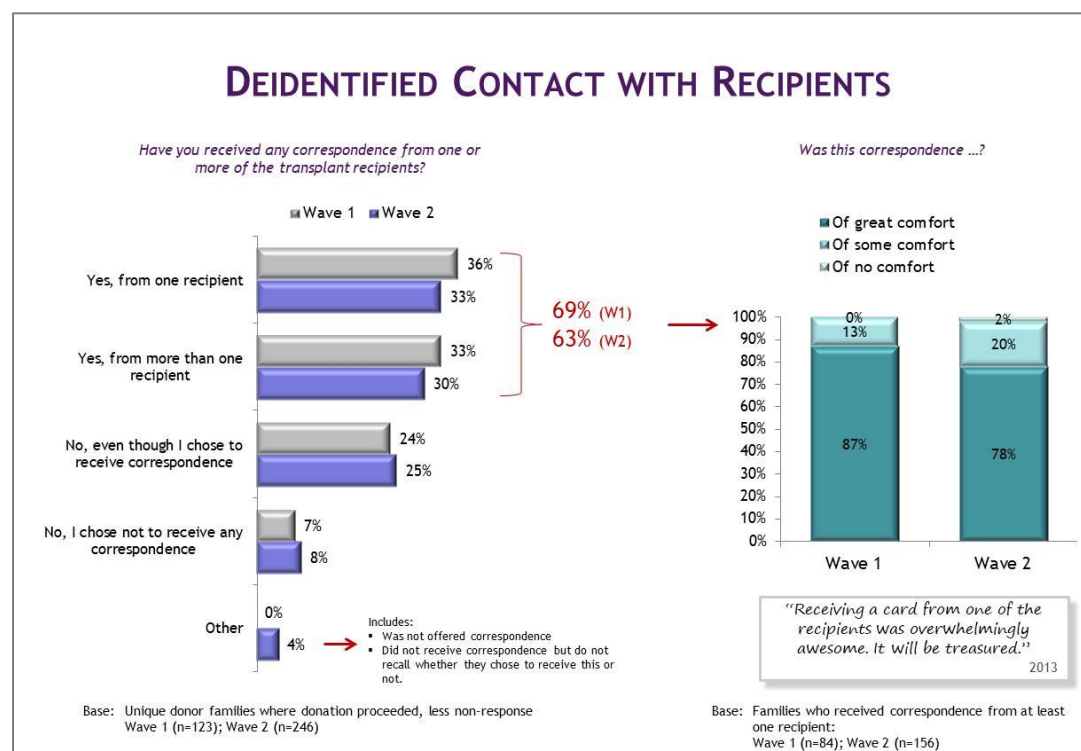
"To give another human a second chance at life is the greatest gift. Her son proudly posts her letters and cards from her recipients and promotes organ transplant. It has helped him greatly."

2012

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.

To this date, one quarter (25%) of donor families in 2012 and 2013 have not received any correspondence from recipients, even though they chose to (consistent with Wave 1 families at 24%).

Figure 37: Deidentified contact with recipients



"I think recipients should be encouraged to write often. I haven't had much communication and it hurts to feel they may take it for granted. I understand some choose not to communicate, although I do find this selfish. To be given a gift of life surely should inspire you to thank those who made it possible."

2012

12.3 IMPACT OF NO CONTACT FROM TRANSPLANT RECIPIENTS

Donor family members who chose not to receive any correspondence from transplant recipients (8% of donor families in Wave 2) are generally comfortable with the decision they made (Table 27).

Table 27: Impact of not receiving letter/ card from recipient

<i>HOW DO YOU FEEL ABOUT NOT RECEIVING ANY CORRESPONDENCE FROM THE TRANSPLANT RECIPIENTS TO DATE?</i>	WAVE 1		WAVE 2	
	WANTED TO RECEIVE CORRESPONDENCE (N=30)	CHOSE NOT TO RECEIVE CORRESPONDENCE (N=8)	WANTED TO RECEIVE CORRESPONDENCE (N=74)	CHOSE NOT TO RECEIVE CORRESPONDENCE (N=20)
Disappointed/ let down/ bitter/ not good/ sad	33%	-	19%	-
Would help in the grieving process / would help provide closure and meaning/ can see how this could help with closure	7%	-	18%	-
Would like to receive correspondence from recipient / would like personal communication with or from recipient	10%	-	14%	5%
Understand if recipients aren't up to it/ might not be easy/ it's their decision/ they will write when ready	10%	-	12%	-
Fine/ ok about no correspondence/ comfortable	10%	63%	12%	47%
Would like to know about the progress of the recipients/ how the donation helped/ who received organs	13%	-	11%	-
A thank-you would be nice/ would show recipients appreciate donation/ selfish of recipients not to write	10%	-	7%	-
Feel disappointed/a bit sad, but accept that it may not be easy to write & respect privacy of recipient	-	-	7%	-
Donation was enough/ not necessary to receive correspondence/ enough to know others were helped	7%	38%	2%	37%
Would have liked correspondence but didn't know it was allowed/ wasn't offered this option	3%	-	2%	-

How do you feel about not receiving any correspondence from the transplant recipients to date?	WAVE 1		WAVE 2	
	WANTED TO RECEIVE CORRESPONDENCE (N=30)	CHOSE NOT TO RECEIVE CORRESPONDENCE (N=8)	WANTED TO RECEIVE CORRESPONDENCE (N=74)	CHOSE NOT TO RECEIVE CORRESPONDENCE (N=20)
Another member of the family received correspondence/ another family member decided about correspondence	3%	-	2%	5%
Not entirely comfortable with receiving correspondence/ would rather not know	-	-	-	11%
Other	-	-	7%	-

"We do not find this necessary. It was enough to know that the people who received the organs were doing well."

2013

On the other hand, as shown in Table 27 above, family members who requested correspondence from recipients and have yet to receive any, can feel disappointed and sometimes bitter. There is some level of understanding that it may be difficult for recipients to write to donor families, however some donor families feel that a letter or card from one or more recipients is what they need for healing and closure. This finding is consistent with Wave 1.

"I think it would help in my grief. I would like to know if they are alright and doing okay - even after a year or more. It would be much appreciated if they had let me know if they are fine."

2012

For some families, not receiving any correspondence from recipients taints their whole donation experience. They equate a lack of correspondence to a lack of appreciation and this can lead to great disappointment. These families believe that recipients should be encouraged to write to donor families.

"I feel rather let down, disappointed that not even a thank you note from any of the recipients was received."

