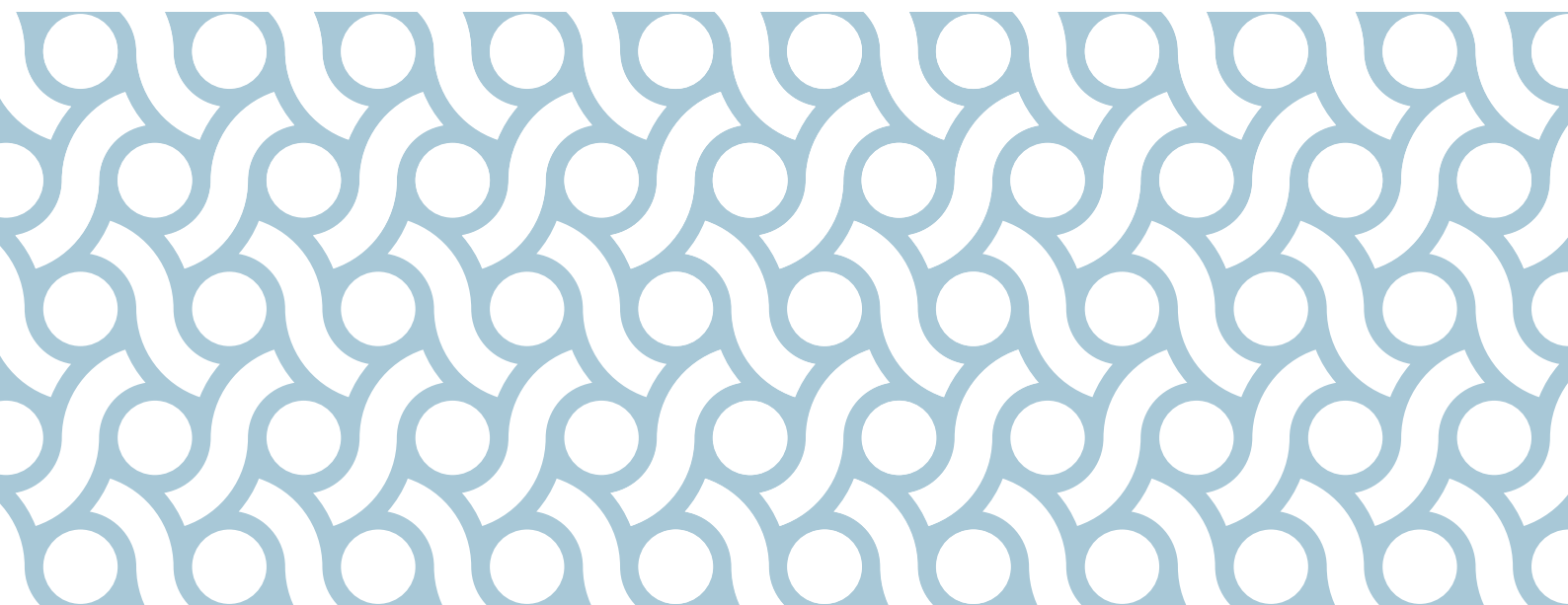


# National Study of **Family Experiences of Organ and Tissue Donation**

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Wave 1 – 2010 and 2011



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



Australian Government  
Organ and Tissue Authority



**Organ and Tissue Authority**

Canberra ACT 2600

PO Box 295 Civic Square ACT 2608

T 02 6198 9800 F 02 6198 9801

E [enquiries@donatelife.gov.au](mailto:enquiries@donatelife.gov.au)

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To access the full report: [donatelife.gov.au](http://donatelife.gov.au)

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## Foreword

This is the first report by the Organ and Tissue Authority (OTA) of the national study of family experiences of organ and tissue donation<sup>1</sup> for transplantation. Previously, similar studies were commissioned by the Australasian Transplant Coordinators' Association (ATCA) and were reported in 1996, 2000, 2004 and 2008 to initiate review and improvement of the care and support provided to Australian donor families.

The OTA was pleased to accept responsibility for the study, at the request of the ATCA, and is conducting the study as part of the Australian Government's national reform programme to implement a world's best practice approach to organ and tissue donation for transplantation.

The OTA will conduct this study as ongoing waves of research that will occur every two years. This report focusses on Wave 1 of the study by the OTA and provides feedback from families who made a donation decision in 2010 and 2011, including families that consented to or declined donation.

I sincerely thank each and every family member who volunteered to participate in this study and share their experience. I appreciate the generosity and strength of these people in recalling this time and sharing their feelings about the quality of care and support they received at such a difficult time of their lives. This feedback is vital so that we can learn from family experiences and ensure that appropriate support is provided in the future.

It is clear in the report that many families feel well supported by hospital and DonatLife staff as they navigate the process of death and donation. While there are some pre-existing factors which can, in part, prepare families for the process of organ and tissue donation the overriding message is that the quality of care, information and support provided are the key determinants of the families' experiences and their assessment of the impact of their donation decision. The report highlights areas where improvement and refinement of that support can still be made. I encourage all professionals involved in the care of organ and tissue donors and their families to read the report and reflect on their own experiences with families, in order to continually improve the support they provide to families.

The results of this study will inform the review of the National Donor Family Support Service (NDFSS) which is offered by the DonatLife Network to Australian donor families. It will also inform future development of the Professional Education Package (PEP) which provides education and training to health professionals to best support families when the opportunity for organ and tissue donation arises.

Again, I would like to thank the family members who shared their experience in this study, and I acknowledge those donors and their families who generously consented to organ or tissue donation.

Ms Yael Cass

Chief Executive Officer  
Organ and Tissue Authority

<sup>1</sup> Refers to organ and tissue donation that occurs after brain death and circulatory death in a hospital, and does not refer to tissue only donation that may occur outside of the hospital setting.

# Summary Report

## Background

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

The purpose of this study was to provide evidence-based insight into families' experiences of the donation process from initial donation conversations through to the follow up support provided to families after a donation decision has been made.

The study aimed to inform improvements in the care and support provided to donor families by:

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

This research builds on similar research undertaken with donor families since 1995, by the Australasian Transplant Coordinators Association (ACTA). The OTA now funds and

manages this research at the request of ATCA, and will undertake ongoing waves of the research to occur every two years.

This Wave 1 of the study by the OTA provides feedback from families who had a donation experience in 2010 and 2011, including families that consented to or declined donation.

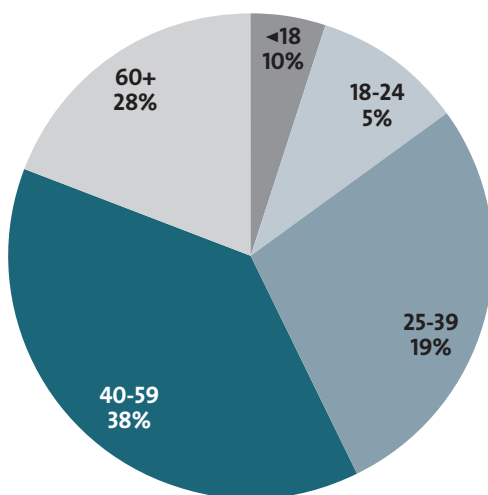
The study commenced in September 2013 and invited 700 Australian families to participate in the study by completing a survey questionnaire and/or participate in a face-to-face interview (including 674 families that consented to donation and 26 families that declined donation).

Of this group, 131 families that consented to donation (185 family members) completed the survey questionnaire. Additionally, a total of 126 family members that had consented to donation agreed to participate in a face-to-face interview. Of these, 28 family members (from different families who had consented to donation) were selected randomly and participated in face-to-face interviews in all states and territories except the Northern Territory.

This study was the first time that families who had declined donation were invited to participate in a national survey of this nature in Australia. A limited number of four states and territories were able to participate in the approach to families that declined donation with 26 of these families contacted. Of this group, one family member agreed to participate in the study and completed a survey questionnaire and agreed to participate in a family interview. An interview was conducted with this person.

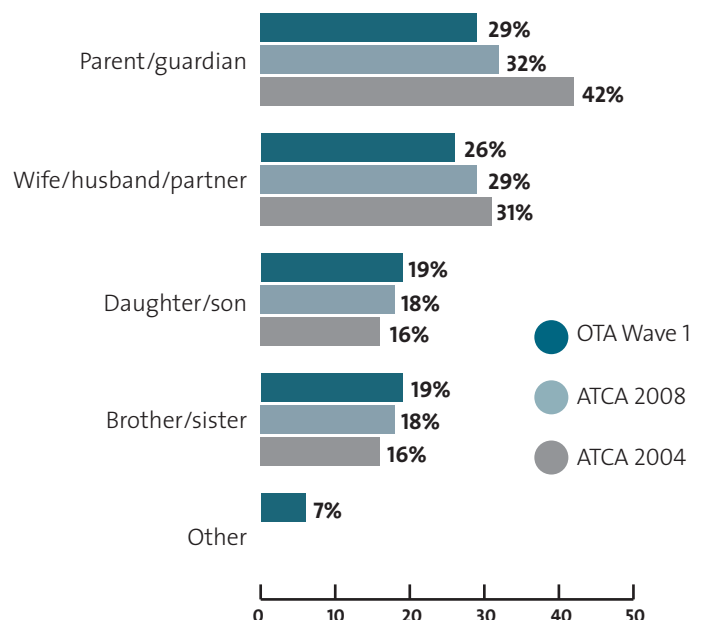
Future waves of the study will aim to invite all families that decline donation to participate in the study so that they have an opportunity to provide feedback and share their experiences.

### Age of Donor



Base: Total sample Wave 1 (n=185);  
2008 (n=159 BD); 2004 (n=131 BD)

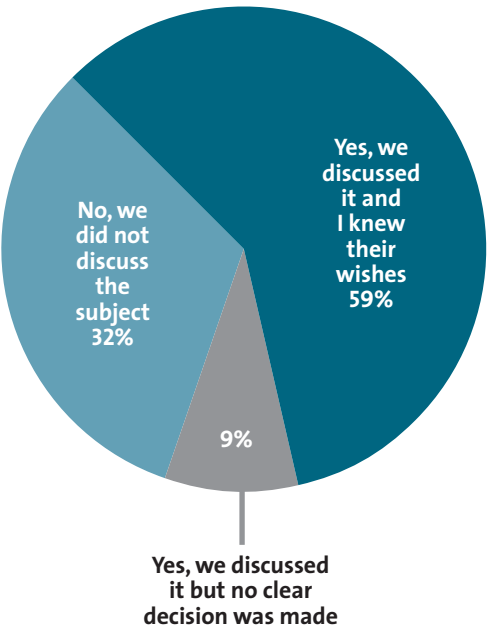
### Relationship to Donor



# Key Findings

## Role of Prior Family Discussion

Approximately six in ten family members (59%) who participated in the study had discussed organ and tissue donation with their family member prior to being asked to consider donation. Families who had discussed organ and tissue donation with each other found the donation decision easier than families who had never had the discussion. In total, 93% of families who had a prior family discussion on donation wishes reported it made their decision easier. In contrast, 17% of those families who had not discussed donation wishes reported it made their decision more difficult.



	Total (n=181)	Discussed and knew wishes (n=109)	Discussed but did not fully know wishes (n=16)*	Did not discuss donation (n=56)
Made our decision a lot easier	57%	84%	19%	14%
Made our decision a bit easier	11%	9%	37.5%	7%
Did not impact on our decision	26%	6%	37.5	62.5%
Made our decision a bit more difficult	5%	1%	6%	12.5%
Made our decision a lot more difficult	1%	–	–	4%

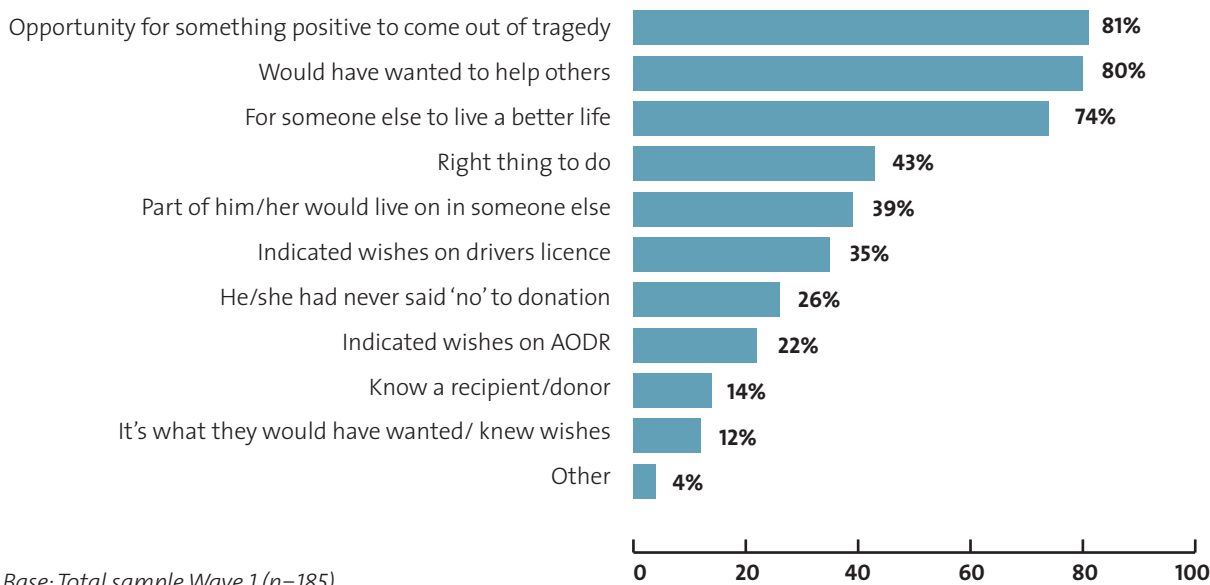
\* Caution: Small base

Note: Highlighted figures are statistically significant results.

## Family Reasons for Donating

The majority of donor families (81%) see organ and tissue donation as a chance for something positive to come out of a tragedy. Other strong motivating factors for donation were that their family member would have wanted to help others (80%) and so that someone else could live a better life (74%).

### Motivations for Donation



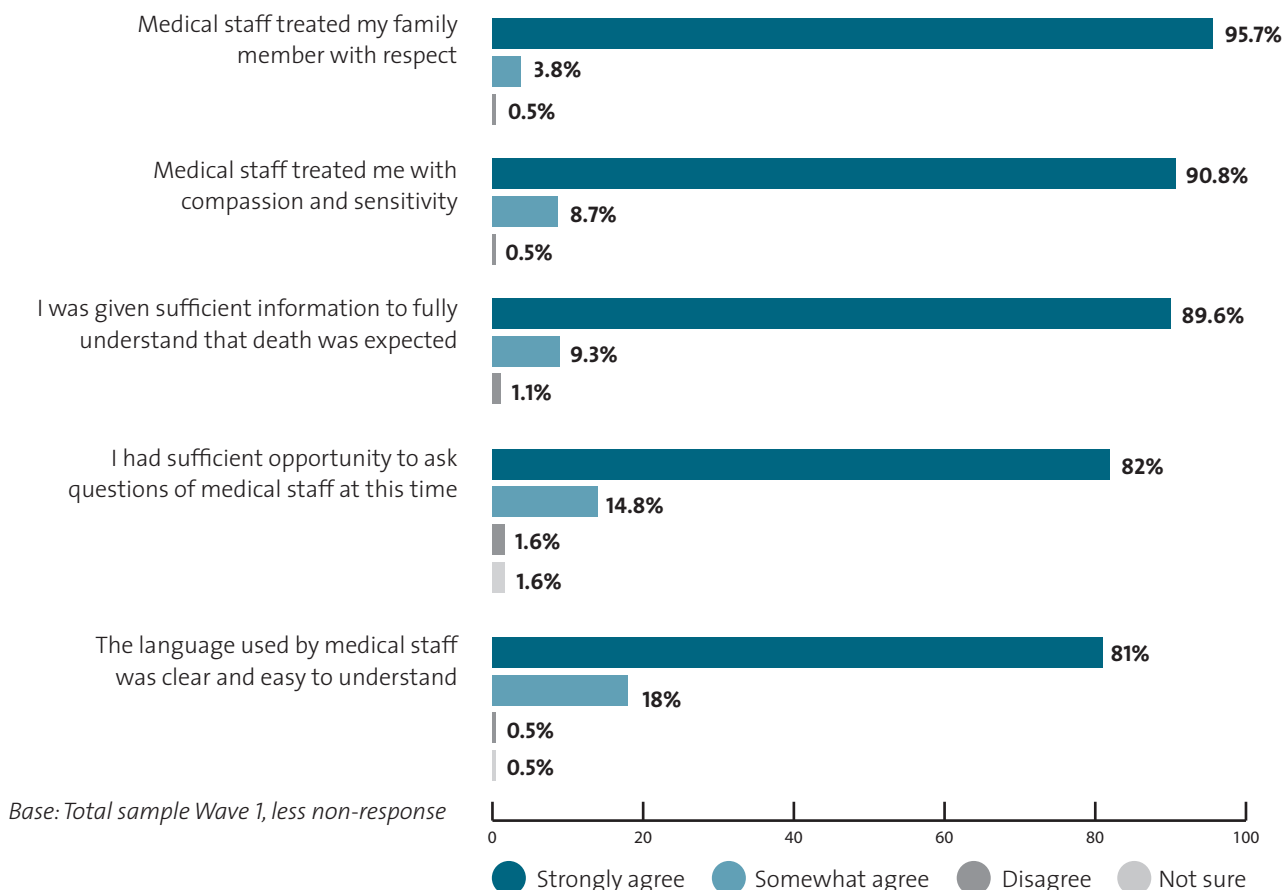
## Support Provided Before, During and After Donation

The majority of donor family members (96%) feel that medical staff treated their family member with respect. Nine in ten donor family members (91%) feel they were treated with compassion and sensitivity during their time at the hospital, prior to consenting to donation.

Whilst ratings are very high, there is some room for improvement around the language used by medical staff (81% strongly agree that the language was clear and easy to understand) and ensuring families have sufficient opportunities to ask questions (82% strongly agree that they had enough opportunities to ask questions of medical staff).

*\*Note – Some responses from families indicate that the term ‘medical staff’ may include doctors, nurses and donation staff.*

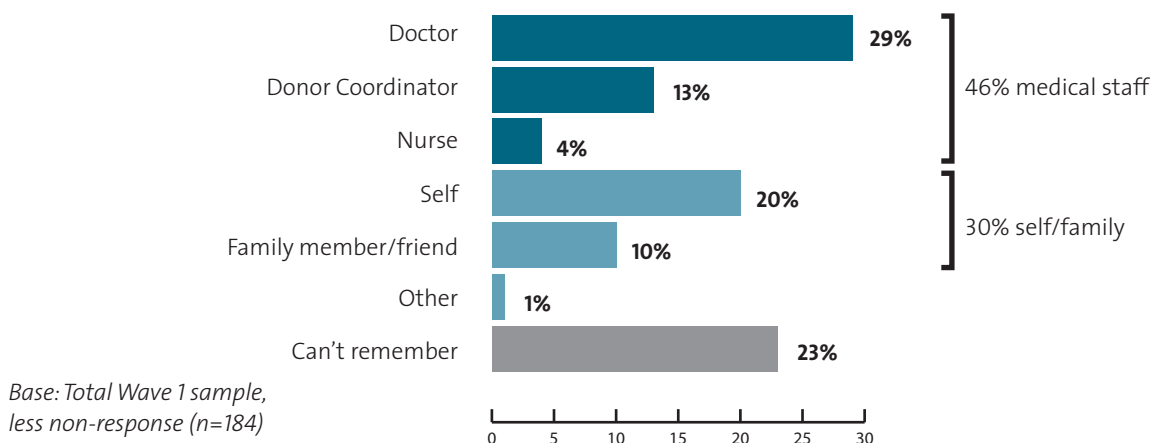
### Treatment by staff



### Raising donation

The possibility of donation is primarily mentioned to families by medical staff (46%). This comprises: doctors 29%; donor coordinators 13%; and nurses 4%.

One in five family members (20%) raise the subject of organ donation with medical staff themselves. In total, the donation topic is raised by the family in 30% of cases.



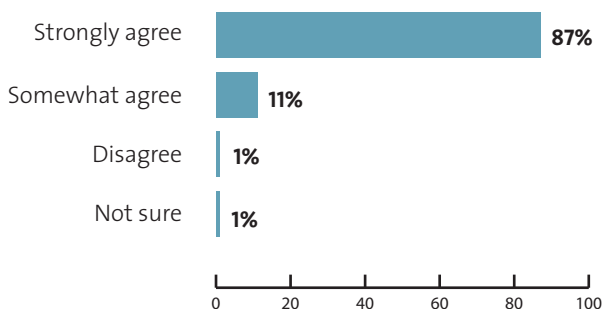


## Family Donation Conversation

Almost all donor family members (98%) agreed that discussions about donation were handled sensitively and with compassion, and 95% of donor family members agreed that they were given sufficient information to make an informed decision about organ and tissue donation.

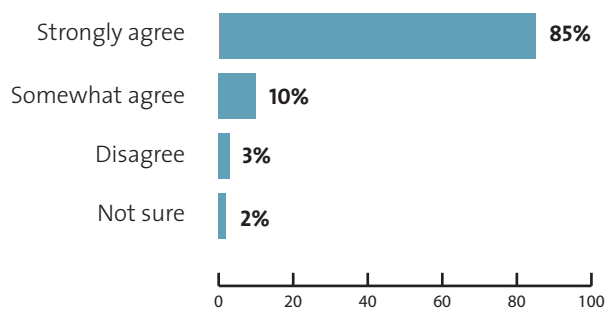
### Agreement/ disagreement with statement:

*Discussions about donation were handled sensitively and with compassion*



### Agreement/ disagreement with statement:

*We were given sufficient information to allow us to make an informed decision*

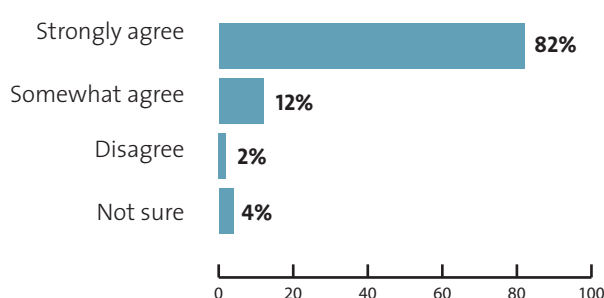


The majority of donor families strongly agree that their family was provided with enough opportunities to ask questions of hospital staff about donation (83%), and that hospital staff answered their questions (83%).