2012

Some families, despite requesting correspondence, are accepting of not receiving any. It is often the case that these families are informed and relatively up-to-date regarding the impact of donation from their contact with DonateLife. For them, this is enough. They would welcome hearing from recipients, but are understanding should this not happen.

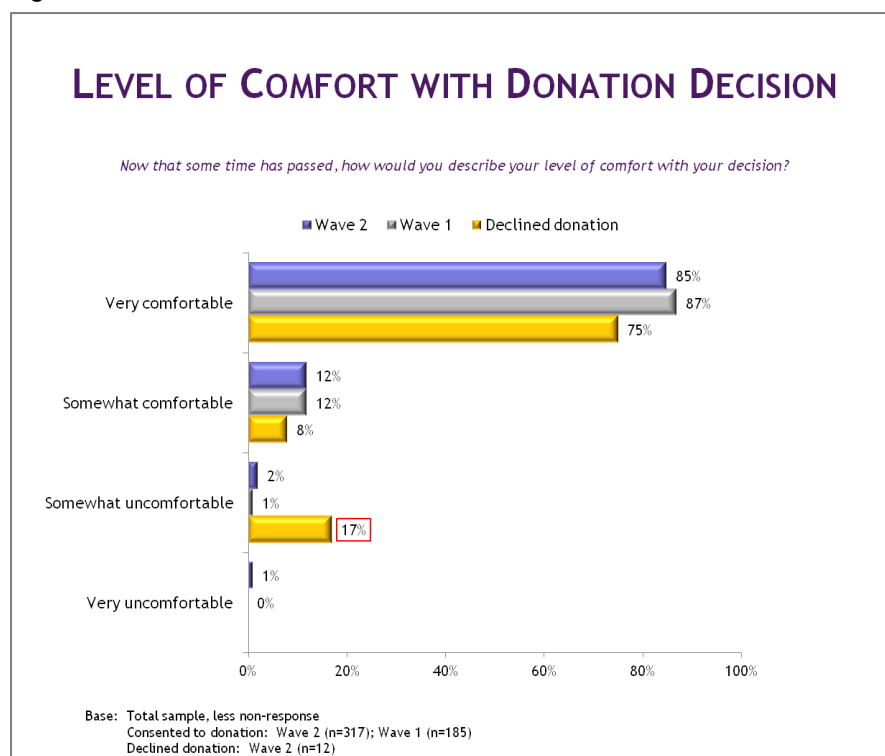
Many family members who have received correspondence from recipients have expectations for further contact. They would love to receive updates from time to time or to receive another letter or card from recipients.

13.0 ON REFLECTION

13.1 LEVEL OF COMFORT IN DECISION

For 97% of donor families (including intended donor families), the donation decision made in 2012/2013 still sits well with them today; 85% very much so. These findings are consistent with Wave 1. As shown in Figure 38, 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 38: Level of comfort with donation decision



"Gave great comfort knowing how many people he helped."

2013

The minority of consenting family members who are not entirely comfortable with their donation decision cite a number of reasons as listed in Table 28. A lack of contact from recipients can lead donor families to regret their decision (15%). Family members can also second guess their donation decision if the wishes of their loved one were not known at the time of the incident (13%). Some family members struggle with the thought that their loved one's body is no longer whole (10%), especially when the family member was buried rather than cremated. These findings are consistent with Wave 1.

Table 28: Stated reasons for not being entirely comfortable with donation decision

PLEASE EXPLAIN WHY YOU ARE NOT ENTIRELY COMFORTABLE WITH YOUR DECISION TO DONATE?	WAVE 1 % (N=22)	WAVE 2 % (N=40)
Not enough information about recipients/ not enough communication from recipients/ no thank you from recipients	14%	15%
Not sure if decision was right/ not sure if decision was the wish of family member who donated	18%	13%
Difficult to come to terms with family member's body not being 'whole'/ hard to 'give away' part of loved one	9%	10%
Unsure whether family member was dead at time the organs were retrieved/ wonder if family member felt pain during donation surgery	5%	10% *
Donation didn't proceed/ donation was unsatisfactory/ tissue donation wasn't done correctly	5%	10%
Difficult coming to terms with the death	9%	10%
Process of deciding is too difficult - felt rushed/ emotional and exhausting time/ traumatic/ very long process	9%	10%
Was life support removed too soon?	5%	5% *
Lack of compassion and support afterwards/ once decision was made/ felt like donor and donor family no longer mattered	5%	5%
Other response	32%	15%

Table 28 above highlights some information gaps in the hospital setting. Fifteen percent (15%) of families (refer *) who are not entirely comfortable today with their donation decision in 2012 or 2013 have unanswered questions regarding the timing of their family member's death and donation.

"Even now I don't really understand, you think & hope they will be ok. It is hard to understand what brain dead is - they are warm, their heart is beating etc. If someone is dead, you accept that because their heart has stopped. I think more information, in terms and wording we can understand, would be helpful."

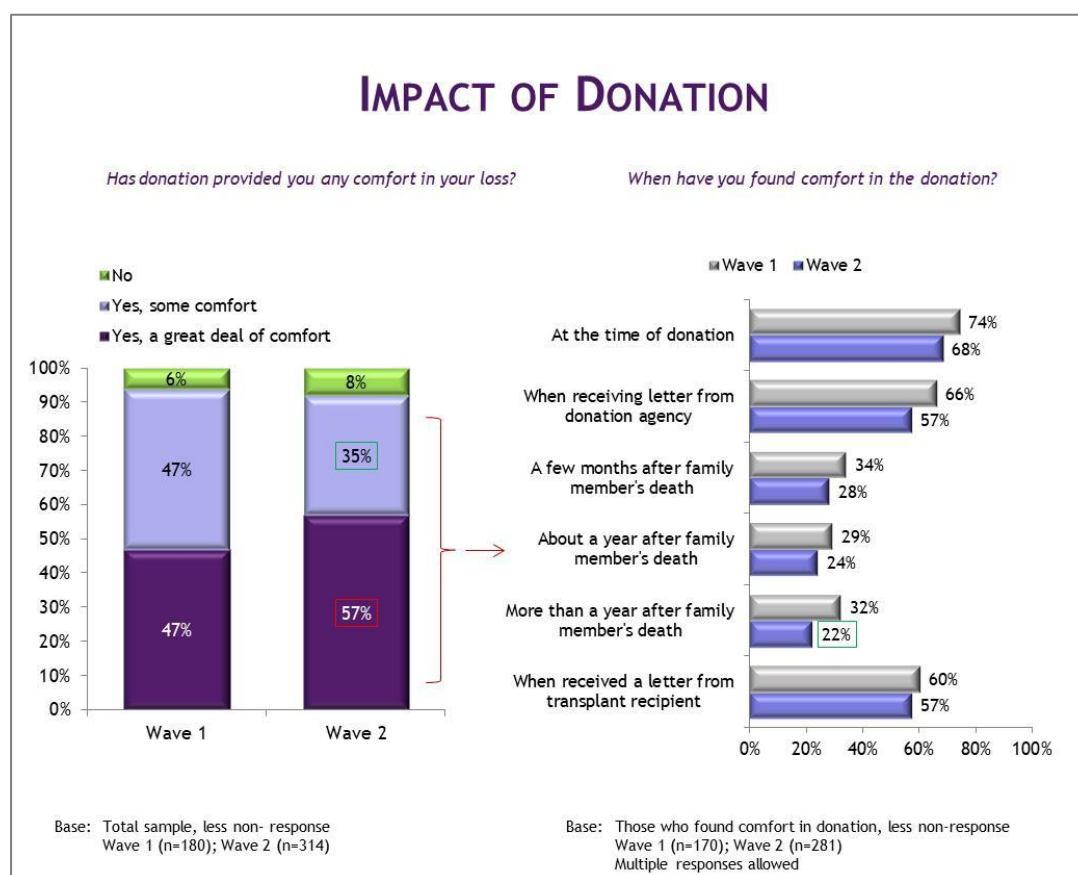
2013

13.2 THE IMPACT OF DONATION

The vast majority of donor families (92% in Wave 2) found comfort in the donation of their loved ones organs. 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* (Figure 39), consistent with Wave 1.

Figure 39: The impact of donation



“I’m really not sure. Some days ‘yes’ and other days ‘no’!! I’m angry that some families haven’t said ‘thank you’. Only received letters from 2 out of 5 transplant recipients.”

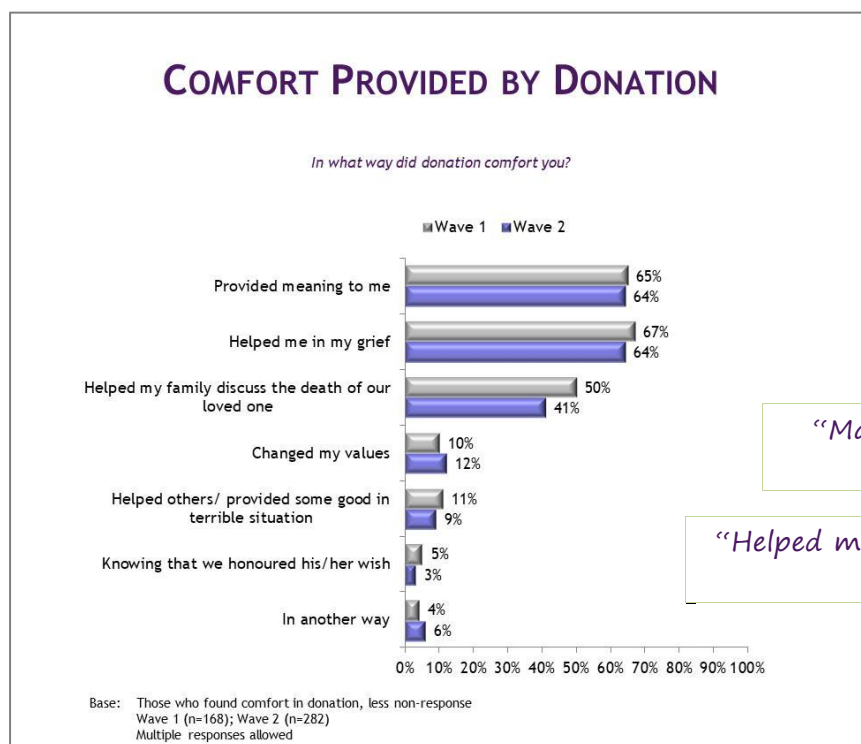
2012

The figures above also demonstrates the importance of contact from transplant recipients. Three in five (57%) donor family members who are comforted in their loss by donation feel that sense of comfort when they receive a letter from a recipient.

“Receiving the letter of thanks from the single recipient reinforced that our decision was the correct decision.”
2012

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 (Figure 40), consistent with Wave 1.

Figure 40: How donation has provided comfort



“Makes us very proud.”
2012

“Helped make sense of my loss.”
2013

“I feel it helps other family members gain some closure. It makes you reflect on the life the donor had prior to death.”
2012

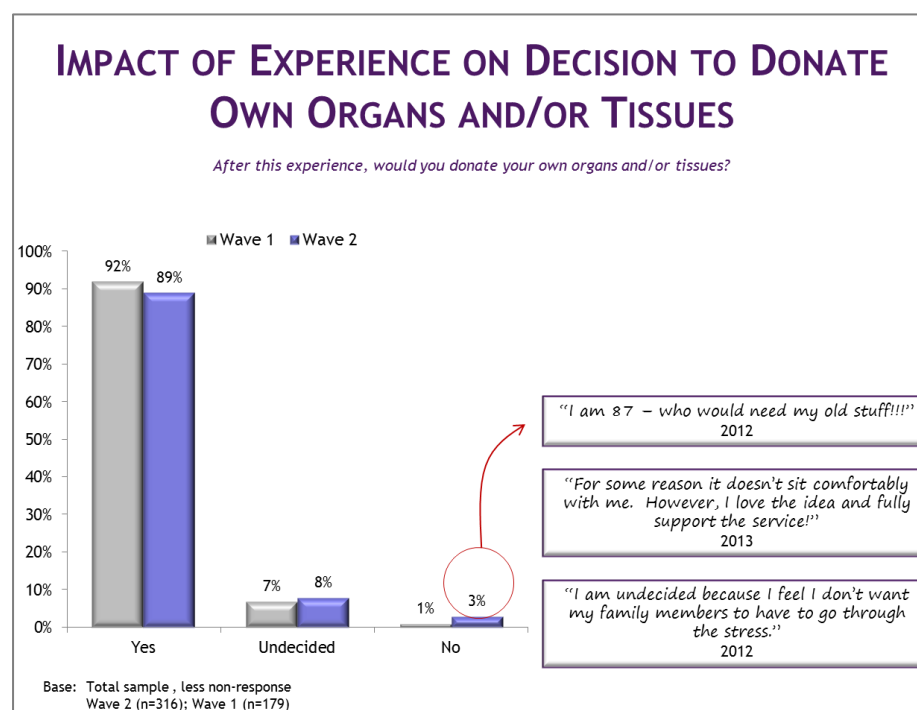
During the personal interviews, many family members discussed the positive outcomes that donation enabled in an otherwise terrible situation. Donation helped them to know that because of their loved one’s generosity, other lives were saved or improved. It gave their loved one’s life more meaning and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

Another small point of comfort for some family members occurred when learning about the health of their loved one's organs. Many were proud of how healthy and active their family members were, especially those of older age, and they enjoyed receiving positive reports about what good condition their organs were found to be in. Other were surprised, given the age or lifestyle of their loved one, that certain organs were viable. This gave them a little something to smile about at this very sad time. Unfortunately the opposite is also true - it can be disappointing, having agreed to donation, if it could not take place for medical suitability reasons.