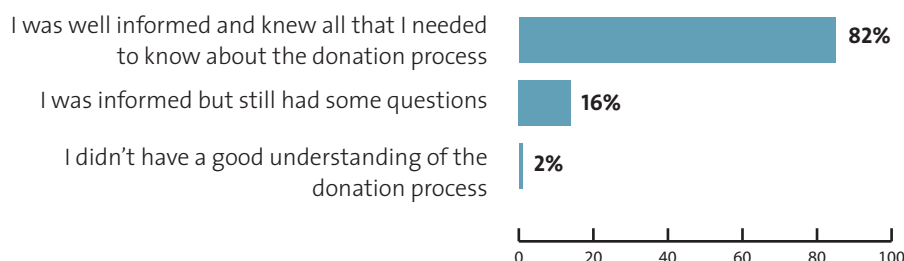
### Agreement/ disagreement with statement:

*My family was given enough time to discuss donation and to make our decision*

While 94% of families in total felt they were given enough time to discuss donation and to make a decision (82% strongly agree), some families felt rushed or pressured to make a decision. It is important to allow families a broad timeframe to make their decision.



*"Which statement best describes your understanding of the donation process after speaking with the donor coordinator / donation nurse or doctor?"*



After meeting with the donor coordinator or donation nurse/ doctor, 82% of donor families felt well informed and felt that they knew all they needed to know about the donation process.

Some families (16%) still had unanswered questions, while a further 2% of families left the meeting with no clear understanding of the donation process.

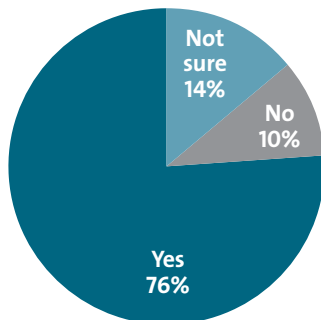
## Family Support Services

### Support Offered to Families

Just over 3 in every 4 donor family members (76%) were offered the support of a social worker, counsellor or chaplain at some time during their family member's stay in hospital. In 85% of cases, families were offered ongoing contact with staff from the hospital or organ and tissue donation agency, following donation.

#### During Family Member's Stay in Hospital

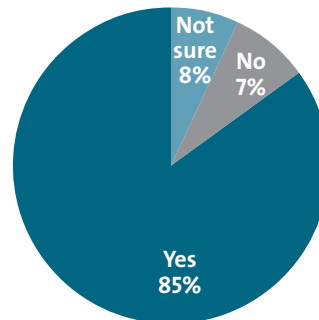
*"Were you offered the support of a social worker, counsellor or chaplain at any time during your family member's stay in hospital?"*



Base: Total sample Wave 1, less non response (n=183)

#### Following Donation

*"Were you offered any ongoing contact with staff from the hospital or organ and tissue donation agency, for example, a social worker, chaplain or donor coordinator / donation nurse or doctor?"*

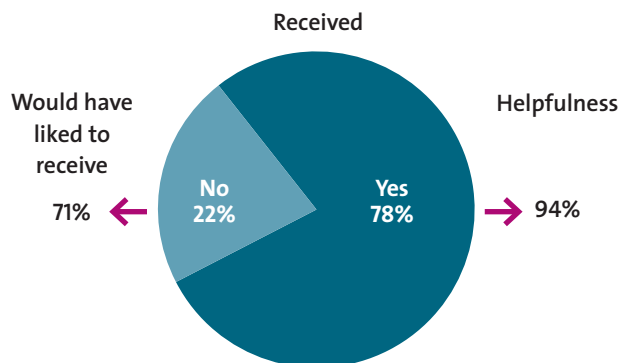


Base: Total sample Wave 1, less non response (n=182)

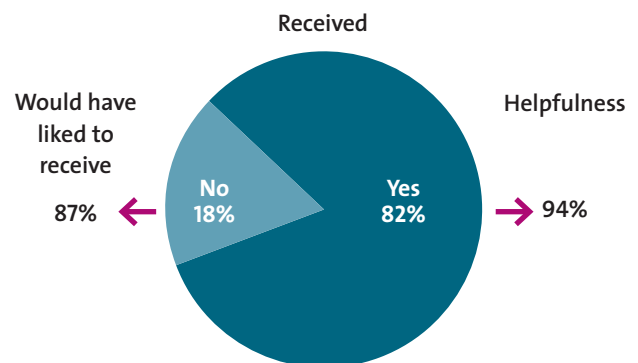
### Services Received / Would Like to Have Received

The study reported the services that were received by donor family members and whether they found those services helpful. It also reported whether the family members who did not receive each service would have liked to.

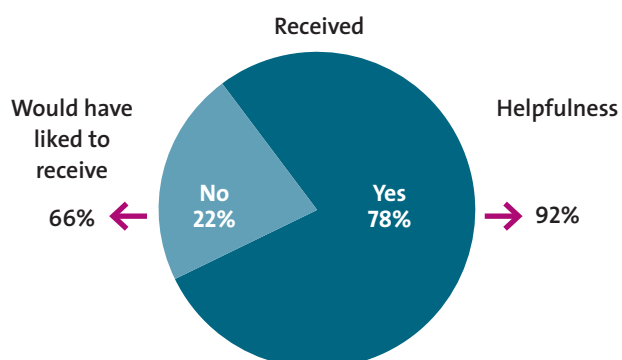
#### A follow up phone call from the donor coordinator / donation nurse or doctor



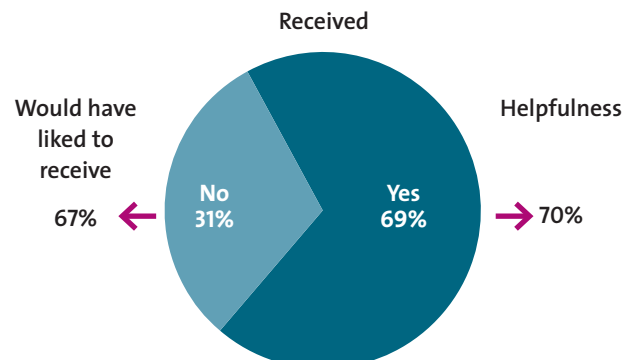
#### Basic information about the transplant recipients



#### Follow up from the donor family support coordinator



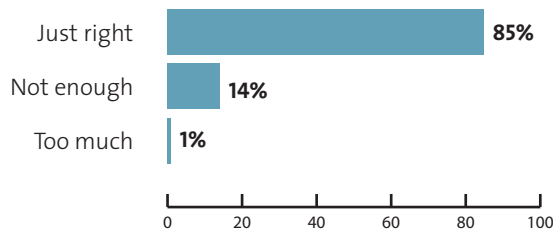
#### Information about bereavement support services in your area



Base: Total sample Wave 1, less non response (n=176)

### Level of Contact With Donation Agency Staff

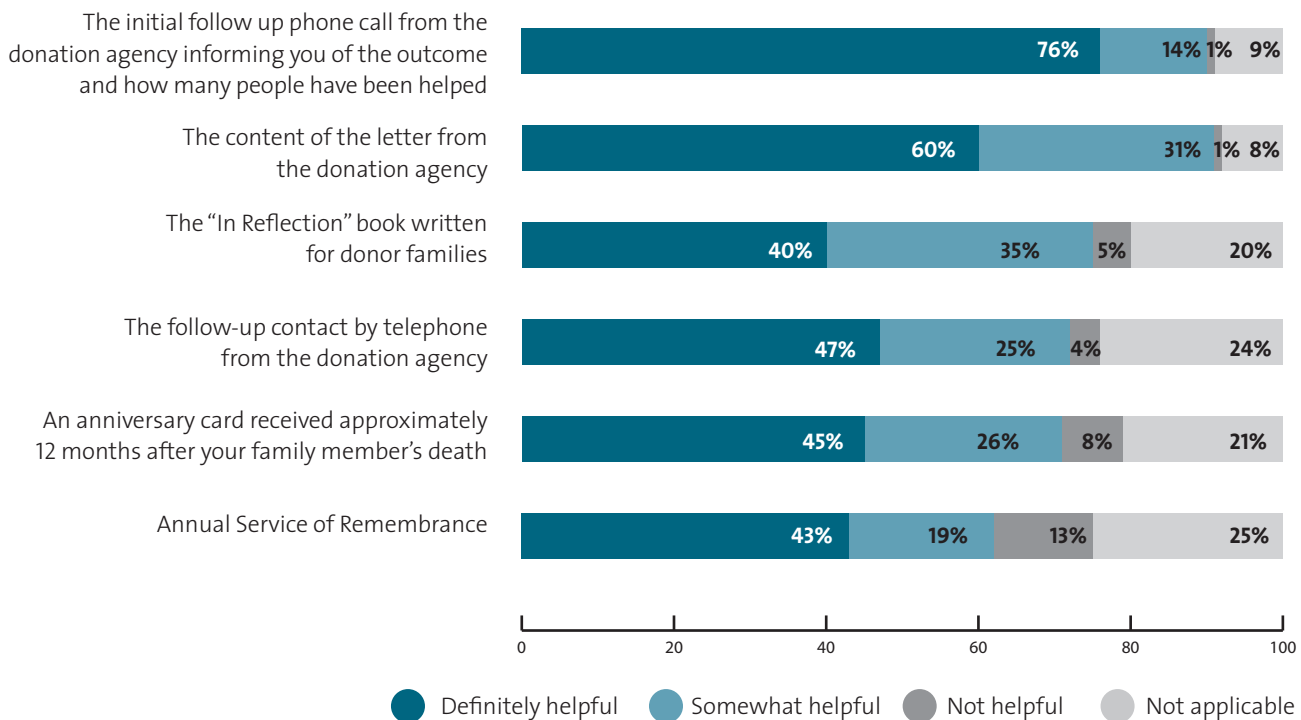
Most donor family members (85%) feel the contact they have had with donation agency staff has been at the right level. A small group of family members (14%) would have liked more follow-up contact after donation.



Base: Total sample Wave 1, less non response (n=177)

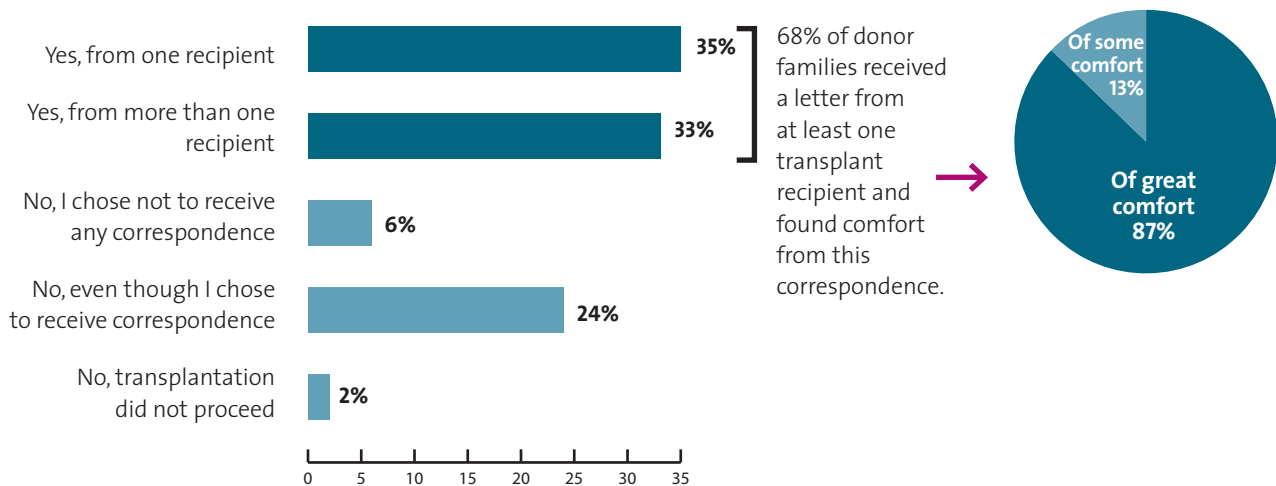
### Helpfulness of Support Provided

Donor family members appreciated the range of support services provided, with the majority of family members (90%) finding the initial follow-up phone call from the donation agency to be the most helpful. When asked about other support services that could be offered, donor family members expressed a desire to have more information about recipients post transplant.



Base: Total sample Wave 1, less non response  
Base sizes vary by type of support (n=170 to n=175)

## Deidentified Contact with Recipients



Base: Total Wave 1 sample of unique donor families, less non response (n=125)

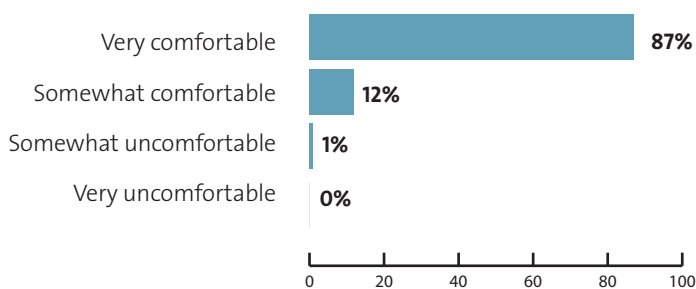
Base: Families who have received correspondence from at least one recipient, less non response (n=84)

Approximately seven in every ten donor family members (68%) received a deidentified letter from at least one transplant recipient. This letter provided great comfort to these family members.

One quarter of donor family members (24%) had not received any correspondence from recipients, even though they chose to.

## Level of Comfort with Donation Decision

Almost all of the donor family members who participated in the study (99%) are comfortable with the decision to donate their family member's organs and/or tissues, with 87% being very comfortable with this decision.

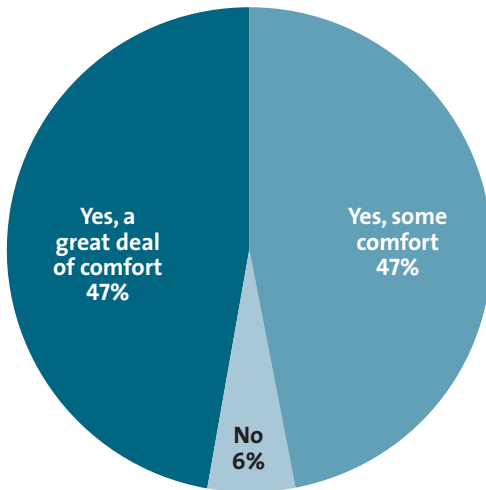


Base: Total sample Wave 1 (n=185)

## The Impact of Donation

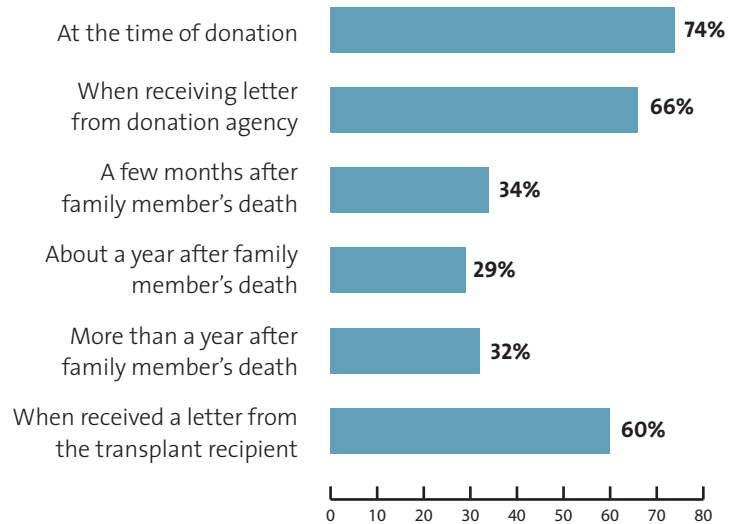
The majority of donor family members report that donation provided them with comfort in their loss (94%). Of these, 74% said they found comfort in the donation at the time of donation, and at other milestones after the donation. These responses show that organ and tissue donation can provide immediate and longer term comfort.

*Has donation provided you any comfort in your loss?*



Base: Total sample Wave 1, less non response (n=180)

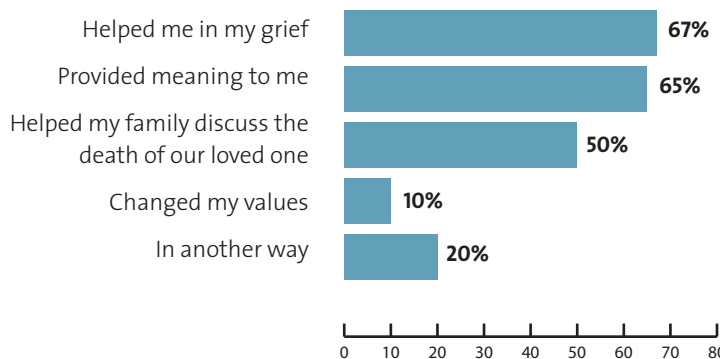
*When have you found comfort in the donation*



Base: Those who found comfort in the donation (n=170)  
Multiple response

## Comfort Provided by Donation

Donor family members say that donation has helped them in their grief (67%), provided meaning to them (65%) and helped their family to discuss the death of their loved one (50%)



Base: Those who found some comfort in donation (n=170)  
Multiple response

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*"I feel entirely satisfied with the decision and even a little proud of it." 2011*

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The following report was submitted by Proof Research to the Organ and Tissue Authority providing outcomes of the national study of family experiences of organ and tissue donation for transplantation.

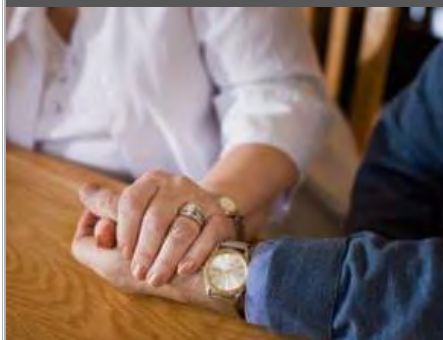






KNOW HOW. KNOW MORE.

# NATIONAL STUDY OF FAMILY EXPERIENCES OF ORGAN AND TISSUE DONATION WAVE 1: EXPERIENCES IN 2010 AND 2011 - RESEARCH REPORT -



Prepared for:  
Organ and Tissue Authority



Prepared by:  
Rhonda McLaren  
& Silvia Munoz  
Proof Research Pty Ltd

Tel: (07) 3392 4446  
Level 1, 48 Wharf Street  
BRISBANE QLD 4169



# Part A – Research Overview

## 1.0 RESEARCH BACKGROUND

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In 1995, the Australasian Transplant Coordinators Association (ATCA) initiated its first survey of donor family perceptions of the quality of care they received from health professionals during and after their donation experience. The survey was designed to provide information and evidence to inform and improve professional practice.

ATCA continued to conduct the survey on a four yearly basis in 1996, 2000, 2004 and 2008, with families who had agreed to organ donation in 1994, 1998, 2002 and 2006 respectively. Following an approach by ATCA to the Organ & Tissue Authority (OTA) in March 2012, OTA agreed to fund and coordinate the donor family survey.

Since the study first commenced in 1995, a number of developments have occurred in the organ and tissue donation sector in Australia. In 2009 the 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. A variety of measures have been implemented which include enhanced support for donor families, increased capability and capacity within the health system to maximize donation rates and to raise community awareness and stakeholder engagement across Australia to promote organ and tissue donation.

OTA appointed Proof Research to conduct Wave 1 of the research, representing families who agreed to organ and/or tissue donation in 2010 and 2011. Similarly to the 2008 study, the target population for Wave 1 includes families who have experienced either donation pathways, specifically donation after brain death and donation after circulatory death.

In addition, Wave 1 of the national study was the first time that families who *did not* consent to organ and/or tissue donation were included. Wave 1 also differed from previous studies by:

1. Providing an online survey option in addition to a hardcopy postal survey.
2. Including a qualitative strand, involving face-to-face in-depth interviews with families.

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*Wave 1 of the National Donor Family Study explored all aspects of the donation process and experiences in depth, allowing a profound insight into donor family experiences.*

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## 2.0 RESEARCH OBJECTIVES

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The overall aim of this research study was to:

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*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 was 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

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### 3.1 RESEARCH METHOD - CONSENTED TO DONATION

A mixed methodology research program, with quantitative and qualitative strands, was designed to address the aim and objectives of Wave 1 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) submission and approval process
- Stage 4: Fieldwork including quantitative and qualitative research
- Stage 5: Analysis and reporting

#### 3.1.1 STAGE 1: INCEPTION MEETING AND PROJECT SET UP

At the outset of the project, introductory meetings between OTA, Proof Research, and the Donor Family Support Implementation Group (DFSIG)<sup>1</sup> were set up so Donor Family Support Coordinators (DFSCs) and key team members from OTA and Proof Research could meet and discuss the study. Proof Research presented the proposed research methodology, and through a consultative process with OTA and the DFSCs, the research program was confirmed to proceed.

#### 3.1.2 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 DFSIG, the instruments were amended in light of feedback received and finalised before distribution. The final set of research instruments used includes:

- Participant Information Statement (PIS).
- Consent Form A (for participation in the survey) and Consent Form B (for participation in a face to face interview).

---

<sup>1</sup> The Donor Family Support Implementation Group (DFSIG) is a forum in which all Donor Family Support Coordinators (DFSCs) come together with OTA and a representative from the Australasian Transplant Coordinator Association (ACTA), to discuss the implementation, monitoring and review of the Donor Family Support Service across Australia.

- Questionnaires:
  - For families that consented to organ and/or tissue donation.
  - For families that declined organ and/or tissue donation.
- Discussion Guides for use in the in-depth personal interviews:
  - With families that consented to organ and/or tissue donation.
  - With families that declined organ and/or tissue donation.



The Human Research Ethics Committee (HREC) approved survey instruments and consent forms are included at the end of this report, from page 77 onwards.

### 3.1.3 STAGE 3: HUMAN RESEARCH ETHICS COMMITTEE SUBMISSION PROCESS

Prior to commencing the fieldwork, an extensive consultation and submission process for ethics approval was carried out. As the national study involved families across a range of jurisdictions, a number of state/territory-based ethics committees were consulted to determine the correct requirements and submission process. One of the first submissions made during this stage involved submitting the National Ethics Application Form (NEAF) to the Department of Health and Ageing (DoHA)<sup>2</sup> Departmental Ethics Committee.

The NEAF was submitted, together with copies of the research tools. The latter included a Participant Information Statement (PIS), Consent Forms, Questionnaires and Discussion Guides (see STAGE 2 for further details regarding the research instruments). After addressing various queries from DoHA, approval by the ethics committee was granted. A number of state/territory and institution-based lead HRECs were also consulted according to the jurisdictions for the DonateLife Agencies across Australia. An outline of the HRECs the project team liaised with and attained ethics approval from is provided below.

- Australian Red Cross Blood Service Ethics Committee [*national & VIC*]
- South Australia Department of Health Human Research Ethics Committee [*SA*]
- The Royal Adelaide Hospital - Research Governance, Intellectual Property & Contracts Office [*SA*]

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2 Under the Administrative Arrangement Order of 18 September 2013, this Department is now named the Department of Health.