After the donation experience, 89% of donor family members would donate their own organs and/or tissues after death (Figure 41). One in 12 family members (8%) is undecided, while 3% would not wish to donate. These findings are consistent with Wave 1.

Figure 41: Impact of experience on decision to donate own organs and/or tissues



Eighty percent (80%) of *intended* donor families would donate their own organs and/or tissues, while 20% are undecided.

“We felt that the donation was appreciated even though none of his organs or tissue could be used. It was disappointing that these could not help another.”

2012 - INTENDED DONOR FAMILY

Table 29 shows that prior to their donation experience, 84% of family members held positive views about donation, 14% had mixed feelings and 2% held negative views. The donation experience strongly influences a person’s own views and wishes when it comes to donation; a positive experience can lead a person to change their previously held negative views, while a negative experience can turn a person away from donation.

A significant and impactful learning for many donor family members was realising how rare donation is and how few people, even amongst those who consent, are actually able to donate. They were also deeply moved by the inspiring stories shared with them by DonateLife about the impact on the lives of others. It is these messages, together with the message to consider, register and talk widely about donation, that many family members most want to get out to the wider community.

Table 29: Impact of donation on personal views

PERSONAL VIEWS ABOUT DONATION	TOTAL (N=317)	WOULD DONATE OWN ORGANS AND/OR TISSUES?	
Generally positive	84%	Yes	94%
		No	2%
		Undecided	4%
Mixed feelings	14%	Yes	58%
		No	9%
		Undecided	33%
Generally negative	2%	Yes	67%
		No	33%

It is pleasing to see that of those family members who held negative views towards donation, two thirds (67%) would now donate their own organs. For some who initially held negative views about donation, experiencing it for themselves completely dispelled the myths they previously held on to.

“I was always against it because Dad didn't talk about his wishes. As a family, we made the decision and at the beginning there was no mutual agreement.”

“I found the constant letters from one recipient very useful.”

2012

14.0 SUMMARY OF COMPARISON BETWEEN WAVE 1 AND WAVE 2

This section of the report provides a quick reference and comparison between the research data in Wave 1 (based on a sample size of n=185 donor family members) and that in Wave 2 (based on a sample size of n=319 family members), where direct comparisons can be made.

14.1 THE DECISION TO DONATE

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Donation pathway	Brain death	89%	88%	Table 5
	Circulatory death	11%	12%	Table 5
Prior discussion	Yes and knew wishes	59%	59%	Figure 6
	Yes, but unclear on wishes	9%	9%	Figure 6
	Did not discuss	32%	32%	Figure 6
Impact of knowing wishes of family member (amongst those who had previously had discussion): <ul style="list-style-type: none"> Wave 1 - n=125 Wave 2 - n=216 	Made decision a lot easier	76%	80%	Table 12
	Made decision a bit easier	13%	11%	Table 12
	No impact	10%	8%	Table 12
	Made decision a bit more difficult	2%	1%	Table 12
	Made decision a lot more difficult	-	-	Table 12
Main reasons for agreeing to donation (top 3 reasons - Wave 2)	Opportunity for something positive to come out of a tragedy	81%	78%	Figure 8
	Family member would have wanted to help others	80%	76%	Figure 8
	For someone else to live a better life	74%	66%	Figure 8

14.2 AT THE HOSPITAL (PRIOR TO CONSENTING)

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Hospital staff made it clear that family member would not survive	Yes	94%	95%	Figure 10
	No	4%	2%	Figure 10
	Not sure	2%	3%	Figure 10
ICU/ED staff treated family with consideration and sensitivity	To a great extent	89%	91%	Figure 9
	To some extent	11%	8%	Figure 9
	Not at all	1%	1%	Figure 9
Was given sufficient information to understand that death was expected	Agree (strongly + somewhat)	99%	97%	Figure 11
	Disagree/ not sure	1%	3%	Figure 11
Language used by medical staff was clear and easy to understand	Agree (strongly + somewhat)	99%	98%	Figure 11
	Disagree	1%	2%	Figure 11

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Medical staff treated family with compassion and sensitivity	Agree (strongly + somewhat)	99.5%	99%	Figure 11
	Disagree	0.5%	1%	Figure 11
Medical staff treated donor with respect	Agree (strongly + somewhat)	99%	99%	Figure 11
	Disagree	1%	1%	Figure 11
Had sufficient opportunity to ask questions of medical staff	Agree (strongly + somewhat)	97%	96%	Figure 11
	Disagree	3%	4%	Figure 11
Had enough private time with family member <u>after</u> receiving grave news	Yes	91%	91%	Figure 13
	No	7%	6%	Figure 13
	Not sure	2%	3%	Figure 13
BRAIN DEATH TESTING				
Offered to be present during brain death testing	Yes	24%	24%	Figure 12
	No	50%	62%	Figure 12
	Not sure	26%	14%	Figure 12
Chose to be present during brain death testing (among those who were offered)	Yes	55%	73%	Figure 12
	No	45%	27%	Figure 12
Seeing tests helped in understanding that loved one had died (among those who attended brain death testing)	Yes	91%	91%	Figure 12
	No/ not sure	9%	9%	Figure 12
Would have helped to have option of being present (among those who were not offered)	Yes	18%	20%	Figure 12
	No/ not sure	82%	80%	Figure 12

14.3 THE DONATION CONVERSATION

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Who initially raised donation	Doctor	29%	34%	Figure 14
	Donor coordinator	13%	21%	Figure 14
	Nurse	4%	7%	Figure 14
	<i>Health professional - Net</i>	46%	58%	Figure 14
	Self	20%	22%	Figure 14
	Family member	10%	11%	Figure 14
	<i>Self/ family - Net</i>	30%	33%	Figure 14
When donation was first raised (in relation to being told of family member's death or expected death)	Before	10%	10%	Figure 16
	At the same time	40%	38%	Figure 16
	Within 1 hour	24%	17%	Figure 16
	More than 1 hour	12%	19%	Figure 16
Appropriateness of timing	Yes	74%	73%	Figure 17
	No/ not sure	26%	27%	Figure 17