- ACT Health Human Research Ethics Committee - Survey Resource Group [ACT]
- Northern Territory Central Australian Human Research Ethics Committee [NT]
- Human Research Ethics Committee for the Northern Territory Department of Health and Menzies School of Health Research [NT]
- Tasmania Social Sciences Human Research Ethics Committee [TAS]
- South Eastern Sydney Local Health District - Human Research Ethics Committee [NSW]
- Queensland Health Office of Health & Medical Research, Human Research Ethics Committee (Public Health Application) [QLD]
- Government of Western Australia, Department of Health, Sir Charles Gairdner Hospital, Department of Research [WA].

In addition to the committees listed above, the project team also consulted the NSW Population and Health Service Research Ethics Committee, the NSW Ministry of Health (Office of Health and Medical Research), Victoria Department of Health and Department of Human Services HREC and the Government of Western Australia, Department of Health HREC.

#### 3.1.4 STAGE 4: FIELDWORK

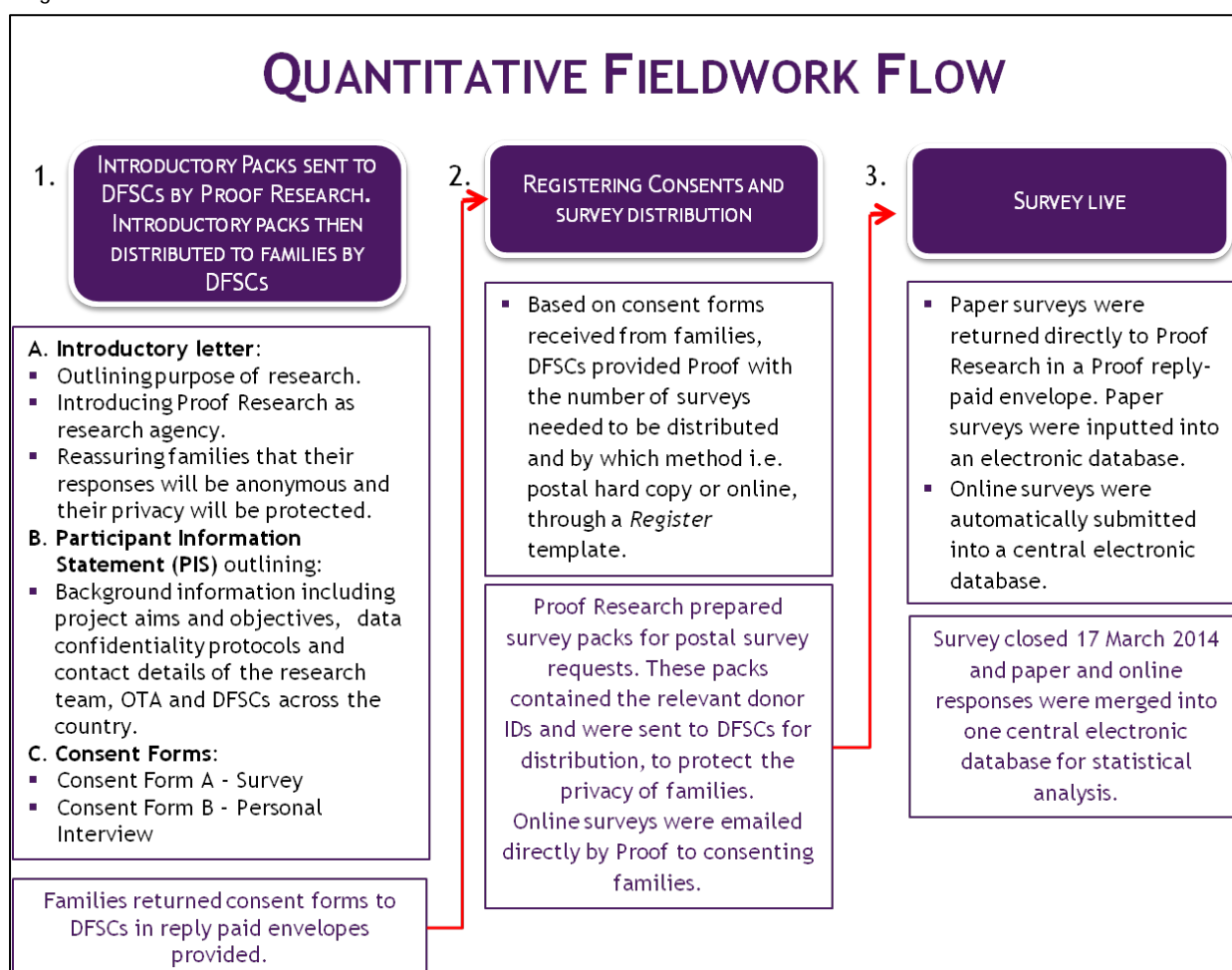
The fieldwork comprised two strands of research activities:

- Quantitative
- Qualitative

##### *Quantitative Fieldwork*

A summary of each main research activity for the quantitative fieldwork is provided in Figure 1.

Figure 1: Quantitative fieldwork flow chart



Firstly, *introductory* packs were prepared by Proof Research and distributed to DFSCs for postage to donor families in the target population. The packs contained:

- Introductory letter from OTA
- Participant Information Statement (PIS)
- Consent Form A (Survey) and Consent Form B (Personal Interview)
- A reply paid envelope for families to return consent forms to the DonatLife Agency in their state or territory.

Each pack was coded with a unique identifier. Each unique ID was matched to a donor family contact in the DonatLife Agency database, therefore allowing each DFSC to identify the correct postal details for each pack. At no point were the contact details of families shared with Proof Research. Unique IDs were the main identifiers used to initially distribute the packs and later distribute survey instruments, maximising family anonymity and data confidentiality throughout the entire project.



The date that each introductory pack was dispatched to DFSCs throughout Australia is shown in Table 1.

Table 1: Sample frame

STATE / TERRITORY	TOTAL NO. OF INTRODUCTORY PACKS DISPATCHED BY PROOF TO DFSCs	DATE POSTED BY PROOF RESEARCH
ACT	16	09/08/2013
NT	6	09/08/2013
TAS	16	09/08/2013
VIC	241	12/08/2013
SA	70 + 9	12/08/2013 and 21/08/2013
QLD	143 + 121	Hand delivered: 15/08/2013 and 22/08/2013
NSW	356	20/08/2013
WA	62 + 17	23/10/2013 and 29/10/2013
<b>TOTAL</b>	<b>1,057</b>	

As shown above, introductory packs were sent to all States/Territories except Western Australia during August 2013. Packs for Western Australia were distributed during October 2013, in accordance with the timings and requirements outlined by the ethics committee for that jurisdiction.

The first set of consent forms from donor families were returned to DFSCs in August 2013. The DFSCs then used a *Register of Contacts* to record the consent form information including:

- Whether the person consented to, or declined, to participate in the survey and/or personal interviews.
- The preferred method of completing the survey i.e. paper copy or online.
- The number of surveys required (e.g. 3 paper copies, 2 online surveys).
- Email addresses of individuals for the online survey.
- Contact details of participants consenting to take part in a personal interview.

The *Register of Contacts* was submitted to Proof Research at regular intervals. Consent forms continued to be received during the next 6 months, with the last consent form received on 12 March 2014.

In line with consent forms received, the Proof Research team prepared *survey* packs for postal survey requests, each coded with a unique ID to maximise the privacy of families and allow DFSCs to distribute the packs to the correct families. These packs were then sent to the DFSCs for postage to donor families. Distribution of the survey packs occurred between September 2013 and March 2014.

Families who chose to take part in the research via an online survey were sent a covering email containing the survey link. This was sent directly to consenting families by Proof. In order to provide families with sufficient time to respond and submit a completed questionnaire, a specific closing date was not put in place.

Reminder emails were sent to families that had consented to take part in the online survey. The survey was live between 12 September 2013 and 17 March 2014.

The confidentiality of online survey respondents was guaranteed. Respondents were assured that their responses would not be reported on individually, but rather used in the calculation of aggregate-level estimates. To further protect the privacy of online respondents, survey responses have been de-identified and are not stored with participants contact details or unique ID number.

### *Qualitative fieldwork*

Face-to-face in-depth interviews with families that consented to participate in a personal interview (i.e. Consent Form B) were conducted by Proof Research. Interviews were conducted with families across Australia (with the exception of Northern Territory)<sup>3</sup>, at a time and place that suited the family. Rhonda McLaren, Director of Proof Research, carried out all interviews, with the interview length averaging 60 minutes.

Face-to-face interviews were conducted between 18 October 2013 and 15 February 2014. With the permission of families, the interviews were recorded for transcription and analysis purposes.

### **3.1.5 STAGE 5: ANALYSIS AND REPORTING**

All fieldwork closed on 17 March 2014. Hard copy questionnaires and online responses were then merged into one central electronic 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.

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<sup>3</sup> No donor families in Northern Territory consented to take part in the research.

All personal interviews were transcribed and full content analysis on each was carried out.

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

### 3.2 RESEARCH WITH FAMILIES WHO DECLINED DONATION

For the first time, families who did not consent to organ and/or tissue donation were included in Wave 1 of the study. It was considered important to provide families who declined donation with the same opportunity to share their experiences as those families who consented to donation.

Four States/Territories participated in this strand of research. These were Tasmania, Australian Capital Territory, Northern Territory and South Australia. The quantitative and qualitative fieldwork with declining families was conducted using the same process as that outlined earlier (see 3.1 RESEARCH METHOD, STAGE 4).

The only additional component for these families was the inclusion of a letter from the hospital in which their donation experience occurred, sent with their introductory pack.

This additional step was taken to ensure confidentiality of records and to protect the privacy of the family. The letter was printed on hospital letterhead and signed by the Director of the Intensive Care Unit (ICU) of the participating hospital. The hospitals that participated in this strand were:

- The Royal Hobart Hospital
- Canberra Hospital
- The Royal Darwin Hospital
- The Royal Adelaide Hospital

### 3.3 SAMPLE SIZE - CONSENTED TO DONATION

#### 3.3.1 QUANTITATIVE

All families that consented to organ and/or tissue donation in a hospital setting during 2010 and 2011 were invited to participate in Wave 1. This represented a total of 674 families and 1,032 individual family members. It was left to the discretion of the DFSCs whether invitations were sent to one person in a family (i.e. a main contact who could then liaise with other family members regarding participation in the study), or whether individual invitations were sent to multiple family members registered on the DonatLife database.

A total of 168 families consented to participate in the survey, with 278 family members requesting individual surveys. Over half of family members (58%) requested an **online survey**; the remaining 42% opting to complete a **paper questionnaire**.

The final sample for Wave 1 comprises **185 family members from 131 donor families**. The distribution of the sample across States and Territories (Table 2) is in line with the distribution of the donor family population, with New South Wales/Australian Capital Territory representing the highest number of responses (41 donor families, 60 family members), equivalent to nearly a third of the donor family sample (31%). The second largest cohort of donor families is found in Queensland (29%), with 38 donor families and 46 family members participating in the survey.

Table 2: Quantitative sample overview by state/territory

STATE/TERRITORY	TARGET POPULATION		CONSENTING POPULATION		PARTICIPATING POPULATION	
	TOTAL NO. OF DONOR FAMILIES	TOTAL NO. OF FAMILY MEMBERS	TOTAL NO. OF DONOR FAMILIES	TOTAL NO. OF FAMILY MEMBERS	TOTAL NO. OF DONOR FAMILIES	TOTAL NO. OF FAMILY MEMBERS
NSW	147	336	49	83	36	54
ACT	16	16 <sup>4</sup>	6	11	5	6
VIC	241	241 <sup>4</sup>	33	58	25	40
TAS	16	16	8	18 <sup>5</sup>	7	12
QLD	126	269	44	63	38	46
SA	61	70	16	31	14	20
NT	6	6	-	-	-	-
WA	61	78	12	14	6	7
<b>TOTAL</b>	<b>674</b>	<b>1,032<sup>6</sup></b>	<b>168</b>	<b>278</b>	<b>131</b>	<b>185</b>

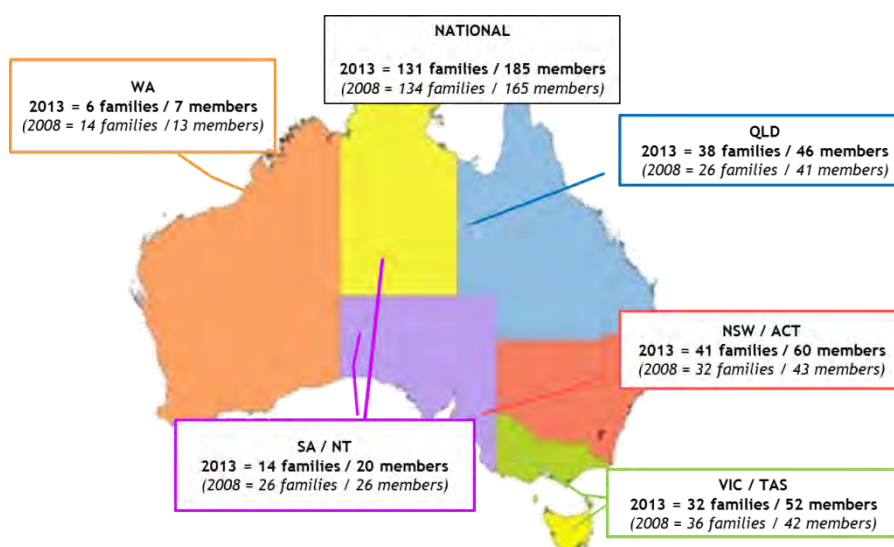
Compared to the 2008 research, a slightly lower number of donor families participated in Wave 1 (134 donor families in 2008, compared to 131 in Wave 1), although a greater number of individual *family members* participated in Wave 1 (185 family members compared to 165 in 2008). Including multiple family members is important as it ensures a range of experiences is included. A comparison of samples across States and Territories is shown in Figure 2.

<sup>4</sup> DFSCs for ACT and VIC decided to send the correspondence to one main contact per donor family.

<sup>5</sup> In Tasmania, two families indicated they each had five family members wishing to participate in the study. This means the total number of consenting family members is greater than the target population for this State.

<sup>6</sup> During fieldwork, DFSCs came across cases where introductory packs were unable to be delivered for a number of different reasons (including family member had moved addresses; no further correspondence was requested etc.). The figure is based on the updated *Register of Contacts* records provided by DFSCs.

Figure 2: Quantitative sample national breakdown



In terms of the year-of-donation breakdown, 41% of families consented to donation in 2010; the remaining 59% in 2011.

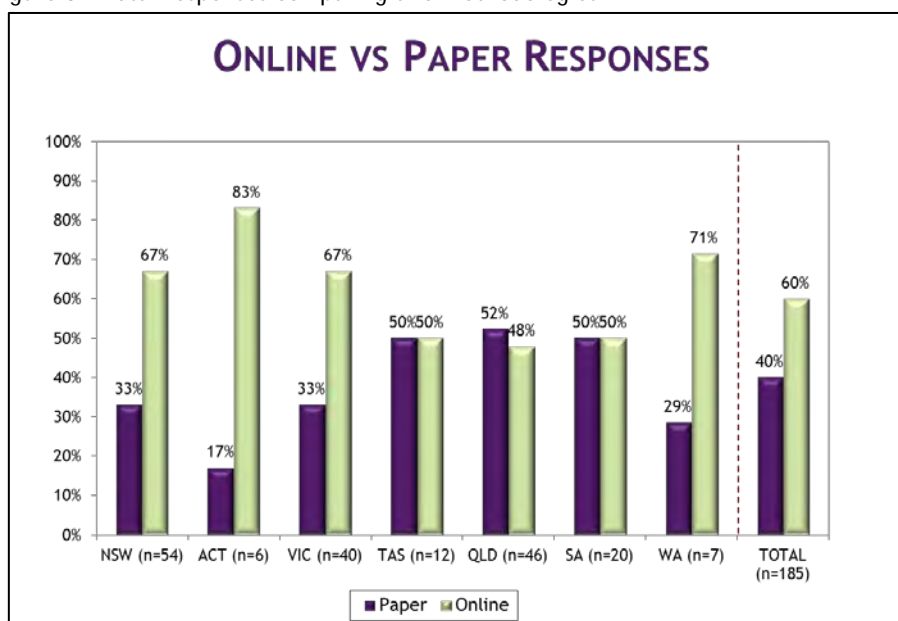
Table 3: Total number of donor families by state/territory and year of donation

STATE/TERRITORY	CONSENTED TO DONATION	
	2010	2011
NSW	13	23
ACT	2	3
VIC	9	16
TAS	4	3
QLD	14	24
SA	8	6
NT	0	0
WA	4	2
<b>TOTAL</b>	<b>54 (41%)</b>	<b>77 (59%)</b>

### *Paper vs. online responses*

Overall, online surveys achieved a higher response rate compared to paper surveys. Sixty percent of family members completed an online survey (equivalent to 111 individuals), with the remaining 40% completing a paper survey (i.e. 74 individuals). Online completions were particularly popular in ACT (83% online), WA (71% online), NSW (67% online) and VIC (67% online).

Figure 3: Total responses comparing two methodologies



### *Donation after circulatory death and brain death donors*

Consistent with the 2008 study, families that consented to donation after their family member was declared brain dead (BD) and those where donation followed circulatory death (DCD), were included in the research.

Table 4: Number of donor families, split by DCD and BD, by state/territory

STATE/TERRITORY	ATCA 2008		OTA WAVE 1	
	DCD	BD	DCD	BD
NSW/ACT	2	30	4	37
VIC/TAS	1	35	2	30
QLD	-	26	7	31
SA/NT	3	13	1	13
WA	-	14	-	6
<b>TOTAL NO. INDIVIDUAL FAMILIES</b>	<b>6</b>	<b>128</b>	<b>14</b>	<b>117</b>

### 3.3.2 QUALITATIVE - PERSONAL INTERVIEWS

A total of 126 donor family members agreed to participate in a personal interview. Of these, 28 people (representing 28 different families) were randomly selected and interviewed face-to-face, with each interview averaging 60 minutes in length.

A summary of the qualitative sample structure is shown in Table 5.

Table 5: Qualitative sample of consenting donor families, by state/territory, year of donation and pathway

	TOTAL NO. OF CONSENTING FAMILY MEMBERS	NO. OF FACE-TO- FACE INTERVIEWS CONDUCTED		YEAR OF DONATION		TOTAL INTERVIEWS FOR EACH STATE/TERRITORY
		BD	DCD	2010	2011	
NSW	37	3	3	3	3	6
ACT	6	2	-	1	1	2
VIC	19	5	1	1	5	6
TAS	8	2	-	1	1	2
QLD	37	5	1	3	3	6
SA	11	1	2	-	3	3
NT	-	-	-	-	-	-
WA	8	2	1	1	2	3
NATIONAL	126	20	8	10	18	28

### 3.4 SAMPLE SIZE - DECLINED DONATION

Across the four participating States/Territories in this strand of research, a total of **26 families** were invited to participate in the study. All families had declined organ and/or tissue donation in 2010 or 2011 within one of the participating hospitals listed earlier in Section 3.2.

Table 6: Sample frame - declined families

	TOTAL NO. FAMILIES
ACT	9
TAS	6
SA	5
NT	6
TOTAL	26

One family responded to the survey and also participated in an in-depth interview (bringing the number of face to face interviews completed to 29). The insight gathered through this family has been valuable in gaining an understanding of the experiences of families that declined donation. However, feedback from more families is required to fully understand their experiences and barriers to donation.

*We encourage the inclusion of families that declined donation in future studies so that all families that are faced with the donation decision have a national channel in which to provide feedback and share their experiences.*

### 3.5 ANALYTICAL NOTES

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

- The analysis throughout this report is primarily based on individual responses, consistent with 2008 and 2004 reporting. Where it makes more sense to report on the views of a unique family unit rather than family members *within* that unit, we have done so and this has been noted.
- Where possible, findings from Wave 1 are compared and contrasted against the findings from the 2004 and 2008 studies. The questionnaire for Wave 1 was however, altered somewhat from questionnaires used in previous studies with the aim of providing greater sensitivity and levels of measurement in the findings. For example, questions that were previously measured with a “yes/no” response were replaced with a positively biased “agree/disagree” scale.
- Throughout this report, statistically significant differences are noted for sub-groups of the sample with this  symbol.

### 3.6 RESPONSE RATES

As shown in Table 7, not all families that consented to participate in the research went on to complete the survey. One quarter of families (25%) consented to participate and 78% of these families went on to complete the survey. This means that one in five donor families (22%) gave their consent to participate but did not actually take part in the research.

Table 7: Response rates by state/territory

STATE/ TERRITORY	UNIQUE DONOR FAMILIES			DONOR FAMILY MEMBERS		
	FROM REQUEST TO CONSENT	FROM CONSENT TO PARTICIPATION	FROM REQUEST TO PARTICIPATION	FROM REQUEST TO CONSENT	FROM CONSENT TO PARTICIPATION	FROM REQUEST TO PARTICIPATION
NSW	33%	73%	25%	25%	65%	16%
ACT	38%	83%	31%	69%	55%	38%
VIC	14%	76%	10%	24%	69%	17%
TAS	50%	88%	44%	113% <sup>7</sup>	67%	75%
QLD	35%	86%	30%	23%	73%	17%
SA	26%	88%	23%	44%	65%	29%
NT	0%	0%	0%	0%	0%	0%
WA	20%	50%	10%	18%	50%	9%
<b>TOTAL</b>	<b>25%</b>	<b>78%</b>	<b>19%</b>	<b>27%</b>	<b>67%</b>	<b>18%</b>

<sup>7</sup> In Tasmania, the total number of consenting family members is more than the target population for this State, therefore achieving a response rate of over 100%. See Table 2 for further details.



Reasons for this drop-out rate cannot be determined with the data available, however feedback provided by some families suggest that the task of completing a questionnaire was emotionally too difficult.

*“I am aware that my eldest son responded to the online questionnaire months ago and I admire and respect his courage in doing so. Unfortunately the remaining family members and I have endeavoured to complete the survey on a number of different occasions but find the task too emotionally challenging at this point in our bereavement journey.*

*Thank you for your understanding and acceptance of our decision not to proceed with the National Survey.”*

2011

### 3.7 SAMPLE STRUCTURE

#### 3.7.1 RELATIONSHIP AND AGE

Figure 4 shows the relationship of respondents to donors compared with the 2004 and 2008 findings, while Figure 5 shows the age of donors.