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
DISCUSSIONS WITH HOSPITAL STAFF ABOUT DONATION PRIOR TO DONATION DECISION BEING MADE				
Discussions were handled sensitively and with compassion	Agree (strongly + somewhat)	98%	96%	Figure 19
	Disagree/ not sure	2%	4%	Figure 19
Family had enough opportunities to ask questions about donation	Agree (strongly + somewhat)	93%	97%	Figure 21
	Disagree/ not sure	7%	3%	Figure 21
Hospital staff answered questions	Agree (strongly + somewhat)	95%	98%	Figure 21
	Disagree/ not sure	5%	2%	Figure 21
Given sufficient information to allow an informed decision to be made	Agree (strongly + somewhat)	95%	97%	Figure 20
	Disagree/ not sure	5%	3%	Figure 20
Given enough time to discuss donation and make decision	Agree (strongly + somewhat)	94%	96%	Figure 22
	Disagree/ not sure	6%	4%	Figure 22
Feel pressured or rushed	Yes	8%	8%	Figure 22
	No	88%	87%	Figure 22
	Not sure	4%	5%	Figure 22

14.4 MOVING TOWARDS DONATION

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Met with DonateLife coordinator, nurse or doctor	Yes	91%	92%	Figure 23
	No	5%	4%	Figure 23
	Not sure	4%	4%	Figure 23
Understanding of donation process after speaking with DonateLife coordinator, nurse or doctor	Well informed	82%	83%	Figure 23
	Still had questions	16%	14%	Figure 23
	Not a good understanding of donation process	2%	2%	Figure 23
Made aware that donation may not happen even after consent	Yes	90%	88%	Page 59
WRITTEN INFORMATION				
Received written information	Before decision was made	16%	27%	Figure 24
	After decision was made	24%	20%	Figure 24
	Did not receive written information	15%	14%	Figure 24
	Can't recall	48%	41%	Figure 24
Read information (amongst those who received it)	Yes, in detail	53%	54%	Figure 25
	Yes, skimmed through it	46%	41%	Figure 25
	Did not read	1%	5%	Figure 25
When information was read (amongst those who received information)	Before finalising decision	28%	35%	Figure 25
	After finalising decision	64%	43%	Figure 25
	Not sure	7%	21%	Figure 25

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Usefulness of written information (amongst those who read it)	Very useful	55%	52%	Table 18
	Quite useful	41%	44%	Table 18
	Not useful	5%	2%	Table 18
SUPPORT FROM HEALTH PROFESSIONALS - AFTER CONSENTING TO DONATION				
Staff in ICU or ED treated family with consideration and sensitivity after consenting to donation	To a great extent	89%	89%	Figure 26
	To some extent	10%	10%	Figure 26
	Not at all	1%	1%	Figure 26
Offered support of a social worker, counsellor or chaplain	Yes	76%	79%	Figure 27
	No	10%	10%	Figure 27
	Not sure	14%	11%	Figure 27
DONATION PROCESS				
Given enough time with family member prior to surgery	Yes	95%	95%	Figure 29
	No	5%	5%	Figure 29
Given the information you wanted about donation surgery	Yes	83%	85%	Figure 28
	No/ not sure	17%	15%	Figure 28
Information about donation surgery	Too detailed	2%	3%	Figure 28
	Too broad	5%	3%	Figure 28
	Too brief	8%	4%	Figure 28
	Just right	85%	89%	Figure 28
Staff in ICU treated family member with respect	To a great extent	91%	94%	Figure 30
	To some extent	8%	6%	Figure 30
	Not at all	1%	-	Figure 30

14.5 AFTER DONATION SURGERY

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Offered opportunity to spend time with family member after donation surgery	Yes	49%	47%	Figure 31
	No	37%	36%	Figure 31
	Not sure	14%	17%	Figure 31
Spent time with family member after survey (amongst those who were offered)	Yes	53%	56%	Figure 31
	No	47%	44%	Figure 31
Would liked to have had opportunity to see family member post-surgery (amongst those who were not offered)	Yes	10%	11%	Figure 31
	No	66%	61%	Figure 31
	Not sure	24%	28%	Figure 31

14.6 FOLLOW-UP SERVICES

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Offered ongoing contact following donation from DonateLife coordinator, nurse or doctor, a DFSC, hospital social worker or hospital chaplain	Yes	85%	95%	Page 77
Level of contact with DonateLife agency staff to date	Too much	1%	3%	Figure 35
	Not enough	14%	11%	Figure 35
	Just right	85%	85%	Figure 35

14.7 CONTACT WITH RECIPIENTS

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Received correspondence from any transplant recipients (amongst unique donor families): <ul style="list-style-type: none"> Wave 1 - n=125 Wave 2 - n=246 	Yes, from one or more	69%	63%	Figure 37
	No, even though I wanted to	24%	25%	Figure 37
	No, I chose not to receive any	7%	8%	Figure 37
Correspondence from recipients (amongst unique donor families who received any correspondence from recipients): <ul style="list-style-type: none"> Wave 1: n=84 Wave 2: n=156 	Of great comfort	87%	78%	Figure 37
	Of some comfort	13%	20%	Figure 37
	Of no comfort	-	2%	Figure 37

14.8 ON REFLECTION

EXPERIENCE		WAVE 1	WAVE 2	LOCATION
Level of comfort with donation decision	Very comfortable	87%	85%	Figure 38
	Somewhat comfortable	12%	12%	Figure 38
	Somewhat uncomfortable	1%	2%	Figure 38
	Very uncomfortable	-	1%	Figure 38
Donation provided any comfort in loss	Yes, a great deal of comfort	47%	57%	Figure 39
	Yes, some comfort	47%	35%	Figure 39
	No	6%	8%	Figure 39
In what way donation has provided comfort (amongst those who found comfort in donation) - top 3 responses	Provided meaning	65%	64%	Figure 40
	Help in time of grief	67%	64%	Figure 40
	Helped my family discuss the death of our loved one	50%	41%	Figure 40
After donation experience, feelings towards donation personally	Yes, would donate after death	92%	89%	Figure 41
	No, would not donate after death	1%	3%	Figure 41
	Undecided	7%	8%	Figure 41

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

Donor Family Member, 2013

Appendices

Glossary of Key Terms

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

TERM	DEFINITION
Australasian Transplant Coordinators Association (ATCA)	A member organisation that aims to promote communication and collaboration amongst organ and tissue donor and transplant coordinators in Australia and New Zealand. This includes the promotion of research, development and education in organ and tissue donation and transplantation.
Brain Death Testing	A series of clinical tests carried out by two medical practitioners with experience and qualifications according to state and territory laws to determine that brain death has occurred. Two separate series of tests, one by each medical practitioner, is performed, however these tests may not be conducted simultaneously. Brain death may also be tested using special x-rays of the head to demonstrate that there is no blood flow to the brain if aforementioned clinical tests are unable to be completed.
DonateLife agencies	Organ and tissue donation agencies responsible for implementing the national reform agenda in their respective state or territory. DonateLife agencies employ specialist staff in organ and tissue donation coordination, professional education, donor family support, communications and data and audit roles.
Donation after brain death (DBD)	When organ donation occurs after brain death has been determined and before cessation of circulation.
Donation after circulatory death (DCD)	When organ donation occurs after circulatory (formerly cardiac) death has been determined to have occurred, on the basis of the absence of circulation (and of other vital signs).
Donor Family Support Coordinator (DFSC)	Support Coordinators provide counselling, coordinate and assist in the provision of support to donor families.
Donor Family Support Implementation Group (DFSIG)	A forum in which all DFSCs come together with the Organ and Tissue Authority (OTA) and a representative from ACTA, to discuss the implementation, monitoring and review of the Donor Family Support Service across Australia.
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).
Hospital staff	Specialist hospital staff, including hospital medical directors and hospital senior nurses, funded by the Australian Government to facilitate organ and tissue donation and to educate and support hospital staff involved.

TERM	DEFINITION
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 DonatLife resource that provides information for donor families in dealing with the grieving process.
Interviews	A research tool in which a researcher asks questions (mostly open ended questions) of participants. Interviews are conducted face-to-face and are audio-taped (with permission of the respondent) for later transcription and analysis.
National Reform Programme	The programme agenda sets out nine measures that describe the key strategies of the Australian Government’s 2008 ‘World’s Best Practice Approach to Organ and Tissue Donation for Transplantation’.
Organ and Tissue Authority (OTA)	Statutory body established under the <i>Australian Organ and Tissue Donation and Transplantation Authority Act 2008</i> to implement the national reform agenda. The OTA’s role is to work with states and territories, clinicians, consumers and the community sector to implement a world’s best practice approach to organ and tissue donation and transplantation system for Australia.
Participant Information Statement (PIS)	Document provided to research participants. It outlines in plain and simple language, information about the project, including what participating in the project involves, benefits and risks of participation and privacy statements, so individuals can make an informed decision regarding participation in the research study.
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 part of the organ and tissue donation and transplant journey.
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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Research Instruments

1.0 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 an online survey by emailing Rhonda@proofresearch.com.au for the survey link.

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

SECTION 1 - YOUR FAMILY MEMBER AND THE DECISION TO DONATE

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

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

Parent/ guardian	<input type="checkbox"/> 1
Wife/ husband/ partner	<input type="checkbox"/> 2
Daughter/ son	<input type="checkbox"/> 3
Brother/ sister	<input type="checkbox"/> 4
Other (please specify) _____	<input type="checkbox"/> 5

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

Aboriginal	<input type="checkbox"/> 1
Torres Strait Islander	<input type="checkbox"/> 2
Neither	<input type="checkbox"/> 3

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

No	<input type="checkbox"/> 1	
Yes	<input type="checkbox"/> 2	→ Which language? _____

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

5. When did your family member die? _____ month _____ year

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

Brain death ⁵	<input type="checkbox"/> 1	Circulatory Death ⁶	<input type="checkbox"/> 2	Not sure	<input type="checkbox"/> 3
--------------------------	----------------------------	--------------------------------	----------------------------	----------	----------------------------

7. In which state or territory did the donation occur? (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

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

Generally positive	<input type="checkbox"/> 1
Generally negative	<input type="checkbox"/> 2
Mixed feelings	<input type="checkbox"/> 3

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

Yes, we discussed it and I knew his/her wishes	<input type="checkbox"/> 1
Yes, we discussed it but no clear decision was made	<input type="checkbox"/> 2
No, we did not discuss the subject	<input type="checkbox"/> 3

⁵ Brain death occurs when a person's brain permanently stops functioning.

⁶ Circulatory death occurs when a person's heart permanently stops functioning.

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

- | | |
|---|----------------------------|
| It made our decision a lot easier | <input type="checkbox"/> 1 |
| It made our decision a bit easier | <input type="checkbox"/> 2 |
| It did not impact on our decision to donate | <input type="checkbox"/> 3 |
| It made our decision a bit more difficult | <input type="checkbox"/> 4 |
| It made our decision a lot more difficult | <input type="checkbox"/> 5 |

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

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

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

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

- | | | |
|------------------------|----------------------------|--------------------|
| Very comfortable | <input type="checkbox"/> 1 | ➔ GO TO Q15 |
| Somewhat comfortable | <input type="checkbox"/> 2 | |
| Somewhat uncomfortable | <input type="checkbox"/> 3 | |
| Very uncomfortable | <input type="checkbox"/> 4 | |

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

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

SECTION 2 - AT THE HOSPITAL

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

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

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

To a great extent ☐ 1

To some extent ☐ 2

Not at all ☐ 3

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

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

	Strongly agree 3	Somewhat agree 2	Disagree 1	Not sure 9
a) I was given sufficient information to fully understand that death was expected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) The language used by medical staff was clear and easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Medical staff treated me with compassion and sensitivity at this time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Medical 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 medical staff at this time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

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

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

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

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

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

Yes ☐ 1
 No ☐ 2 → **GO TO Q26**

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

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

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

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

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

SECTION 3 - DISCUSSING ORGAN AND TISSUE DONATION

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

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

- | | | | |
|--|----------------------------|-----|------------------|
| Doctor | <input type="checkbox"/> 1 | } → | CONTINUE |
| Nurse | <input type="checkbox"/> 2 | | |
| DonateLife coordinator | <input type="checkbox"/> 3 | | |
| Family member/ close friend | <input type="checkbox"/> 4 | | |
| Other (<i>relationship to you:</i> _____) | <input type="checkbox"/> 5 | } → | GO TO Q32 |
| I raised it myself | <input type="checkbox"/> 6 | | |
| Can't remember | <input type="checkbox"/> 9 | → | CONTINUE |

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

- | | |
|---|----------------------------|
| Before I was told of my family member's death or expected death | <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 death or expected death | <input type="checkbox"/> 4 |
| Can't remember | <input type="checkbox"/> 9 |