Figure 4: Relationship to donor

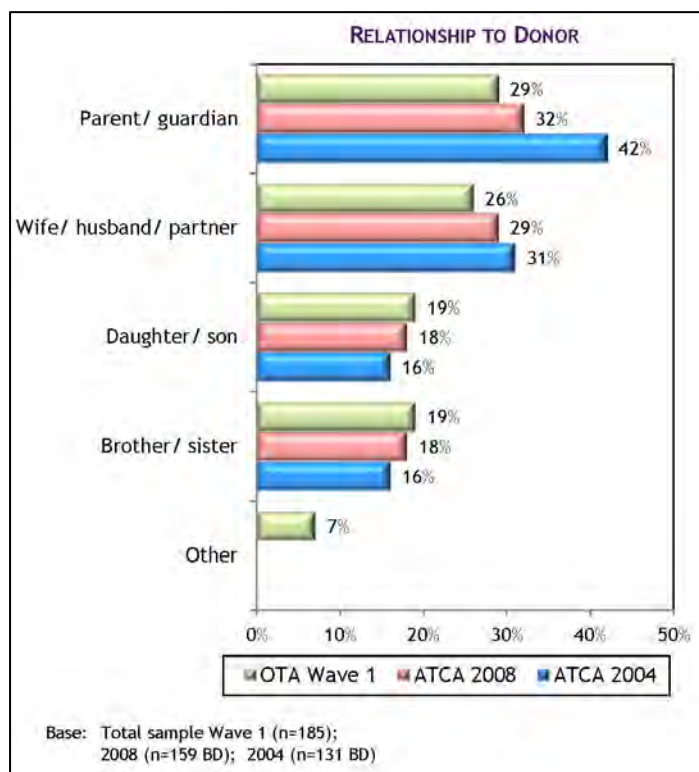
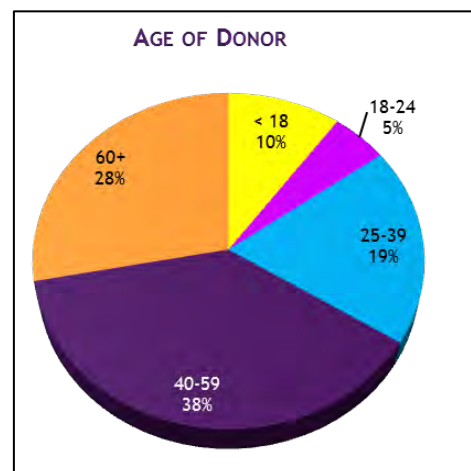


Figure 5: Age of donor



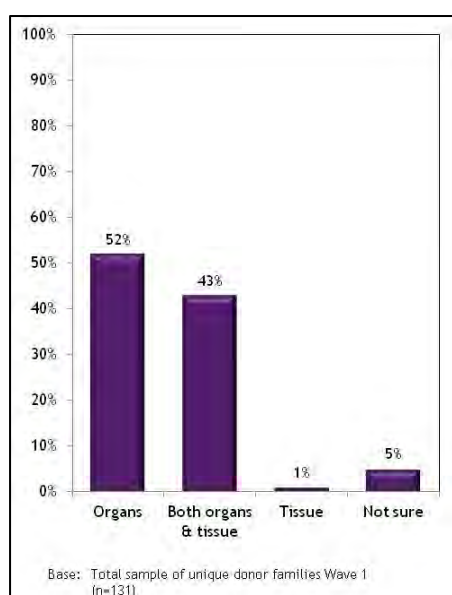
Parents of donors represent 29% of the Wave 1 sample, and as shown in Table 8, the average age of their donor children is 27 years.

Table 8: Relationship of respondent to donor and age of donor

RELATIONSHIP OF RESPONDENT TO DONOR "I WAS HIS/ HER ...."	AVERAGE AGE OF DONOR	AGE RANGE OF DONOR
Parent/ guardian	27 years	3 to 51
Wife/ husband/ partner	56 years	24 to 77
Daughter/ son	63 years	49 to 79
Brother/ sister	43 years	16 to 65

### 3.7.2 WHAT WAS DONATED

Figure 6: What was donated



Half of donors in 2010 and 2011 donated organs only; a further 43% donated organs and tissue. Five percent of donor families are not sure what their family member donated.

Table 9 shows that there are no significant differences between donor families in 2010 and those in 2011.

Table 9: Donation by year of donation

	YEAR OF DONATION (UNIQUE DONOR FAMILIES)	
	2010 (N=54)	2011 (N=77)
Organs only	48%	55%
Organs & tissue	50%	38%
Tissue only	-	1%
Not sure	2%	6%

### 3.8 LESSONS LEARNT - METHODOLOGY

Following are some learnings to consider for the future enhancement of the National Study of Donor Family Experiences.

Of prime consideration should be viewing this research as a long term, ongoing study comprising multiple waves. Waves could be conducted on an annual or biennial basis, as determined by OTA. This would allow forward planning of the study and would require ethics approval to be sought only once at the outset.

#### 3.8.1 DISTRIBUTION OF RESEARCH INSTRUMENTS

In conducting this research, there was a requirement that all contact with donor families was to be via DonateLife. This requirement was put in place to protect the privacy of donor families.

The quantitative research strand therefore had to involve multiple stages of distribution. All Introductory Packs were distributed by Proof Research via the DFSCs, and they in turn received all consent form information which they passed to Proof Research. Survey packs with paper questionnaires were also distributed to families via the DFSCs. The process was cumbersome and added significant pressure on DFSCs to coordinate the distribution of material.

All DFSCs were supportive in ensuring material was distributed in a timely manner, however future studies should consider alternative approaches to minimise the burden on DFSCs. Options for consideration include:

1. **Promotion of the online survey** - Wave 1 saw the introduction of an online survey option in addition to the traditional paper survey. This reduced the quantity of distribution required by DFSCs as Proof Research emailed the online link directly to families.
2. **Distributing the questionnaire together with the PIS and consent forms** - this year, ethics committee conditions for conducting the study required the PIS and consent forms to be posted to families first (Stage 1 of our methodology). Only on receipt of completed consent forms could surveys then be distributed to the families.

The distribution process would be simplified if the questionnaire accompanied the PIS. Receipt of a completed questionnaire would then be deemed as consent to

participate, therefore requiring only one stage of distribution. Consultation with relevant ethics committees may be in order to determine any barriers to this approach.

3. **Send reminders to family members who have consented to the research but not yet responded** - email reminders were sent to families opting in to the online survey, however reminders were not sent to those opting in to receiving a hard copy questionnaire. Whilst this would involve more administrative work from both the research agency (in tracking responses and preparing reminders) and the DFSCs (in distributing reminders), this process would serve to achieve a greater response rate.
4. **Removing DFSCs from survey distribution and fieldwork** - allowing the research company to be fully responsible for the distribution and tracking of consents and questionnaires, thereby removing the need for DFSC involvement. This would eliminate the administrative burden for DFSCs and may improve the response rate due to the anonymous nature of the study (i.e. some donor families may be more likely to take part in the research study if it is seen to be completely independent from DonateLife agencies).
5. **Revising the approach to “declining families”** - capturing contact details of declining families at a hospital level is required in order to boost the inclusion of a declining families sample in the research. If possible, these families should be asked if they consent to being contacted by a research agency in the future to take part in a survey of their experience in the hospital setting. This would allow the research agency to have direct contact with families and would remove the need for DonateLife to be the conduit. A process independent of DonateLife may encourage greater response rates.

The views of this cohort would be particularly useful in understanding barriers to donation and in ensuring that families who are faced with the donation decision are fully informed at the time and comfortable with their decision in the future.

### 3.8.2 QUALITATIVE RESEARCH

The qualitative research with donor families was a great success in terms of both response rates and effectiveness of participation. Initial concerns about the emotional wellbeing of participating families proved to be unfounded.

The researcher found that 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.

In many instances, participants proudly shared photos and mementos of their loved one with the researcher, even after the interview had finished.

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.

### 3.8.3 ETHICS COMMITTEES

The ethic committee consultation and submission process was extensive. Since the national study entails working with DonateLife Agencies located at different sites across the country, applications to ethics committees covering national and local jurisdictions were required.

Having said this, further to the point made in 3.8 above, the study would benefit from being treated as a long term, ongoing study comprising multiple waves. This would allow forward planning of the study and would require ethics approval to be sought once at the outset. Naturally any amendments to the methodology or the survey instruments would be provided to the various HRECs for approval. This approach would save considerable time.

To ensure the correct approvals are obtained before commencing fieldwork, we recommend firstly liaising with each DFSC to understand the location and site/ authorising delegates for their DonateLife Agency. Obtaining this information at the start of any future studies will swiftly identify the ethics committees that need to be approached and avoid delays.

Discussions should be had, and debate encouraged with lead national, regional and institutional HRECs regarding the recognition of ethics approvals across jurisdictions. Whilst the application process has become more streamlined over the years and many HRECs are increasingly accepting of the National Ethics Application Form (NEAF), the boundaries of what authorisations are required are not clear.

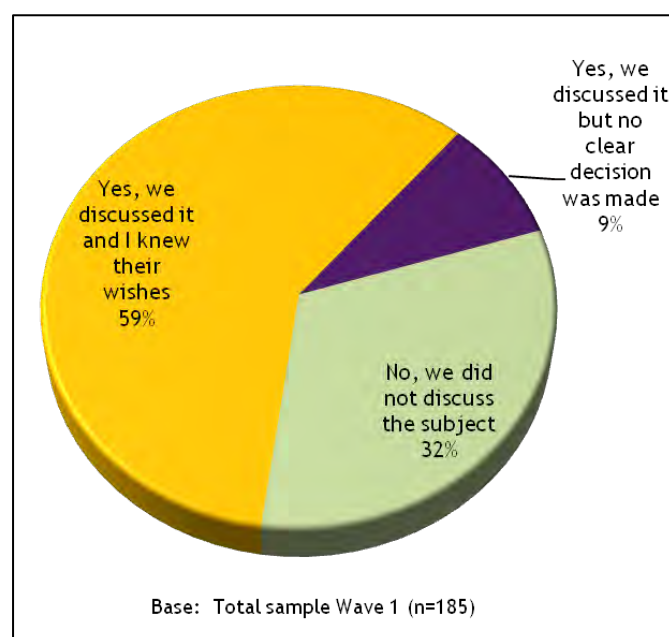
# Part B – Research Findings

## 4.0 THE DECISION TO DONATE

### 4.1 IMPACT OF PRIOR DISCUSSION

Approximately six in ten family members (59%) had discussed organ and tissue donation with their family member prior to being asked to consider donation.

Figure 7: Prior discussion of organ donation



Families who have discussed organ and tissue donation with each other, no matter how brief the conversation, find the donation decision considerably easier than families who have never had the discussion.

*"It was his decision to donate his organs. I don't know if I would have agreed to donation if I had not known his wishes. He gave the ultimate gift – the gift of life."*

2011

*"At the time I was quite traumatised by the situation. I found myself in a confronting situation with so many questions being asked and little time to think. I was glad I knew my husband's wishes."*

2011

As shown in Table 10, families who did not have the discussion are more likely to find the donation decision a difficult one (17% compared with just 1% of those who discussed donation).

Table 10: Impact of donation discussion on donation decision

	TOTAL (N=181)	DISCUSSED AND KNEW WISHES (N=109)	DISCUSSED BUT DID NOT FULLY KNOW WISHES (N=16)*	DID NOT DISCUSS DONATION (N=56)
Made our decision a lot easier	57%	84%	19%	14%
Made our decision a bit easier	11%	9%	37.5%	7%
Did not impact on our decision	26%	6%	37.5	62.5%
Made our decision a bit more difficult	5%	1%	6%	12.5%
Made our decision a lot more difficult	1%	-	-	4%

\* Caution: Small base

## 4.2 MOTIVATIONS FOR DONATION

The majority of donating families (81%) see organ and tissue donation as a chance for something positive to come out of a tragedy. Donation can give families a 'silver lining' and therefore help them to cope with their loss.

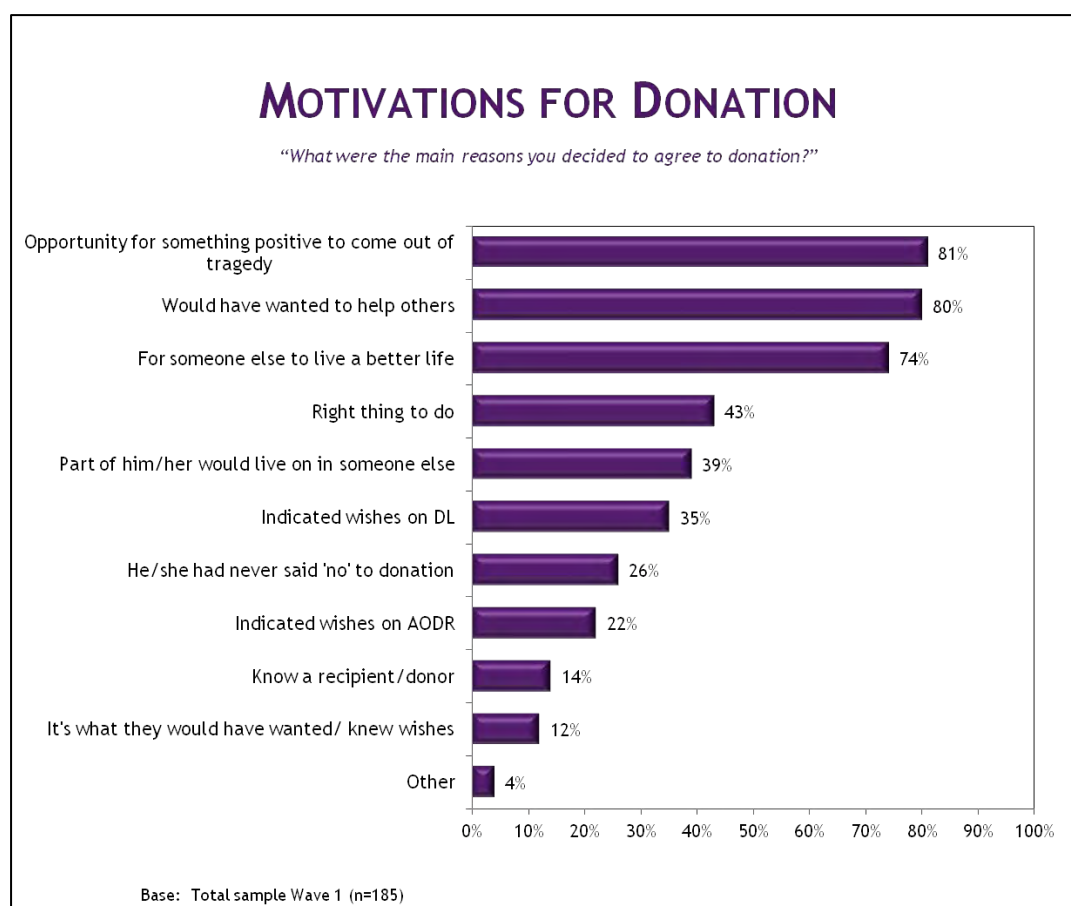
*"I was pretty keen that something positive came out of it. Donation was the one redeeming thing that I could possibly get from the situation. So to me it was important to proceed."*

2011

*"Four organs were donated from my brother and three families got new life. It's hard to find a silver lining in such a bad tragedy, but we held onto that."*

2010

Figure 8: Motivations for donation



In addition, as shown in Figure 8, eight in ten consenting family members (80%) feel that donation fits with their family member's core values of helping others. This is a strong motivating factor.

Three quarters of donor family members (74%) are motivated to consent by the thought of someone else being able to live a better life.

### 4.3 BARRIERS TO DONATION

Further research with families who decline donation is required in order to fully identify and understand barriers to donation.

One family who declined donation took part in the research. This family completed the online questionnaire and also took part in an in-depth personal interview.



In the case of this particular family, the donation request was declined for a simple but rational reason - the wishes of the person who had died were being honoured.

*"I firmly believe in organ donation but he was vehemently against it. He was a good Catholic boy but his simplistic interpretation was that your full soul had to be there when you went to meet your maker. His interpretation was all body parts intact."*

2010 - DECLINED DONATION

The wishes of this person's family member actually went against her own beliefs, as shown in the verbatim comment above. This person felt quite strongly that the final act she could do for her loved one was to ensure his wishes were carried out.

In this case, the participant felt that medical staff were not accepting of her decision to decline donation. The participant's recollection is that staff tried multiple times to change her mind and as a result, she felt pressured and distressed.

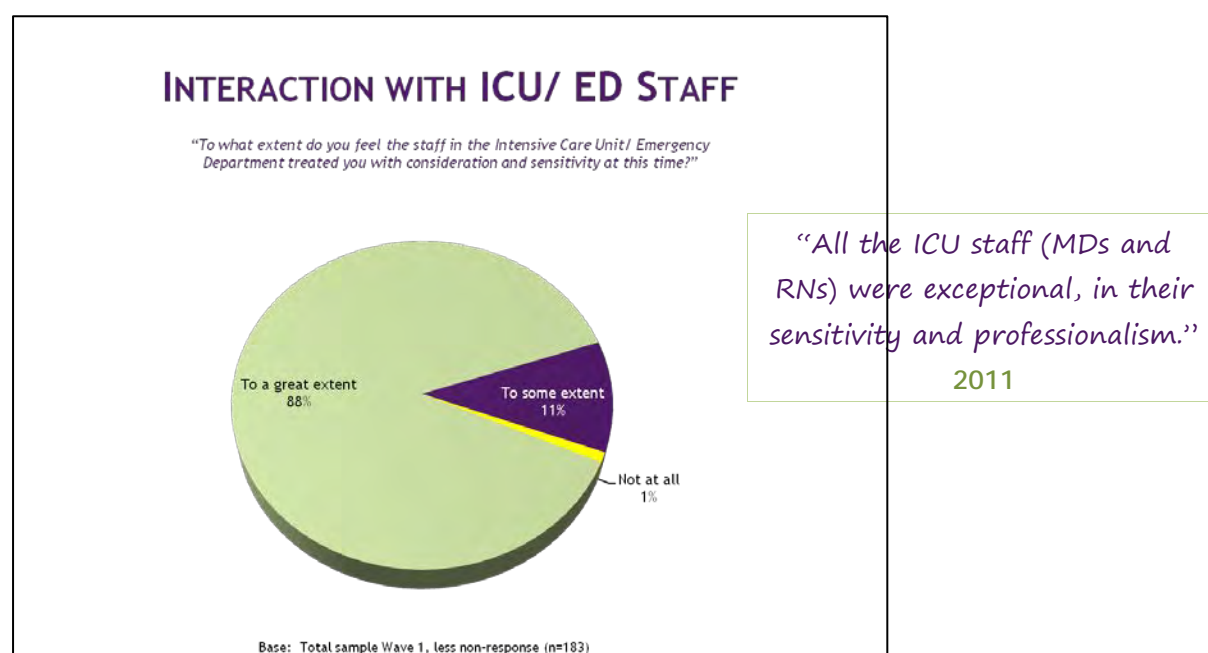
This approach is not compatible with standard practice in Australia. Furthermore, recent training initiatives led by the OTA have focussed on ensuring families are provided with sufficient information to make the donation decision that is right for them, to ensure that the decision sits well with the family in the future.

## 5.0 AT THE HOSPITAL – PRIOR TO CONSENTING

### 5.1 INTERACTION WITH ICU/ ED STAFF

Almost all families (99%) feel that the staff in the Intensive Care Unit (ICU) or Emergency Department (ED) treated them with consideration and sensitivity (88% feel this occurred to a great extent; 11% to some extent). In 2008, the proportion of donor families stating ‘yes’ to this question was 97%.

Figure 9: Interaction with ICU/ED staff



*“I cannot commend the staff who cared for our family highly enough. We felt as though we were the only people in the unit and were allowed so much privacy and time, care and consideration.”*

2011

*“The staff were incredible, just incredible. The way they handled such an intense and horrific situation with sensitivity and grace, humour and humanity, made it possible to get through the experience. I am incredibly grateful to them.”*

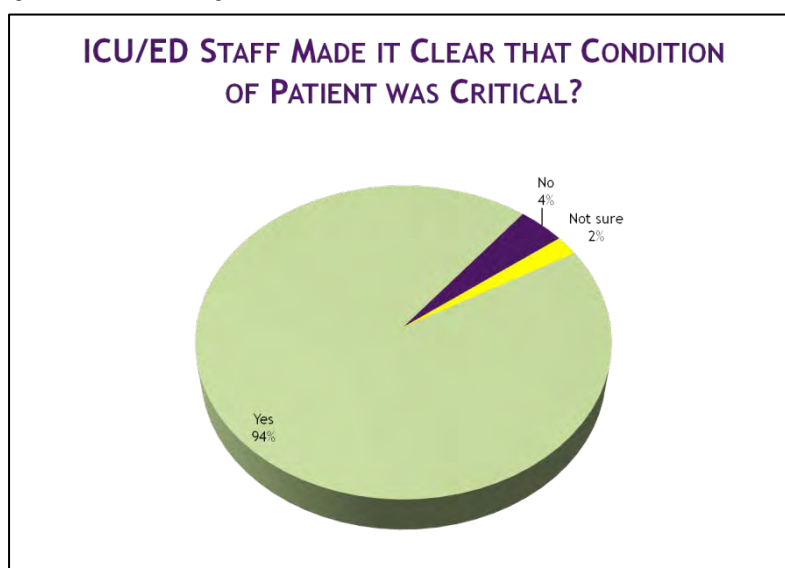
2011

As shown in Figure 9 above, just 1% of donor families feel that the staff did not treat them with consideration and sensitivity. Areas of concern involve:

1. Not being given sufficient information
2. Medical staff not showing empathy towards the family
3. Family members feeling that medical staff did not treat them as individuals (translates to a feeling that staff are impersonal)

## 5.2 DELIVERING BAD NEWS

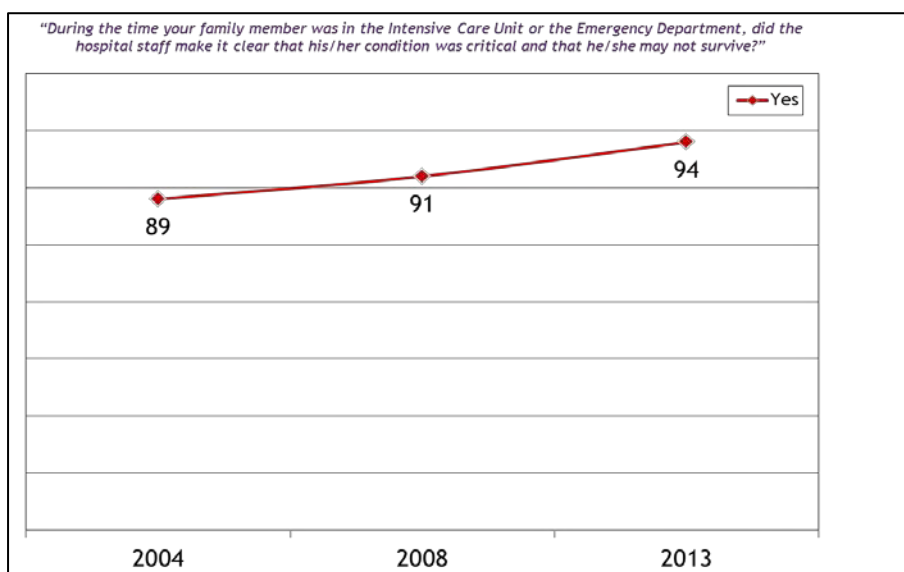
Figure 10: Delivering bad news



In the majority of cases, ICU and ED staff have been skilled at ensuring family members fully realise the gravity of the situation and that their loved one may not survive (Figure 10).