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

- Yes ☐ 1 No ☐ 2 Not sure ☐ 3

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

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

- | | |
|--|----------------------------|
| It added to my family's distress | <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 |

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

	Strongly agree 3	Somewhat agree 2	Disagree 1	Not sure 9
a) The discussions about donation were handled sensitively and with compassion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) My family had enough opportunities to ask questions of hospital staff about donation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hospital 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"/>

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

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

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

Consenting to organ and/or tissue donation

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

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

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

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

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

- Yes ☐ 1 No ☐ 2 Not sure ☐ 3

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

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

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

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

40. When did you read the information about donation?

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

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

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

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

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

43. What further comments would you like to make? ✍

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

- Yes ☐ 1
 No ☐ 2
 Not sure ☐ 3

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

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

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

OR:

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

The donation process

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

- Yes ☐ 1 No ☐ 2

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

- Yes ☐ 1 No ☐ 2 Not sure ☐ 3

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

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

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

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

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

After the donation surgery

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

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

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

Yes ☐ 1
No ☐ 2 → **GO TO Q56**

54. If you answered 'yes' at Q53. How would you describe this experience? *(Please tick ☒ one box only)*

Positive ☐ 1 Negative ☐ 2 Not sure ☐ 3

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

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

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

SECTION 4 - FOLLOWING DONATION

Follow up services and resources

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

	Definitely helpful 3	Somewhat helpful 2	Not helpful 1	Contact Not offered	Chose not to receive
a) DonatLife coordinator, nurse or doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Donor Family Support Coordinator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hospital social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Other hospital support staff such as a chaplain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) External professional counselling services (other than from DonatLife agencies)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Other - please specify _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

59. If you ticked that ongoing contact was not offered to you in Q57.

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

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

	Definitely helpful 3	Somewhat helpful 2	Not helpful 1	Did not receive/ N/A	Would like to receive
a) The initial follow-up phone call from DonateLife informing you of the outcome and how many people had been helped	<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 <u>content</u> 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 Donor Family Support Coordinator	<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"/>
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) Resources and Assistance leaflet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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

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

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

Your feelings about organ and tissue donation

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

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

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

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

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

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

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

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

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

Contact with recipients

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

- Yes, from one recipient ☐ 1
 Yes, from more than one recipient ☐ 2
 No, I chose not to receive any correspondence ☐ 3 → **GO TO Q71**
 No, even though I chose to receive correspondence ☐ 4 → **GO TO Q71**
 No, transplantation did not proceed ☐ 5 → **GO TO Q73**

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

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

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

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

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

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

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

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

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

2.0 QUESTIONNAIRE - FAMILIES WHO DECLINED DONATION

Family Experiences of Organ and Tissue Donation A National Family Survey

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

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

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

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

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

There are two ways to provide your feedback:

1. Complete this questionnaire and return it using the reply paid envelope enclosed.
2. Complete an online survey by emailing Rhonda@proofresearch.com.au to request a survey link.

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

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

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

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

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

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

Yours sincerely

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

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

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

Parent/ guardian	<input type="checkbox"/> 1
Wife/ husband/ partner	<input type="checkbox"/> 2
Daughter/ son	<input type="checkbox"/> 3
Brother/ sister	<input type="checkbox"/> 4
Other (please specify) _____	<input type="checkbox"/> 5
2. Was your family member of Aboriginal or Torres Strait Islander descent?

Aboriginal	<input type="checkbox"/> 1
Torres Strait Islander	<input type="checkbox"/> 2
Neither	<input type="checkbox"/> 3
3. Did your family member speak a language other than English at home??

No	<input type="checkbox"/> 1	
Yes	<input type="checkbox"/> 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
ACT	<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	<input type="checkbox"/> 1
Generally negative	<input type="checkbox"/> 2
Mixed feelings	<input type="checkbox"/> 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	<input type="checkbox"/> 1
Yes, we discussed it but no clear decision was made	<input type="checkbox"/> 2
No, we did not discuss the subject	<input type="checkbox"/> 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	<input type="checkbox"/> 1
It made our decision a bit	<input type="checkbox"/> 2
It did not impact on our decision	<input type="checkbox"/> 3
It made our decision a bit more difficult	<input type="checkbox"/> 4
It made our decision a lot more difficult	<input type="checkbox"/> 5

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

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

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

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

- | | | |
|------------------------|----------------------------|--------------------|
| Very comfortable | <input type="checkbox"/> 1 | → GO TO Q14 |
| Somewhat comfortable | <input type="checkbox"/> 2 | |
| Somewhat uncomfortable | <input type="checkbox"/> 3 | |
| Very uncomfortable | <input type="checkbox"/> 4 | |

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

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

SECTION 2 - AT THE HOSPITAL

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

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

- Yes ☐ 1 No ☐ 2 Not sure ☐ 3

16. To what extent do you feel the staff in the Intensive Care Unit /Emergency Department treated you with consideration and sensitivity 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, medical staff may have discussed with you either testing for brain death or turning off the ventilator. Thinking back to that time, do you agree or disagree with each of the following statements? (Please tick ☒ one box only for each statement)

	Strongly agree 3	Somewhat agree 2	Disagree 1	Not sure 9
f) I was given sufficient information to fully understand that death was expected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) The language used by medical staff was clear and easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Medical staff treated me with compassion and sensitivity at this time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Medical staff treated my family member with respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) I had sufficient opportunity to ask questions of medical 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
 Not sure ☐ 3 } → **GO TO Q24**

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

Yes ☐ 1
No ☐ 2 → GO TO Q25

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

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

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

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

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

SECTION 3 - DISCUSSING ORGAN AND TISSUE DONATION

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

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

Doctor	<input type="checkbox"/> 1	} → CONTINUE
Nurse	<input type="checkbox"/> 2	
DonateLife coordinator	<input type="checkbox"/> 3	
Family member/ close friend	<input type="checkbox"/> 4	} → GO TO Q31
Other person (Relationship to you: _____)	<input type="checkbox"/> 5	
I raised it myself	<input type="checkbox"/> 6	
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 staff member and not a family member, how did that make you feel? (You may select as many as you like).

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

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

	Strongly agree 3	Somewhat agree 2	Disagree 1	Not sure 9
f) The discussions about donation were handled sensitively and with compassion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) My family had enough opportunities to ask questions of hospital staff about donation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Hospital staff answered our questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) 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"/>
j) 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 a Donatelife coordinator, nurse or doctor? (Please tick ☒ one box only)

- Yes ☐ 1
 No ☐ 2 → **GO TO Q36**
 Not sure ☐ 3 → **GO TO Q36**

35. Which of these statements best describes your understanding of organ and tissue donation after speaking with the DonateLife coordinator/ nurse or doctor? *(Please tick ☒ one box only)*

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

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

- Yes, before the decision to decline donation was made ☐ 1
 Yes, after the decision to decline donation was made ☐ 2
 No, I did not receive written information ☐ 3 → **GO TO Q40**
 I can't recall ☐ 4 → **GO TO Q40**

37. Did you read the information? *(Please tick ☒ one box only)*

- Yes, in detail ☐ 1
 Yes, skimmed through it ☐ 2
 No ☐ 3 → **GO TO Q40**

38. When did you read the information about donation?

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

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

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

40. To what extent do you feel the staff in the Intensive Care Unit or Emergency Department treated you with consideration and sensitivity 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 agencies

44. Were you offered any ongoing contact with staff from the hospital or organ and tissue donation agency, for example, a social worker, chaplain or organ donor agency? *(Please tick ☒ one box only)*

Yes ☐ 1 → **GO TO Q46**
 No ☐ 2
 Not sure ☐ 3

45. If you answered 'no' or 'not sure' to Q44. Would you have liked somebody to contact you?

Yes ☐ 1 } **GO TO Q49**
 No ☐ 2 }
 Not sure ☐ 3 }

46. If you answered 'yes' to Q44. From whom did you receive contact? *(Please tick ☒ all that apply)*

Social worker ☐ 1
 DonateLife coordinator, nurse or doctor ☐ 2
 Hospital Chaplain ☐ 3
 DonateLife Donor Family Support Coordinator ☐ 4
 Other () ☐ 5

47. To what extent did you find this contact helpful? *(Please tick ☒ one box only)*

To a great extent ☐ 1
 To some extent ☐ 2
 Not at all ☐ 3 → Why? _____ → **GO TO Q49**

48. In what way was the contact helpful?



49. To help hospitals and organ and tissue donation agencies provide the best service, which of the following services, if any, would you have found helpful? *(Please tick ☒ all that apply)*

A follow up phone call from the DonateLife agency
Information about bereavement support services

☐ 1
☐ 2

50. What other services do you feel could be offered to better support family members? */*

Your feelings about organ and tissue donation

51. On reflection, would you make the same decision now? *(Please tick ☒ one box only)*

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

52. Is there anything else you would like to share about your decision? */*

53. In your view as someone who has experienced the loss of a family member and been asked to consider donation, what would help other people in the same situation?

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

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

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

PROOF RESEARCH
REPLY PAID 85405
UPPER MT GRAVATT QLD 4122

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

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

3.0 PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Participant Information

About The Project

The project is a national survey with families across Australia who have consented to or declined organ and/or tissue donation in a hospital setting. The research aims to capture the experiences of families during conversations about the death of a family member and the potential for organ and tissue donation. The research seeks to obtain feedback on the support services provided to families throughout the donation process and following donation.

The Organ and Tissue Authority has commissioned Proof Research Pty Ltd for this important research project which is being conducted as part of the Australian Government's National Reform Programme to create a nationally consistent and coordinated approach to organ and tissue donation for transplantation.

The Organ and Tissue Authority is committed to the ongoing improvement of support services available to families. This study is therefore important to determine if current processes and mechanisms are supporting families, and to identify what aspects of services need to be improved.

Families in Australia who made a decision about organ and tissue donation during 2012 and 2013 in a hospital setting are invited to participate in this research project. This invitation is offered equally to families that agreed to donation and families that declined donation.

Participation is voluntary.

Why Participate?

This research provides families with an opportunity to share their experiences and provide feedback about services they found beneficial and those that were not beneficial and could be improved upon, or other services that could be introduced.

The findings will be used to address gaps and improve donor family support services and professional practice. Your contribution will help to improve these important and sensitive services for other families faced with decisions concerning organ and tissue donation in the future.

Factors To Consider

Many families in the past who have participated in the national survey have commented that they have appreciated the opportunity to share their views. Some have said that the process of completing the survey was an emotional one.

We understand that participation in the research may cause some individuals emotional distress when recalling experiences. Throughout any time in the research, should you wish to speak with someone about any issues concerning organ and tissue donation and the death of your family member, please contact the Donateline 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 Donateline and wish to speak with someone about feelings of loss and grief.

Confidentiality

Information collected from this survey will be non-identifiable (meaning your responses will not be linked to your name) and kept confidential. It will only be disclosed with your permission, except as required by law.

To maximise confidentiality:

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

Proof Research will be responsible for collecting and analysing your responses. If any information is published as a result of this research, your feedback will be provided in such a way that you cannot be identified.

If you have any comments or complaints about any aspect of the project, such as the way it is being conducted or any questions about your rights as a research participant, you may contact Eva Mehakovic at the Organ and Tissue Authority by email to eva.mehakovic@donateline.gov.au or by phoning (02) 6198 9881.

Ethics

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) as issued by the National Health and Medical Research Council. The National Statement provides the guidelines by which the Departmental Ethics Committee and other Human Research Ethics Committees operate. The ethical aspects of this research project have been approved by a number of Ethics Committees across Australia.

V2 10/03/16

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.

Donateline donor family support coordinators

ACT	Donateline ACT	Sean Dicks 02 6174 5625
NSW	Donateline NSW	Allison Barnwell 02 8566 1705
NT	Donateline NT	Andrea James 08 8944 1396
QLD	Donateline Qld	Diane Murphy 07 3176 2350
SA	Donateline SA	Lesley Sheffield 08 8207 7117
TAS	Donateline Tas	Verity Shugg 03 6222 7806
VIC	Donateline Vic	Michelle Skinner 03 8317 7411
WA	Donateline WA	David Easton 08 9222 8557
National	Lifeline 24hr Crisis	13 1114

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

V2 10/03/16



Taking part is voluntary

Consent form A (personal interview)

Study of family experiences of organ and tissue donation

As well as the survey, we will be asking a small number of families to take part in a discussion with a researcher from Proof Research. Your name will be kept confidential and your feedback will be used to make sure that donation agencies provide the best possible service and support to families.

The discussion will last for about 1 hour and you can choose a time and place that suits you. With your permission, discussions will be recorded for the purposes of the research. Families will be randomly selected to take part in these discussions.

Would you like to take part?

- ☐ Yes ☐ 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 confirm that you have read and understood the information provided about the study in the Participant Information Sheet and this consent form. If you have ticked 'Yes' above, your signature also confirms that you agree to take part in the study and are aware that your information will not be linked to your name.

Signature _____ Date _____

Please use the reply paid envelope provided to return this form to Proof Research.