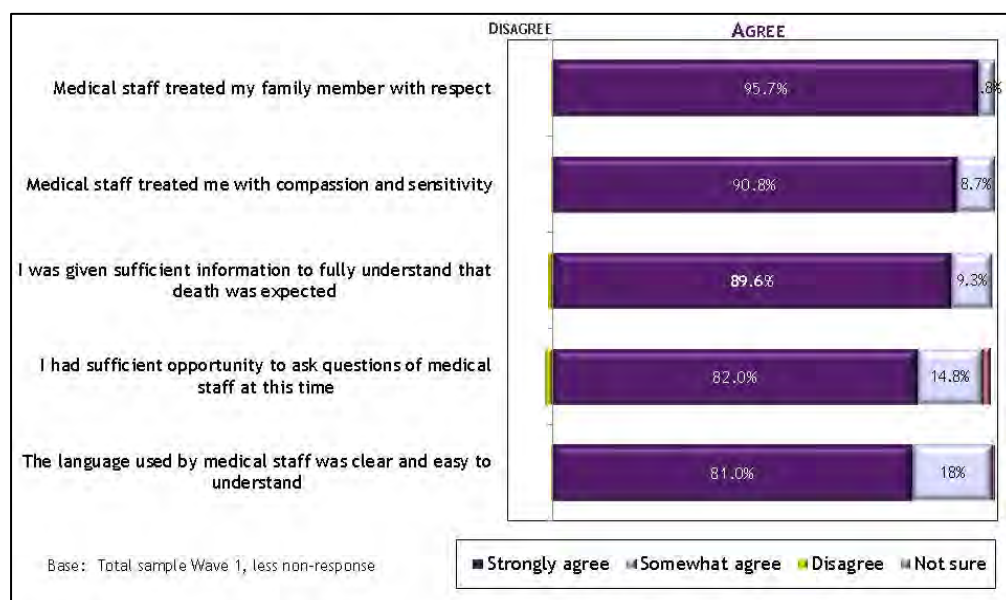
This has increased over time, from 89% in 2004 up to 94% in Wave 1 (Figure 11).

Figure 11: Delivering bad news by year of study



As shown in Figure 12, 96% of donor family members feel that medical staff treated their family member with respect. Further, nine in ten donor family members (91%) feel they were treated with compassion and sensitivity during their time at the hospital, prior to consenting to donation.

Figure 12: Treatment by medical staff



Whilst ratings are very high, there is some room for improvement around the language used by medical staff (81% strongly agree that the language was clear and easy to understand) and ensuring families have sufficient opportunities to ask questions (82% strongly agree that they had enough opportunities to ask questions of medical staff).

To avoid confusion for family members, it is important that all medical staff are 'on the same page' and aware of discussions that have or have not been had with family members. This will avoid families potentially being given conflicting information.

Whilst families need to know that medical staff are doing absolutely all that can be done for their loved one, being given false hope can often be more distressing.

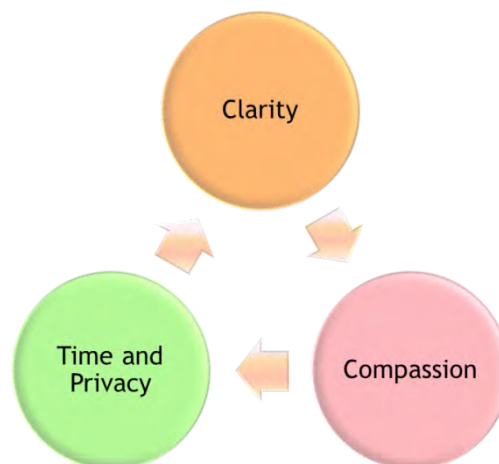
*"Staff at the hospital were never saying that our child would die. They were trying to be very sensitive but it was confusing."*

2011

The tone in which the news is delivered is something that family members remember years later. Donor families mostly feel that medical staff deliver bad news in a professional yet empathetic way, and this is appreciated. There have been instances however, when the tone of delivery has been perceived by donor families as clinical, cold and lacking compassion.

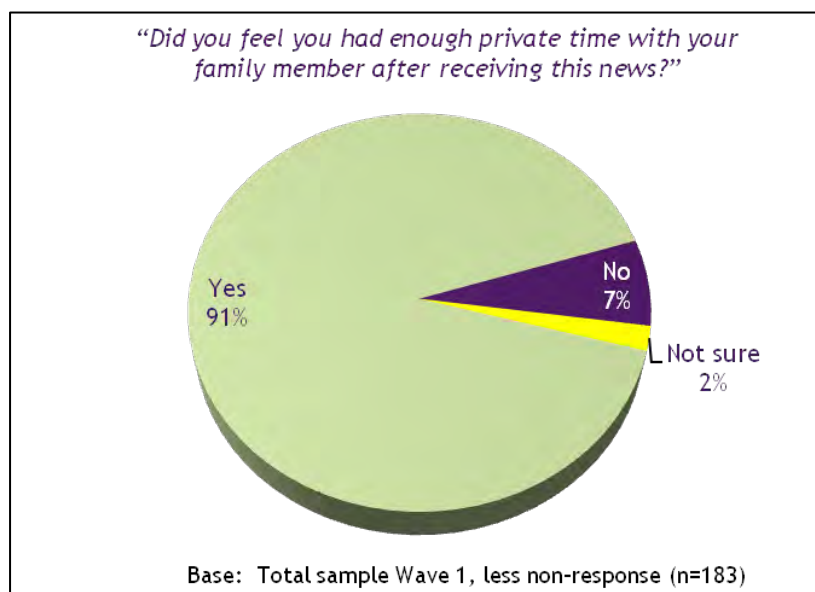
Whilst family members can react in different ways after being given bad news, the three consistent things families appear to need from medical staff at this time are:

- ➔ **Clarity** - of information and of the situation
- ➔ **Compassion** - from medical staff
- ➔ **Time** - to absorb the information and private time to have with their loved one



In 91% of cases, family members feel they were given enough private time with their family member after receiving the bad news. This is consistent with 2004 and 2008 findings (86% given enough private time with family member in 2004; 90% in 2008; 91% in Wave 1).

Figure 13: Amount of private time with family member



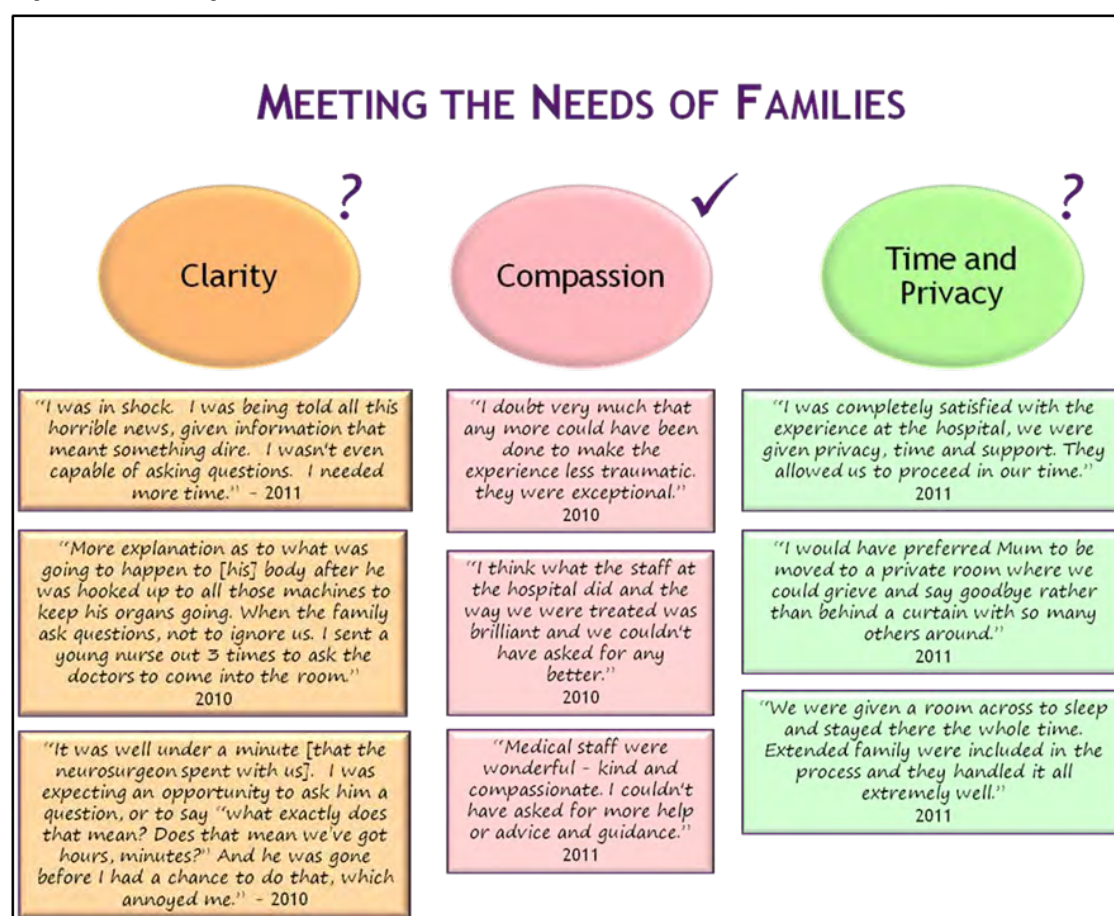
### 5.3 MEETING THE NEEDS OF FAMILIES

Hospital staff successfully meet family needs around **compassion**. Family members recognise the difficult and emotional job that hospital staff have and they praise them for the care and consideration they demonstrate in the face of tragedy.

There is room for hospital staff to improve in the area of providing **clarity** to families. It can be a fine line between ensuring a base level of understanding of the situation and giving upset family members too much information. Families appreciate when information is delivered succinctly but with sincerity and compassion. It is also important to allow families time to digest the information and to check back in with families at a later time, allowing them to ask questions if necessary.

Experiences of donor families vary when it comes to being given **private time** with their family member. Those who were given privacy to grieve and alone time with their family member are very appreciative. It is important for families to not feel rushed and for hospital staff to recognise that this time is precious.

Figure 14: Meeting the needs of donor families

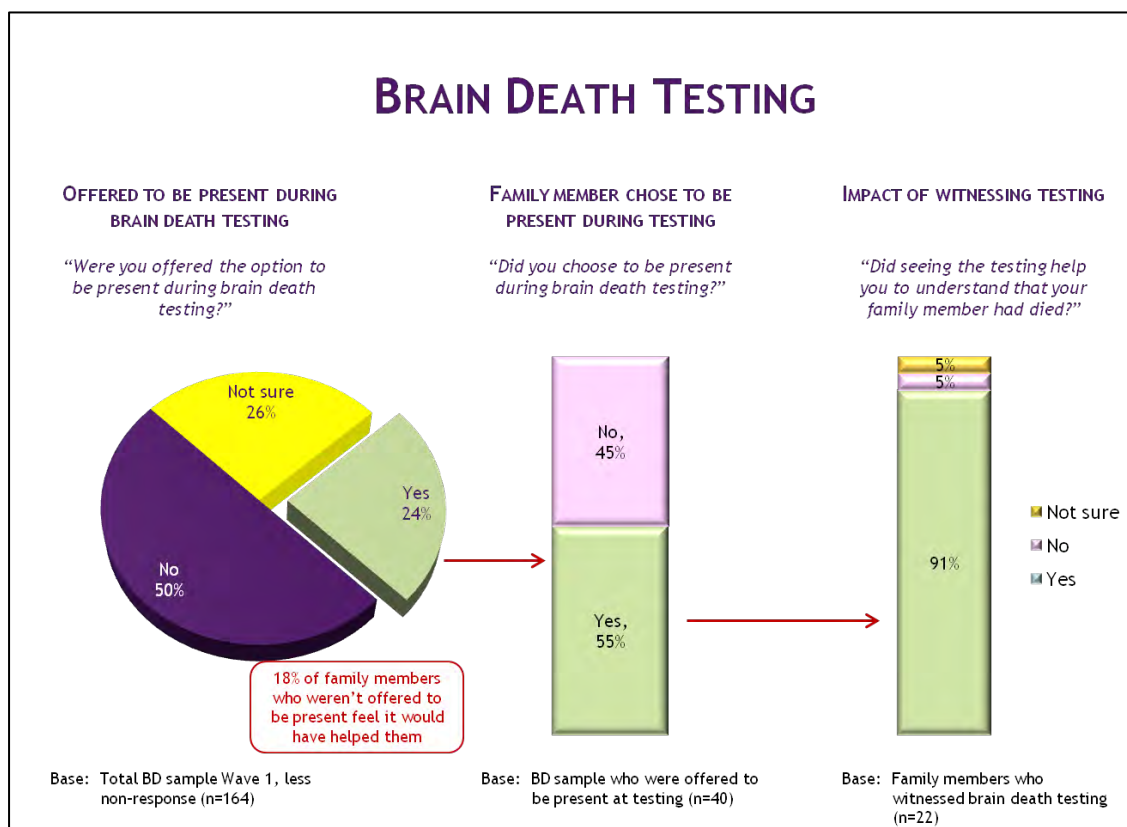




## 5.4 BRAIN DEATH TESTING

Of the participating families in the study, 89% had donor family members who donated after brain death (BD). As shown in Figure 15, 24% of BD donor families were offered the option to be present during brain death testing. Of those, just over half (55%) opted to be present, and for 91% of these family members, seeing the testing helped them to understand that their family member had died. This gave them some sense of closure.

Figure 15: Brain death testing

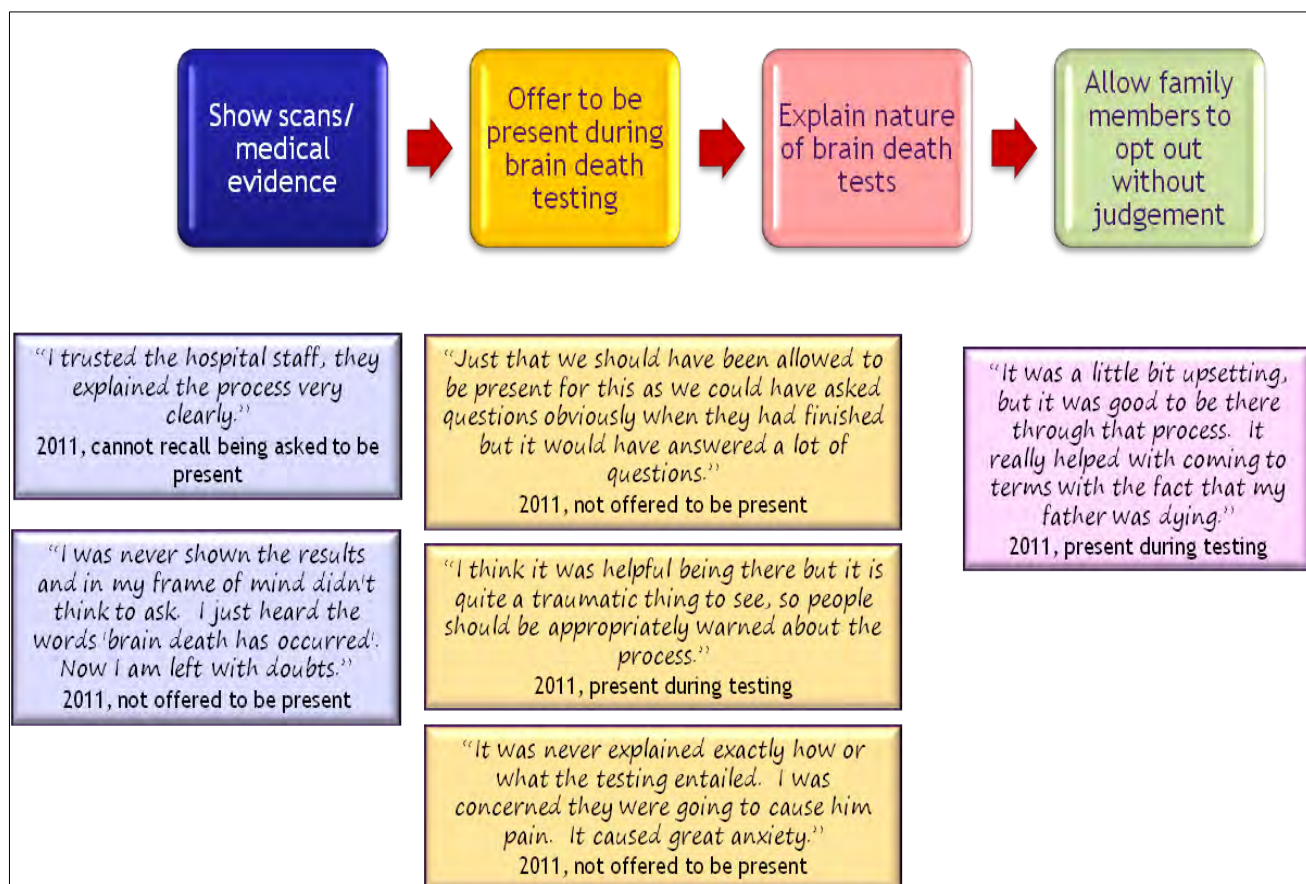


Conversely, approximately one in six family members (18%) who were not offered to be present at brain death testing feel it would have helped them come to terms with their family member's death.

*For these reasons, we suggest that all families are offered the chance to be present at brain death testing and that medical staff explain the nature of the testing, to prepare family members for the confronting experience.*

The recommended process to best support family members is shown in Figure 16.

Figure 16: Beneficial process for donor families





## 6.0 THE DONATION CONVERSATION

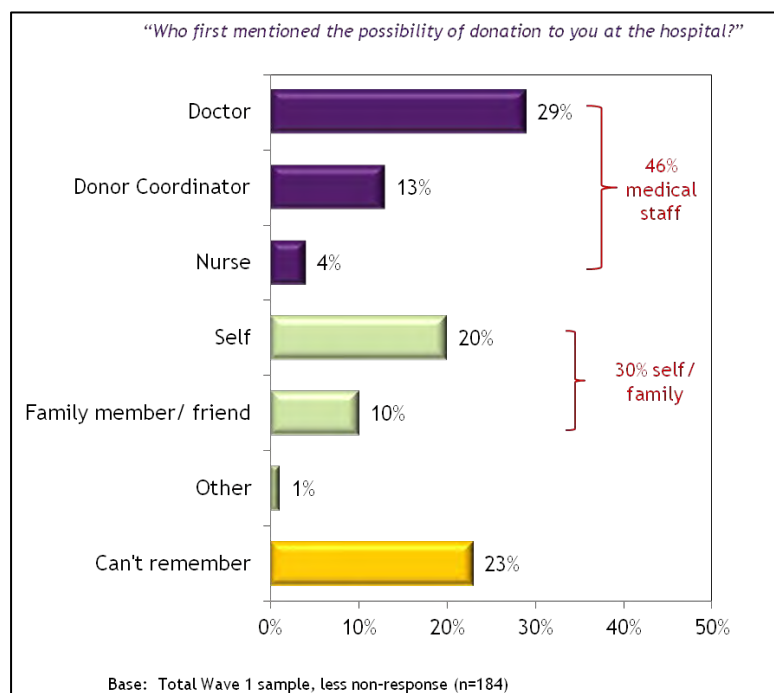
### 6.1 INSTIGATING THE DONATION CONVERSATION

The possibility of donation is primarily mentioned to families by medical staff (46%). This comprises:

- ➔ Doctors - 29%
- ➔ Donor Coordinators - 13%
- ➔ Nurses - 4%

One in five family members (20%) raise the subject of organ donation with medical staff themselves. In total, the donation topic is raised by the family in 30% of cases.

Figure 17: Who initiates the donation conversation



“We were the first to raise organ donation. They [medical staff] seemed a bit shocked that we had raised it.”  
2011

There are no significant differences in terms of who initially raised donation between 2010 and 2011 donor families.

Table 11 shows that in 2008, doctors initially raised the topic of donation in BD cases only to 43% of families. In Wave 1, this figure significantly decreased to 31%. The data suggests that the subject of donation is being raised less often by medical staff (including less often by donor coordinators) and slightly more often by family members, perhaps suggesting a wider acceptance and knowledge of donation in the community.

Table 11: Donation instigator by donation pathway (2004, 2008, Wave 1)

<i>“Who first mentioned the possibility of donation to you at the hospital?”</i>	STUDY			
	ATCA 2004 - BD* (N=131)	ATCA 2008 - BD* (N=159)	OTA WAVE 1 - BD (N=164)	OTA WAVE 1 - DCD (N=20)
Doctor	38%	43%	31%	10%
Nurse	5%	2%	4%	5%
Donor coordinator	14%	21%	12%	20%
<b>Total medical staff</b>	<b>57%</b>	<b>66%</b>	<b>47%</b>	<b>35%</b>
Family member/ close friend	19%	17%	10%	10%
Self	Not measured	Not measured	19%	30%
Other	6%	10%	1%	-
<b>Total family</b>	<b>25%</b>	<b>27%</b>	<b>30%</b>	<b>40%</b>
Can't recall	10%	15%	23%	25%

\* Discrepancies in 2004 and 2008 data. Single response, although percentages do not add to 100%.

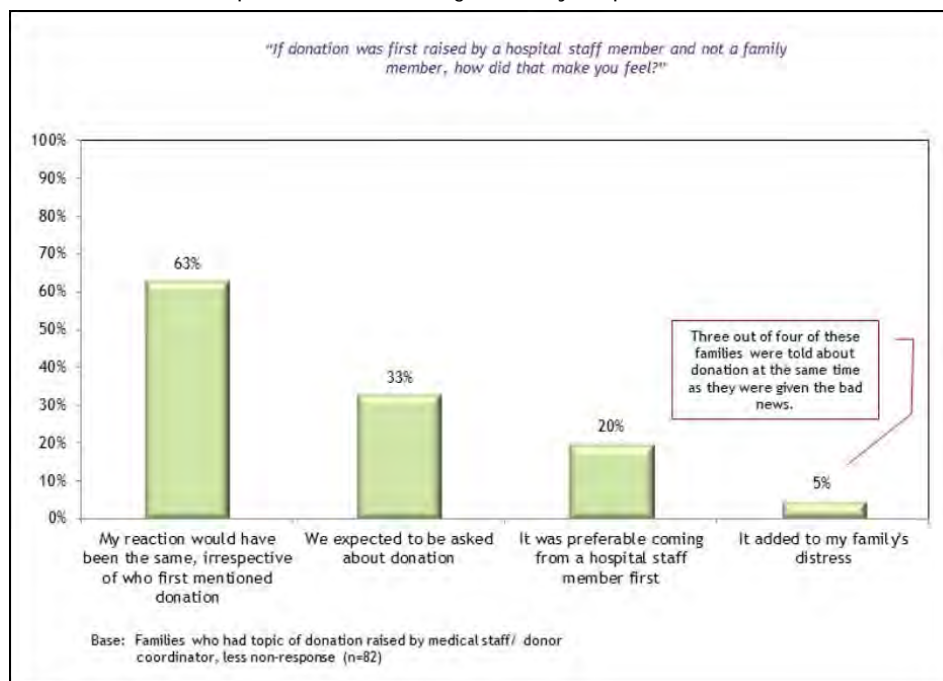
NB: Data in table represents the views of all family members, rather than individual families (to be consistent with the way the question was measured in 2004 and 2008).

Whilst there appears to have been an increase between the 2008 study and Wave 1 study in the number of families who cannot recall who first raised the subject of donation, this increase is not statistically significant.

In 69% of instances where medical staff raised the topic of donation, a DonateLife staff member was present; in 12% of instances, an organ & tissue donation staff member was not present when donation was raised.

To reiterate, amongst the 2010 and 2011 donor families who took part in Wave 1, 46% of families were first asked about organ and tissue donation by a medical staff member. As shown in the following graph (Figure 18), 33% of these family members expected to be asked about donation, while 20% actually found it preferable coming from a hospital staff member rather than a family member.

Figure 18: Reaction to topic of donation being raised by hospital staff member



One in 20 donor families (5%) feel that being asked about donation by a hospital staff member added to their family's distress. Three out of four of these families were told about donation at the same time as they were given the bad news. They may not have had sufficient time to digest and fully understand the situation.

These findings reiterate that *the way* in which organ & tissue donation is raised can be more important than *who* raises it. "

## 6.2 THE DONATION CONVERSATION - TIMING

Two in five (40%) family members were asked about donation by a medical team member *at the same time* as being told of their family member's brain death or expected death (Figure 19). In 2010 and 2011, this was the most common time to be approached. One quarter (24%) of family members were asked about donation by a medical staff member within an hour of being given the bad news; 12% after an hour of being given the news and 10% before being told of their family member's brain death or expected death.

Figure 19: Timing of the donation conversation

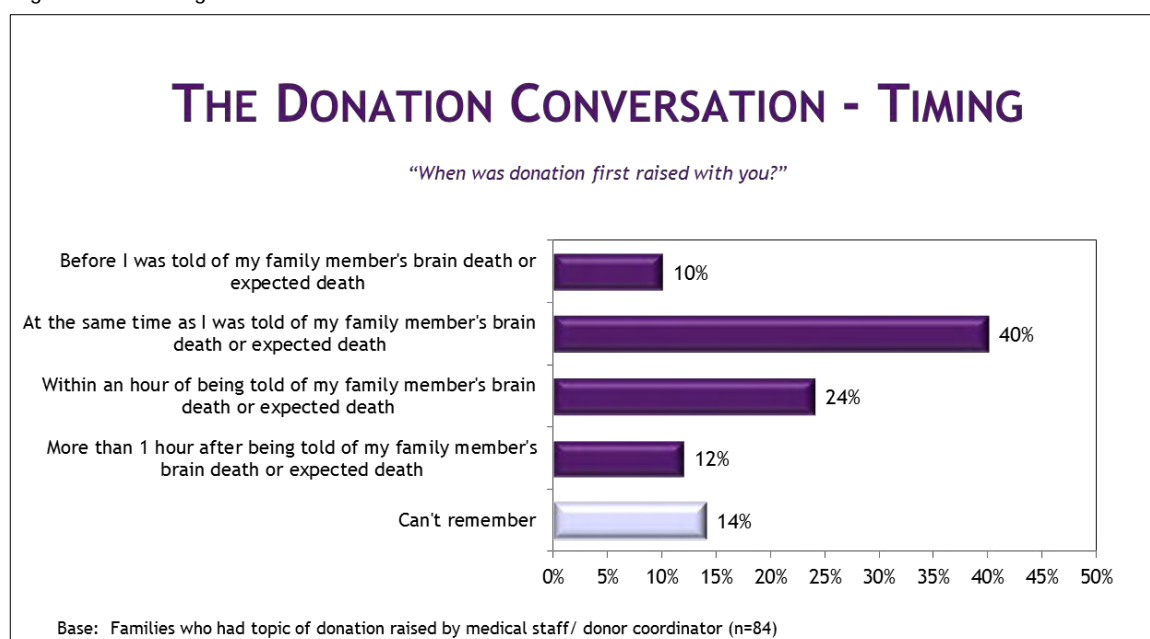


Table 12 breaks down the timing by state.

Table 12: Timing of donation conversation by medical/ DonateLife personnel

	TOTAL (N=84)	QLD (N=25)	ACT (N=2)*	NSW (N=20)	VIC (N=18)*	TAS (N=6)*	SA (N=11)*	WA (N=2)*
Before	10%	12%	-	5%	11%	33%	-	-
At same time	40%	48%	-	50%	33%	-	45%	50%
Within an hour	24%	8%	100%	20%	28%	33%	36%	50%
More than an hour	12%	20%	-	15%	-	33%	-	-
Can't recall	14%	12%	-	10%	28%	-	18%	-

\* Caution: Small base

Table 13 shows the timing of the donation conversation in BD cases, tracked over time.

Table 13: Timing of donation (in BD cases only)

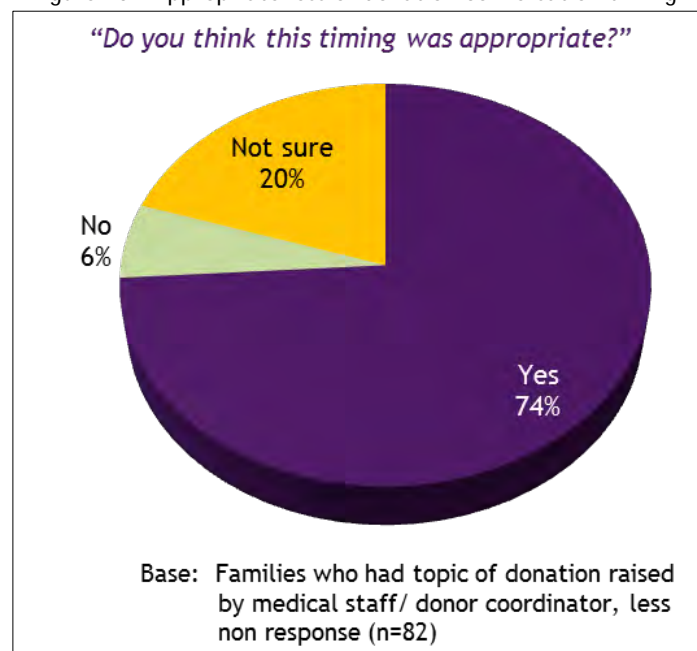
	ATCA 2004	ATCA 2008	OTA WAVE 1 - (N=77)
Before	27%	26%	10%
At same time	29%	30%	38%
Within an hour	22%	21%	26%
More than an hour	8%	8%	12%
Can't recall	13%	19%	14%

NB: Discrepancy in 2008 data. Single response although does not sum to 100% and not likely due to rounding.

Note: Caution is required when comparing Wave 1 findings with 2004 and 2008 findings. Wave 1 data has been filtered to only include families where the subject of donation was first raised by medical personnel, whereas it appears that 2004 and 2008 data was asked of all families (even if they raised donation themselves) and also includes significant non-response.

Whilst the timing of the donation conversation (when raised by medical and/or DonateLife staff) varies slightly by state, in the majority of instances (74%), families feel the timing is appropriate.

Figure 20: Appropriateness of donation conversation timing



Looking at the appropriateness of the timing by when the subject was raised, as shown in Table 14, three quarters (75%) of family members who were asked about donation before being given the grave news, found this timing appropriate; 12.5% felt it was inappropriate, while a further 12.5% are unsure.

Whilst there are no statistically significant differences in Table 14 due to base sizes, the data suggests that the donation conversation should not be instigated *before* or *at the same time* as breaking the bad news to families, rather the timing is considered more appropriate when the subject is broached within an hour of breaking the news.

This gives families some time to reconcile the situation in their minds before being asked to consider and process new information about donation.

Table 14: Raising donation – appropriateness of timing

		DONATION RAISED TIMING IN RELATION TO BEING TOLD OF FAMILY MEMBER’S BRAIN DEATH OR EXPECTED DEATH				
		BEFORE (N=8)	AT SAME TIME (N=34)	WITHIN 1 HOUR (N=20)	MORE THAN 1 HOUR (N=10)	CAN’T RECALL (N=10)
TIMING APPROPRIATE	Yes	75%	68%	95%	50%	80%
	No	12.5%	6%	-	20%	-
	Not sure	12.5%	26%	5%	30%	20%

*"I think that once he was pronounced, I should have had a bit of time to process what was happening, then had the counsellor and DonateLife organ donor doctor come and see us to explain everything rather than being lumped with everything all at once."*

2010

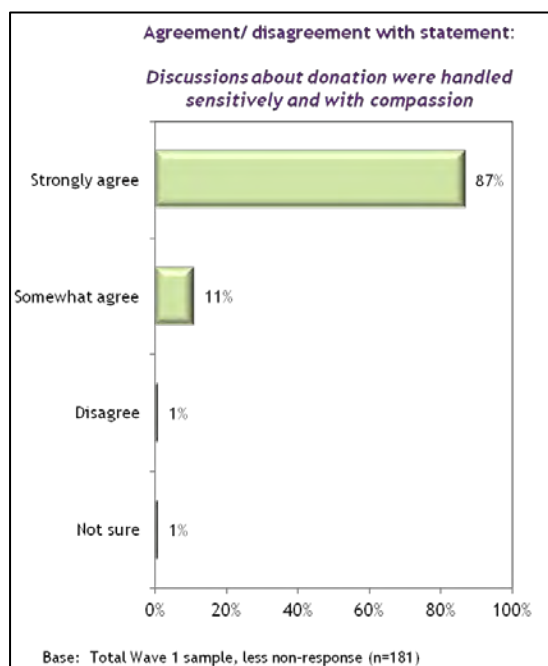
*The donation topic must be raised with empathy and compassion for the family. It should only be raised after brain death or expected death has been confirmed with and understood by the family, and the family provided with some time to digest the news.*

The needs of the family should always be considered *prior* to approaching the family about donation. Medical staff must ensure that family members have a full understanding of brain death or impending death prior to the donation conversation.

Instigating the conversation in a respectful and empathetic manner is key.

In the vast majority of cases, family members feel that discussions about donation were handled sensitively and with compassion.

Figure 21: Handling of donation conversation



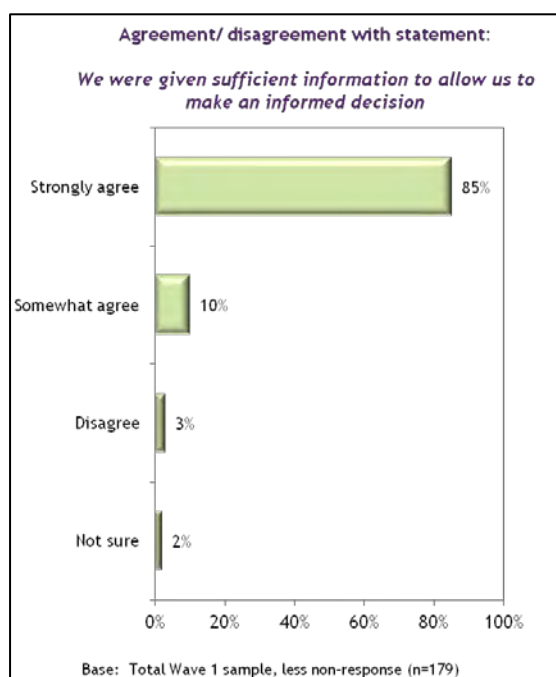
*“The process needs to occur relatively fast. It must be a very awkward topic for any doctor to raise. I don't feel the timing was a problem. The timing didn't change the outcome for our loved one. We were asked respectfully and with consideration.”*

2011

### 6.3 THE DONATION CONVERSATION - INFORMATION

The majority of donor families feel they were given sufficient information to allow them to make an informed decision.

Figure 22: Information to make an informed decision

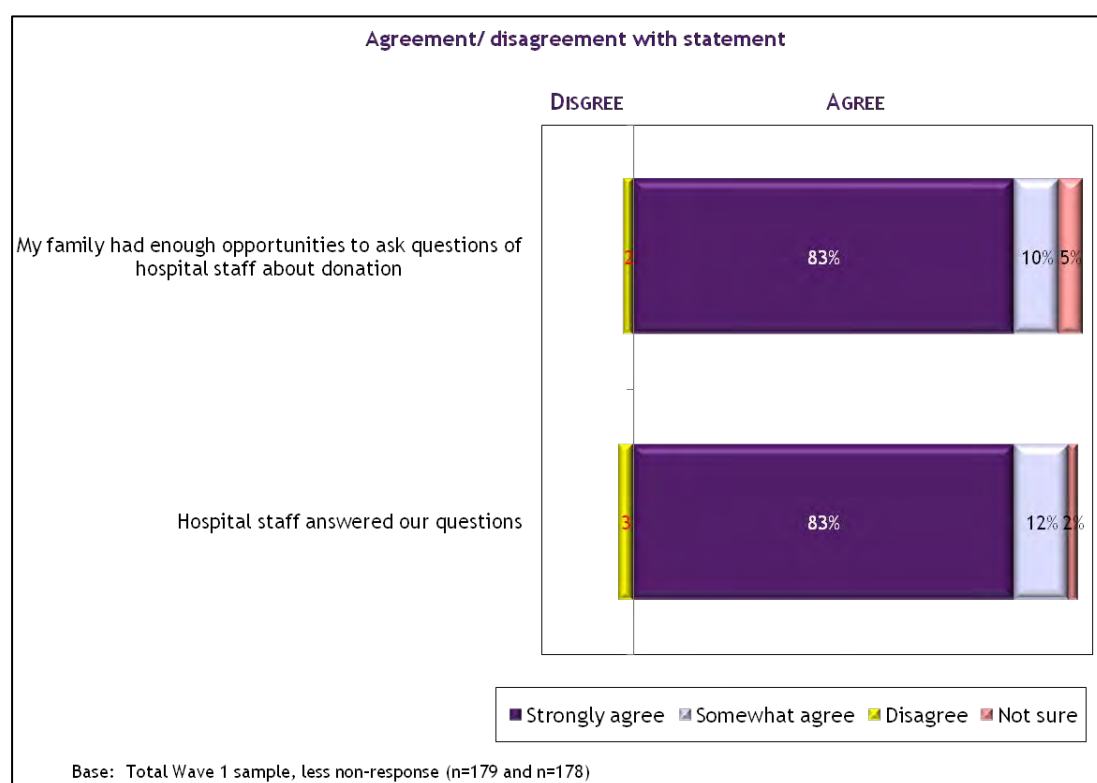


Again, it is important to ensure family members fully understand the gravity of the situation for their loved one *before* raising the subject of organ donation. Family members must be provided with time to process the bad news before being asked to consider new information about donation.

Similarly, staff should be guided by the family members as to the amount of information about organ and tissue donation provided at any one time, so as not to overwhelm family members. Whilst families need information in order to make an informed decision, care must be taken to ensure the timing of the provision of information suits the family.

The majority of donor families strongly agree that their family was provided with enough opportunities to ask questions of hospital staff about donation (83%), and that hospital staff answered their questions (83%).

Figure 23: Opportunities to ask questions



## 6.4 THE DONATION CONVERSATION – TIME TO CONSIDER

Families mostly feel that they were given enough time to discuss donation and to make their decision (94% agree in total, 82% strongly agree). Having said this, 8% of families felt rushed or pressured to some degree.



Figure 24: Pressure to decide

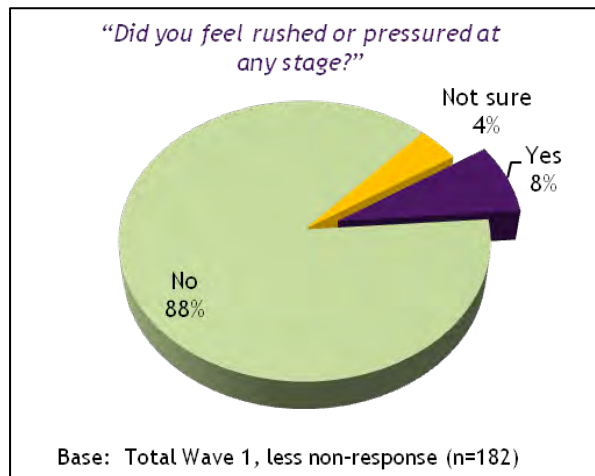
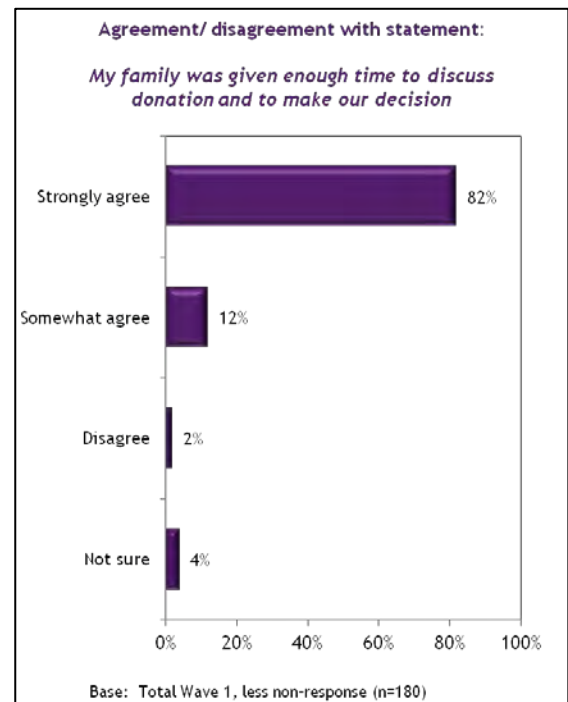


Figure 25: Time to make a decision



Whilst families understand that there are time pressures 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 grave news
2. Digest the request for donation
3. Absorb the information about donation
4. Discuss the way forward with family members

Families may be more responsive if they are provided with a broad timeframe for their decision and then left in private to discuss donation with their 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.*

*“We were provided with time alone in a quiet place to discuss the decision. We were also not pressured into making a rushed decision, although we were provided with a time frame for the decision making process.”*

2011

## 7.0 MOVING TOWARDS ORGAN AND TISSUE DONATION

### 7.1 UNDERSTANDING OF THE DONATION PROCESS

Nine in ten donor families in 2010 and 2011 (91%) recall meeting with the donor coordinator or donation nurse/ doctor. After this meeting, 82% of donor families felt well informed and felt that they knew all they needed to know about the donation process. Some families (16%) still had unanswered questions, while a further 2% of families left the meeting with no clear understanding of the donation process.

Figure 26: Meeting donation staff

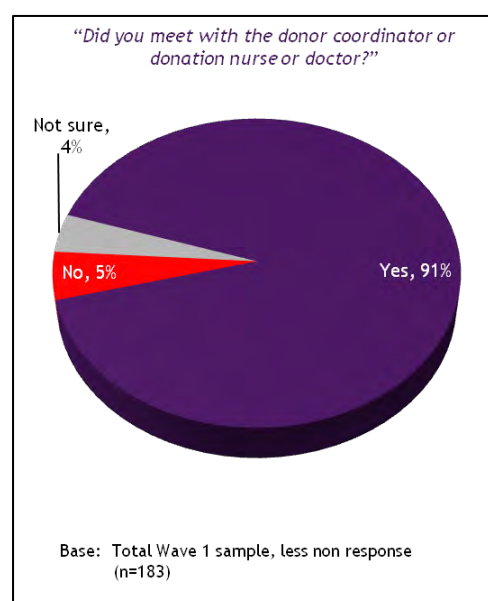
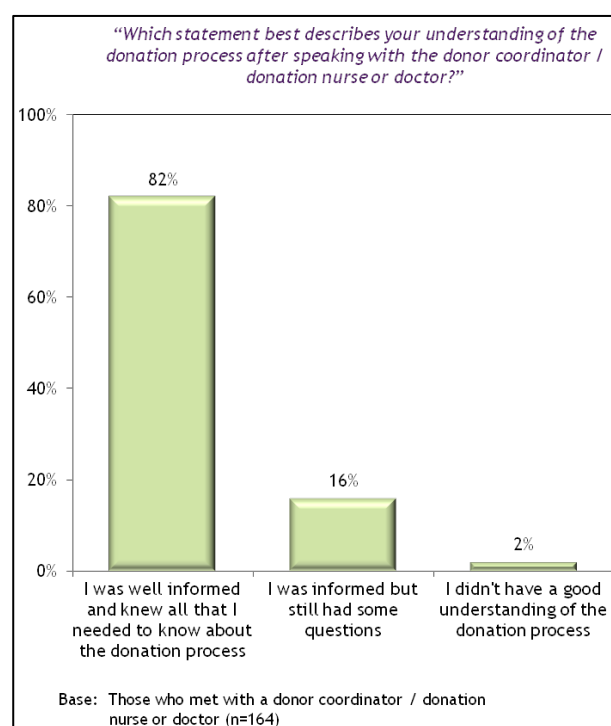


Figure 27: Understanding of the donation process



Donor coordinators made nine in ten families (90%) aware that even if donation was agreed to, the donation may not happen for a number of reasons.

*As part of the information dissemination process, it is important to ensure that all family members receive this information, to avoid potential disappointment (and therefore regret) if donation does not occur.*

## 7.2 WRITTEN INFORMATION ABOUT DONATION

In total, 37% of family members in 2010 and 2011 confirmed that they received written information, either before or after the decision to donate was made; 3% received information before and after making their decision. A further 48% of family members cannot recall if they received written information.

Figure 28: Receipt of written information

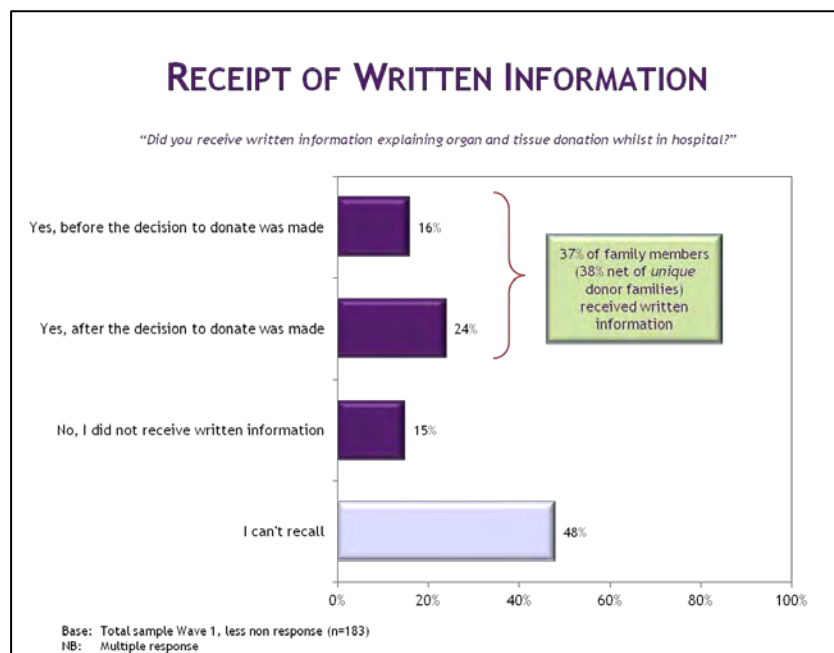


Figure 29: Reading of information

More than half of family members (53%) read this information in detail, while just under half (46%) skimmed through it. Just 1% of families who were given information decided not to read it.

The information is read mostly *after* the families have made the decision to donate (Figure 30).

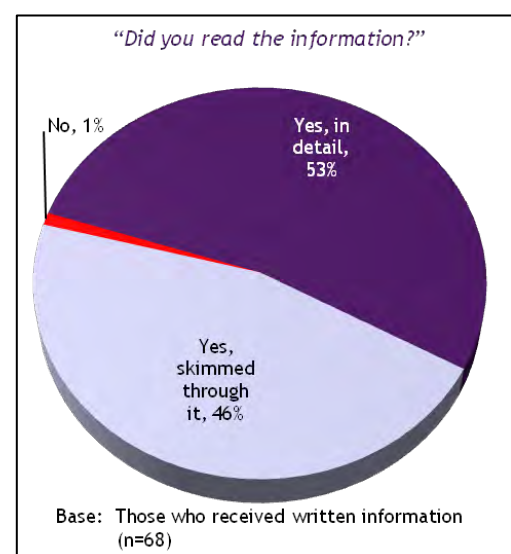
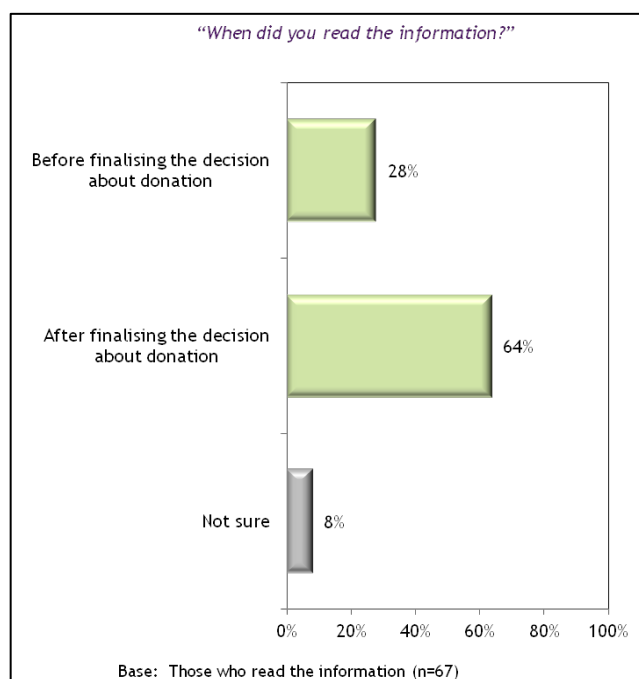


Figure 30: When information is read



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.

As shown in Table 15, those who read the information in detail found it to be more useful (compared to those who skimmed through it). This finding reiterates the importance of encouraging family members to read the information carefully, in their own time.

Table 15: Usefulness of information

	TOTAL (WHO RECEIVED AND READ INFORMATION) (N=66)	READ IT IN DETAIL (N=36)	SKIMMED THROUGH (N=30)
Very useful	54.5%	72%	33%
Quite useful	41.0%	25%	60%
Not useful	4.5%	3%	7%

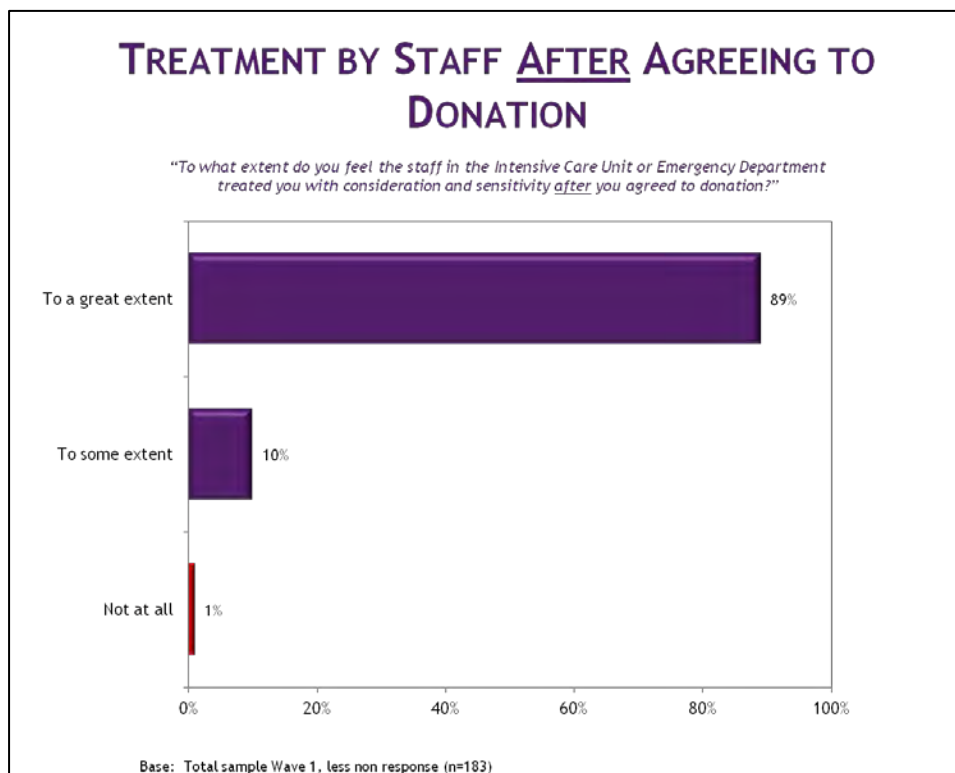
*Written information is important for donor families to receive whilst in hospital, however it should not replace verbal communication from the donor coordinator. Verbal information should be succinct and delivered in layman's terms for ease of processing.*

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

### 7.3 STAFF AND SUPPORT - AFTER CONSENTING TO DONATION

Nine in ten donor families feel that staff in the ICU or ED treated them with consideration and sensitivity *after* they agreed to donation. It is important to note here that the majority of families feel the care given to them post-consent was consistent with that received pre-consent.

Figure 31: Treatment by staff after agreeing to donation



Whilst the scale used in this measure in Wave 1 provides greater sensitivity than the 'yes/no' option used in the 2004 and 2008 studies, the level of consideration displayed to families post-consent to donation appears to be consistent over time (96% in 2008).

*"We were treated with a great deal of consideration and sensitivity from the time of arrival in hospital until organ donation."*

2011

When treatment of families post-consent is inconsistent with that received pre-consent, families are left doubting their donation decision. They can feel abandoned and used by medical staff and this is a feeling that is likely to stay with families for years to come.

*"I felt that once my decision was made, that what I felt was not important anymore."*

2011

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

Figure 32: Support offered during stay in hospital

Just over 3 in every 4 donor family members (76%) were offered the support of a social worker, counsellor or chaplain at some time during their family member's stay in hospital (Figure 32).

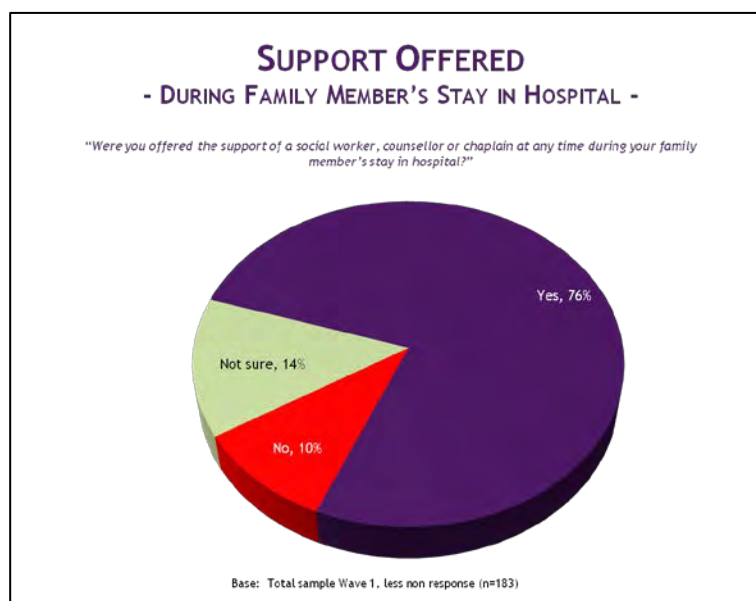


Table 16 shows consistent findings across 2004, 2008 and Wave 1, with between 7 and 8 in every 10 family members of BD donors being offered the support of a social worker, counsellor or chaplain during their family member's stay in hospital. Family members of DCD donors are significantly more likely to be offered this service (95% of DCD families in 2010 and 2011 were offered support of a social worker, counsellor or chaplain).

Table 16: Support offered by social worker, counsellor or chaplain

	DBD FAMILY MEMBERS			DCD FAMILY MEMBERS
	ATCA 2004	ATCA 2008	OTA WAVE 1 (N=163)	OTA WAVE 1 (N=20)
Yes	78%	78%	74%	95%
No	n/s	8%	11%	-
Not sure	n/s	13%	15%	5%

## 7.4 THE DONATION PROCESS

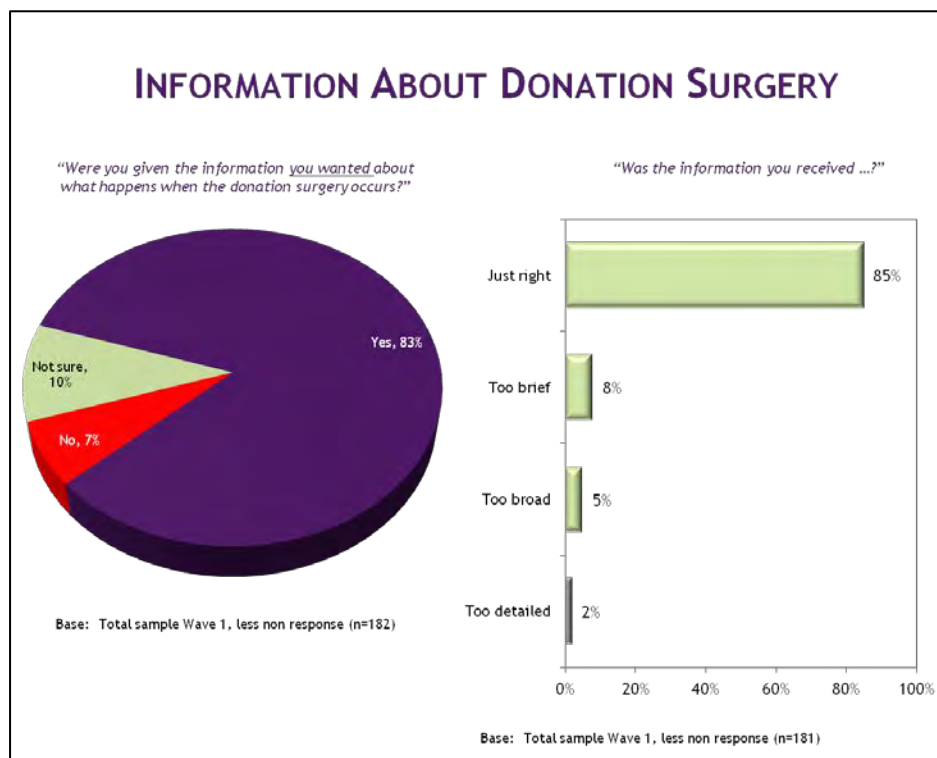
The time between donation consent and when donation takes place can be quite distressing for family members. Whilst the decision to donate has already been made, when it comes to the practical tasks leading up to donation surgery, reality sets in about the finality of their decision and this is where doubts can arise.

As this is a critical time in the process, families must be managed with care. Being kept informed with accurate information and timeframes, as well as being allowed private time with their loved one, can lessen the distress.

### 7.4.1 INFORMATION PROVIDED TO FAMILIES

In terms of the information provided, 83% of family members feel they were given the information *they wanted* about the donation surgery and 85% felt that the *amount of information* they received was just right (Figure 33 over the page).

Figure 33 Information about donation surgery



As shown in Table 17, the majority of families who were *not* given the information *they wanted* complain of the information being too brief.

Table 17: Suitability of information given

	GIVEN INFORMATION YOU WANTED		
	YES (N=152)	No (N=12)	UNSURE (N=17)
Just right	93%	16.5%	53%
Too brief	2%	67%	23%
Too broad	3%	16.5%	18%
Too detailed	2%	0%	6%

*“I would have really loved some extra info on the decision that we had made, definitely in regards to how the procedure takes place, what happens to my son whilst organs are being removed, during the operation is he treated with respect?”*

2010

Two percent of family members felt the information they were given was too detailed.

*“We didn’t need to know that even bits of her bones would be used for this, that and the other. Well I just didn’t feel comfortable with it.”*

2010

#### 7.4.2 INFORMATION SOUGHT FROM FAMILIES

As part of the consent process, family members are asked to nominate which organs and tissues may be donated. A key finding emerging from the research is the difficulty faced by families when asked to make these decisions.

Many family members struggle with this aspect of consent and find the process to be overly lengthy and detailed. They are simply overwhelmed.

*“Providing informed consent for every organ and tissue was confronting and the only time at which I felt I couldn’t bear for this to happen. I don’t know if legally informed consent needs to occur for each type of organ and tissue?”*

2011

Families can be presented with a combination of checklists, documents, and in some cases, diagrams of the human body to select which organs to donate. The process can be very confronting for families and if it is not delivered sensitively, it can create further anguish and grief.



Having experienced staff who are knowledgeable about the processes, but who can also sense when things become too difficult for family members, is critical.

Families who are fully informed of the process appear to manage the situation better than those who have not been told what is involved.

Family members appreciate:

- Being informed of what is involved and why
- Being acknowledged
- Being offered an “out” if necessary

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*To put donor families at ease, staff must have a good level of compassion and empathy, while also remaining professional and efficient.*

---

#### 7.4.3 TIME WITH FAMILY MEMBER BEFORE DONATION SURGERY

During this 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 the last “act”, being surgery. This is a crucial period of time for family members. If not handled with sensitivity, care and efficiency, family members can start to doubt their decision to donate.

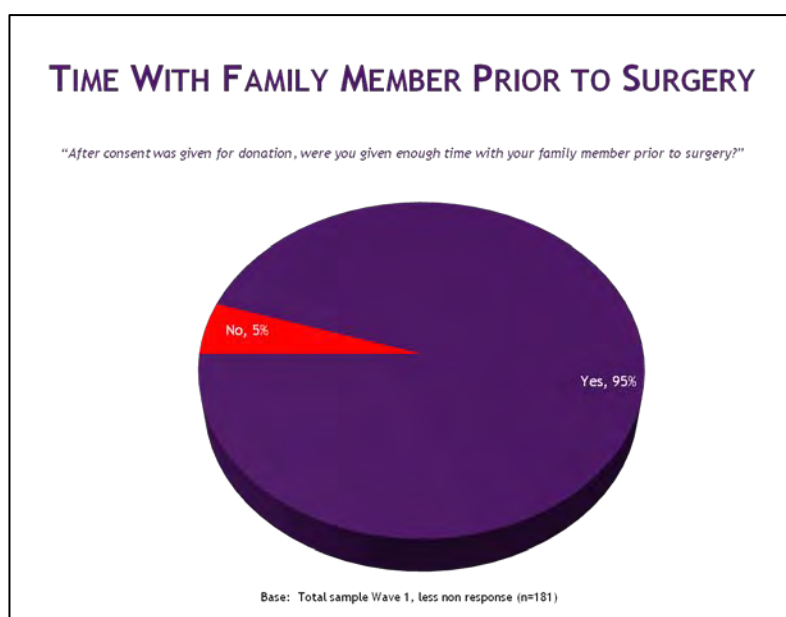
Being provided with an opportunity to simply ‘sit’ with their family member for some quiet time and reflection, as well as allowing family and friends to say their goodbyes, is an important part of the reconciliation process for families, and one that is generally done very well in Australian hospitals.

*“It was great to have extra time with him because of organ donation.”*

2010

Just over nine in every 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 34: Time with family member prior to surgery



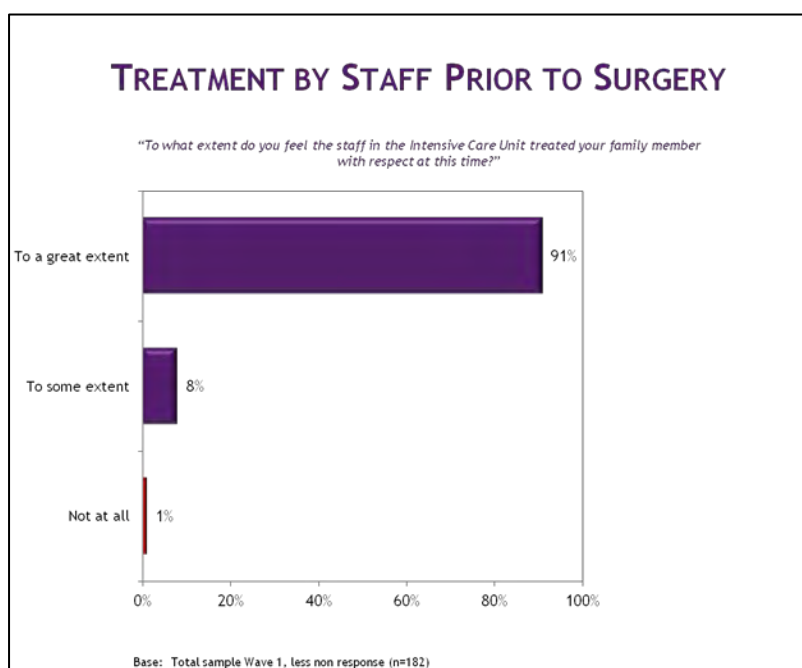
#### 7.4.4 ICU STAFF

The majority of donor family members feel their loved one was treated with respect during the donation process.

*"We saw the staff and coordinator being an advocate for our family member, not the organs."*

2010

Figure 35: Treatment by staff prior to surgery



*"The death of our son obviously caused upset to the staff and this gave us some comfort as they were clearly committed to ensuring he was well looked after."*

2011

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*For donation to be seen as an opportunity and a positive outcome, the process between consent and donation surgery must be efficient and informed. Keep in mind that this is one of the most difficult time periods for families and the period in which doubts are most likely to arise.*

*Families must be kept up-to-date with accurate information regarding the likely time of donation surgery. If there are delays, ensure family members are informed and provide them with the reasons for the delay.*

---

*"I think they should have informed us a little bit earlier, instead of keeping us waiting until 10.45pm. They should have done. They could have done. They didn't."*

2010

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*Families need to be provided with up-to-date and accurate information at regular intervals. Keeping families informed as to the realistic and likely time from death to donation is imperative for families' emotional health.*

---

## 7.5 IMPROVING THE DONATION DISCUSSION

As part of the Wave 1 research study, family members were asked how the donation discussion could have been improved *after* they agreed to donation. As shown by the variety of responses outlined in Table 18, experiences are varied. There are many intangibles, and whilst following a process is necessary, staff must also be flexible to ensure the needs of family members are met.

Table 18: Improving the way donation is discussed at the hospital

"HOW COULD THE WAY IN WHICH DONATION WAS DISCUSSED WITH YOU AT THE HOSPITAL HAVE BEEN IMPROVED AFTER YOU AGREED TO DONATION?"	% (N=97)
It couldn't be improved / it was handled very well / no complaints	49%
We knew their wishes which made it easier	4%
Lengthy process waiting until time of donation / provide more information around timelines	4%
It all happened too quickly / felt rushed	3%
Nothing could make it easier - such a hard decision / confronting decision	3%
More discussion on the stages the donor would go through / what happens after you say 'goodbye' in ICU	3%
A better explanation of why some organs can't be used / may not be suitable	2%
A debriefing process / make sure the family understands what's happening	2%
Discuss it with the broader family, not just one member	2%
Don't go through details of what will be donated	2%
Don't delay meeting with the required staff	2%
Other one-off mentions (listed overleaf)	18%
Don't know	6%

*"The explanation was adequate; the nurse was kind and considerate. The referral process was terrible with long delays and seemingly nobody taking responsibility for it. My brothers were very upset and considered cancelling donation."*

2011

*"I will always remember the way that the donation nurse was just fantastic, she was so excited that we had agreed to donation but the same time she knew how hard it was for us to say goodbye. She was beautiful."*

2011

Other one-off mentions include:

- Little empathy shown
- Take more time to explain and answer questions
- Show some statistics to help understanding
- Would only have been easier if we knew their wishes
- Doctor and Donor Coordinator to discuss beforehand
- Could have been a shorter discussion given we knew their wishes
- Unnecessary repetition of information

- Donor Coordinator was unsure of herself
- Don't keep asking if I want to renege on my decision
- Provide more assistance if donation doesn't happen
- Invasive questions about the lifestyle of the deceased
- Too many people were involved
- Provide a visual representation of the process / a diagram
- Parents may have benefited from being taken aside and able to talk to someone in private

*"It should have been explained more clearly once the life support is turned off they will be wheeled out immediately – was not ready for the quick removal."*

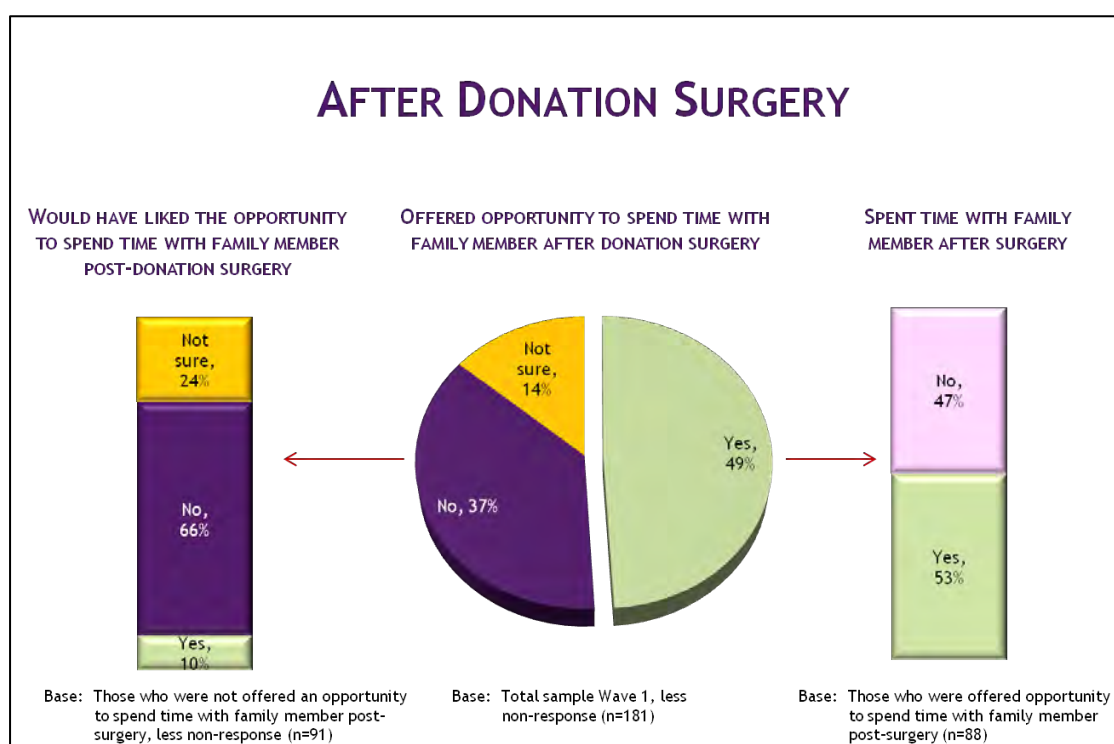
2010

## 8.0 AFTER DONATION SURGERY

As shown in Figure 36, half of donor family members in 2010 and 2011 were offered the opportunity to spend time with their family member after donation surgery. Of those who were offered, just over half (53%) opted to see their family member after surgery.

Ten percent (10%) of those who were not offered this opportunity would have liked to have spent time with their family member post-surgery.

Figure 36: After donation surgery



*Seeing their deceased loved one after donation surgery is not something that all family members are comfortable with. However, as it is a personal decision to be made by individual family members, the opportunity should at least be offered. When offered, it is important to let family members know about the physical changes that would have taken place in their family member, so that a fully informed decision can be made.*

*“Afterwards, my husband was in a private area of ICU and I wasn't prepared for how white he looked or how cold he was, considering his warmth and colour before the surgery. I should have known but my brain wasn't functioning that well.”*

2010

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*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.*

---

Unfortunately, there have been some instances where family members have opted to see their loved one after donation surgery, and the experience has been less than satisfactory.

In many ways, seeing their loved one again is the final opportunity for closure. For families who have struggled somewhat with their donation decision, seeing their family member after surgery, still being treated with care and consideration, will go a long way to ensuring that their donation decision will sit well with them for years to come.

If possible, we suggest a private room that has a feeling of warmth. As suggested by one donor family member below, a small gesture such as a vase of flowers in the room, would mean a lot.

*“I asked to spend time with him after the donation surgery. It felt like we were being hurried. They had my son's organs and now we could leave. Putting a vase of flowers in the room/ward where he was would have made it less clinical, even a chair to sit on.”*

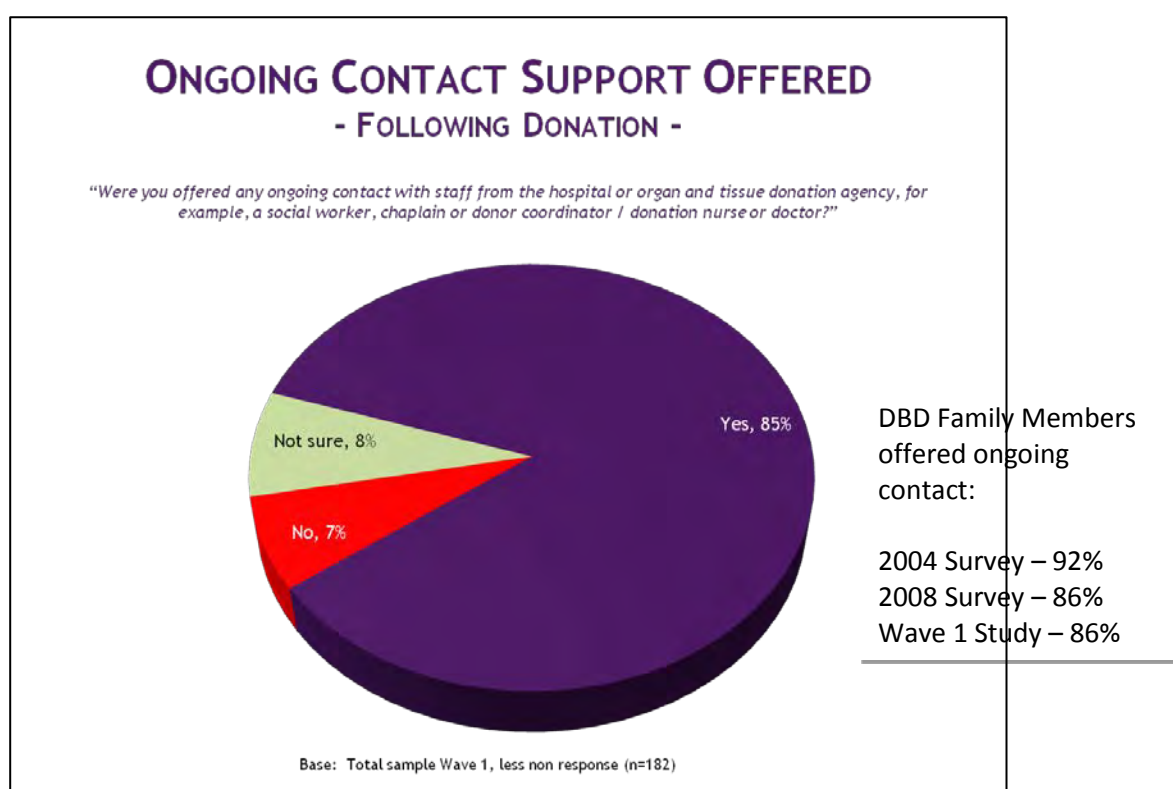
2011

## 9.0 FOLLOW-UP SERVICES

### 9.1 SUPPORT RECEIVED

In 85% of cases (86% for BD families and 80% for DCD families), families were offered ongoing contact with staff from the hospital or organ and tissue donation agency. One in 14 family members (7%) were not offered any ongoing support.

Figure 37: Ongoing contact support offered following donation



In total, 82% of donor family members received ongoing contact from at least one staff member. This is consistent with 2008 findings.

For 2010 and 2011 donor families, support was mostly received from Donor Family Support Coordinators (59% of families received support from DFSCs). Just over half of families (52%) received contact from the Donor Coordinator/ Donation Nurse or Doctor, while significantly fewer families received ongoing contact from a social worker or chaplain (13% and 8% respectively).



Figure 38: Receipt of ongoing contact

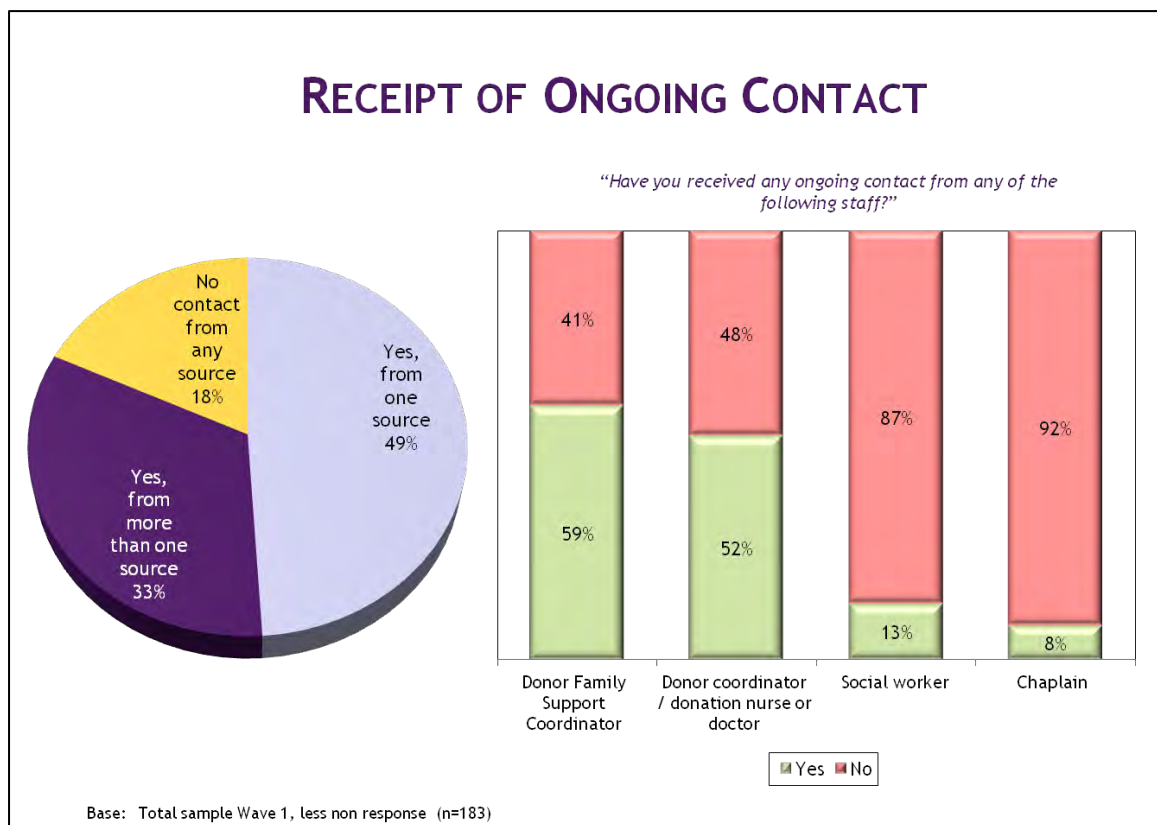


Table 19 details the support distribution by state. Donor families in New South Wales are more likely to have received ongoing contact from a DFSC than in families in other states/territories.

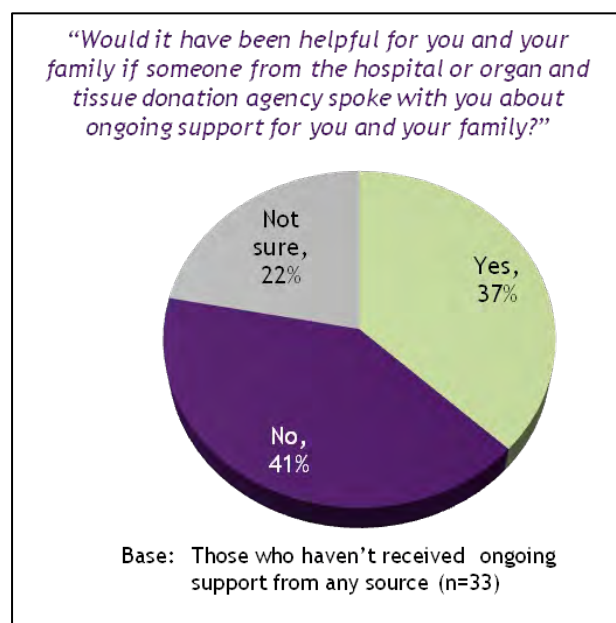
Table 19: Support by state/territory

RECEIVED SUPPORT FROM:	QLD (N=45)	ACT (N=6)*	NSW (N=54)	VIC (N=39)	TAS (N=12)*	SA (N=20)	WA (N=6)*
Donor Family Support Coordinator	69%	50%	76%	39%	67%	30%	50%
Donor coordinator / donation nurse or doctor	58%	83%	43%	28%	83%	70%	83%
Social worker	18%	33%	15%	10%	17%	0%	0%
Chaplain	2%	33%	7%	10%	17%	5%	0%
RECEIVED NO CONTACT	13%	17%	11%	36%	8%	25%	0%

\* Caution: Small base

Around one in five donor family members (18%) did not receive any ongoing contact or support from any source. This is higher for families where the donation took place in Victoria, as shown in Table 19 above. Of family members who did not receive ongoing contact, approximately two in five (37%) would have found it helpful if someone from the hospital or organ and tissue donation agency spoke with them about ongoing support for their family.

Figure 39: Helpfulness of ongoing support if offered



*“I think they should follow it up, like every three months or so. To give you a call, see how you are coping and if there is anything that they can help you with. That type of conversation would be very good. A visit from DonateLife to the house. That'll help immensely the people who are still grieving.”*

2011

## 9.2 IMPACT OF ONGOING CONTACT

Six in ten donor family members (57%) who received ongoing contact found it extremely helpful; a further 37% found it helpful 'to some extent'. Just 6% of donor families did not find the ongoing contact helpful.

*“I felt they were just using a standard format to discuss the matter with me. They did not know the situation or the dynamics of my family and therefore had no idea that what they were saying even made sense.”*

2011

*Care must be taken that all ongoing contact provided to family members is genuine and tailored to the needs of individual family members.*

Family members who found the ongoing contact helpful appreciated being given updates on the progress of recipients. Further, this ongoing contact made family members feel valued which in turn reinforced their donation decision.

Table 20: Helpfulness of ongoing contact

<i>"In what way was the ongoing contact helpful?"</i>	<i>n=122</i>
Found out the outcome of the donation / gave us progress updates on the recipients	30%
Felt like we weren't forgotten / felt like we were cared for	20%
Provided comfort / very compassionate	17%
Our family member is recognised and appreciated for their contribution	16%
Helped the grieving process / gave us closure	13%
It provided useful information / answered our questions	9%
Helped just being able to talk about my family member	7%
Nice to know the support is there if we need it	3%
The support helped validate our decision	2%
Other one-off mentions	11%
Don't know	1%

*"Phone calls from the Donor Coordinator/Nurse cushioned the intensity of this whole experience. We didn't feel alone or forgotten. We were able to discuss/talk with someone who really understood what we were going through."*

2010

*"Our family support coordinator has been wonderful in contacting us to ask how we're going and has given some updates on how the donor recipients were faring. This contact has been of great comfort."*

2011

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*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 act is appreciated. One of the greatest gifts for family members is to know how recipients are doing.*

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*“It reinforced the fact that they were genuine and not just there to secure the organ donations.”*

2011

---

*Donor Family Support Coordinators can play a powerful role in helping families navigate their grief. As many families consent to donation to bring something positive to an unbearable negative, knowing that the donation is appreciated helps to reaffirm and validate their decision.*

---

### 9.3 SERVICES RECEIVED

Figure 40 shows the services that were received by donor family members and whether those services were helpful. In addition, it shows the proportion of family members who did not receive each service, but who would have liked to.

For instance, eight in ten donor family members (82%) received basic information about the recipients. Of these, 94% found the information to be helpful. Of the 18% who did not receive this information, 87% would have liked to have received it. There are no significant differences between 2010 and 2011 donor families.

Figure 40: Services received/ would like to have received



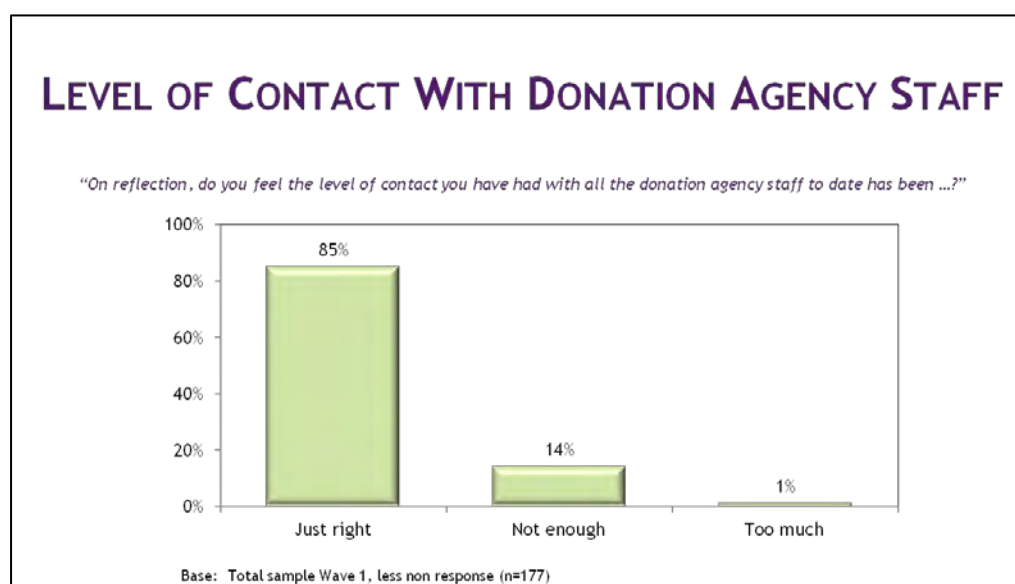
*Consistency of information dissemination is required. Of particular importance is providing basic information about the transplant recipients.*

*Ensure all family members are given the opportunity to opt in to the process of receiving information and support. Particular care should be taken to ensure families in regional areas are supported.*

## 9.4 AMOUNT OF CONTACT WITH DONATELIFE

As shown in Figure 41, most donor family members feel the contact they have had with donation agency staff has been at the right level. One in seven (14%) family members feel that contact with donation agency staff has been lacking.

Figure 41: Level of contact with donation agency staff



There are no statistically significant differences by state/ territory.

Table 21: Level of contact with donation agency staff, by state/territory

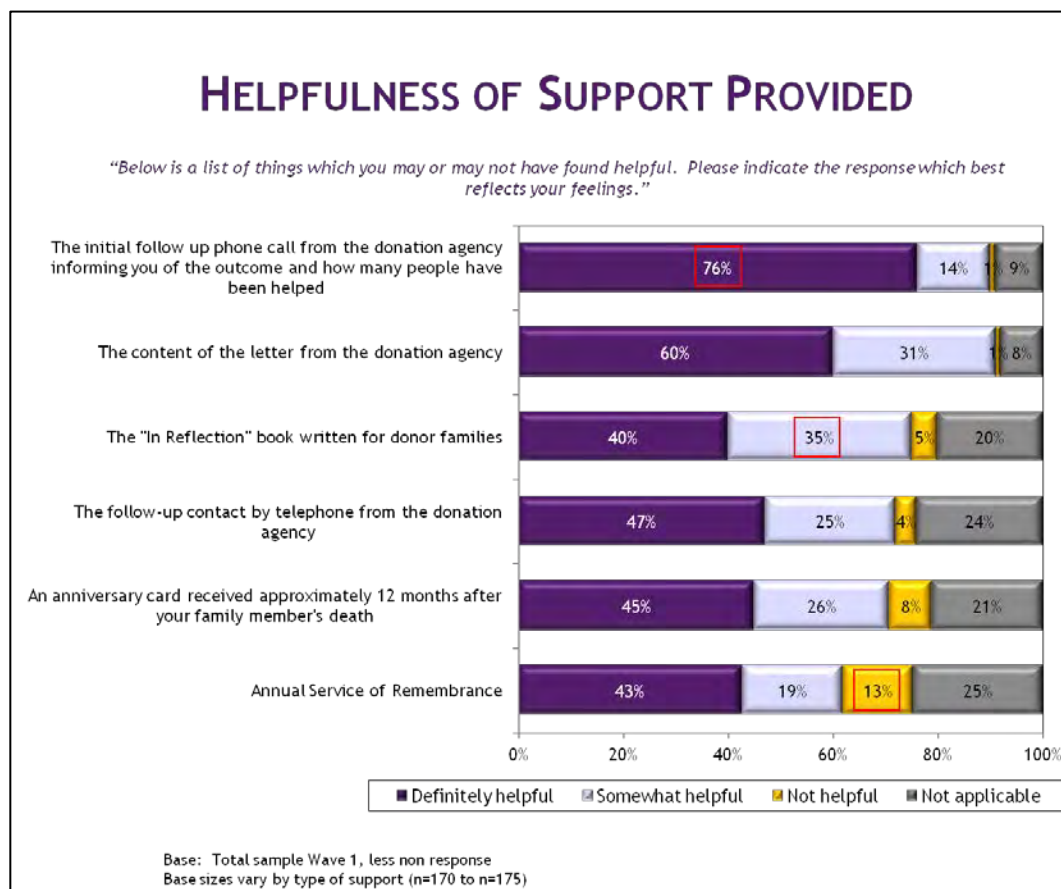
	TOTAL (N=177)	QLD (N=43)	ACT (N=5)*	NSW (N=53)	VIC (N=39)*	TAS (N=12)*	SA (N=19)*	WA (N=6)*
Just right	85%	84%	80%	92%	82%	75%	79%	100%
Not enough	14%	16%	20%	8%	18%	25%	16%	0%
Too much	1%	0%	0%	0%	0%	0%	5%	0%

\* Caution: Small base

## 9.5 HELPFULNESS OF SUPPORT PROVIDED

Respondents were asked to rate the level of helpfulness of six support services provided, that they may or may not have received. Of most use to donor family members is the initial follow up phone call from the donation agency informing them of the outcome of donation. This information is crucial for family members and when a transplant goes well and the health of recipients improves as a result, donor families feel a sense of relief and pride.

Figure 42: Helpfulness of support provided



As shown above, the annual Service of Remembrance is definitely helpful for 43% of family members and somewhat helpful for 19% of family members. One in eight donor family members (13%) do not find the service helpful.

*"The stories of the recipients. It's actually magic. Oh it makes me feel great. You know. There's people not on dialysis anymore.. And there's someone who's got a new heart. Someone's got his kind heart in his body."*

2011

For some, the Service of Remembrance is another way of talking about their loved one and remembering that person.

*"We went to the DonatLife Remembrance Day with some friends. Three of us went. And that was the opportunity to have his photo up with everybody else's. So that was quite a moving day."*

2010

Some of those who do not find the Service helpful feel it should be more spiritual than religious. Others feel that a separate Service for younger people would be beneficial.

*“For me it was like My God, no thank you. Hang out with all the people I don’t know, they don’t know me. Only brought together through tragedy. No thanks.”*

2011

## 9.6 OTHER SERVICES

Donor family members were asked what other services could be offered to better support family members. As shown in Table 22, around 1 in 5 donor family members feel more information on recipients or more contact with recipients would be useful.

Table 22: Other services to support donor family members

	N=114
None / can’t think of any	34%
I got all the support I needed / am happy with the support	20%
Would love to know how the recipients are going / more updates on recipients	15%
Would like to meet recipients or have more contact with them	4%
How to cope with grief	4%
More contact in general / check to see how we’re going	4%
Allow more than one relative to be a contact person / provide support for all family members	3%
Set up a donate family group in our area	3%
More access to social workers / counsellors / ongoing counselling	2%
Extended counselling to extended family members, not just immediate family	2%
We would like to be more involved in Donate Life campaigns / more information on events to raise awareness	2%
Better support in regional areas	2%
Other one-off mentions	12%

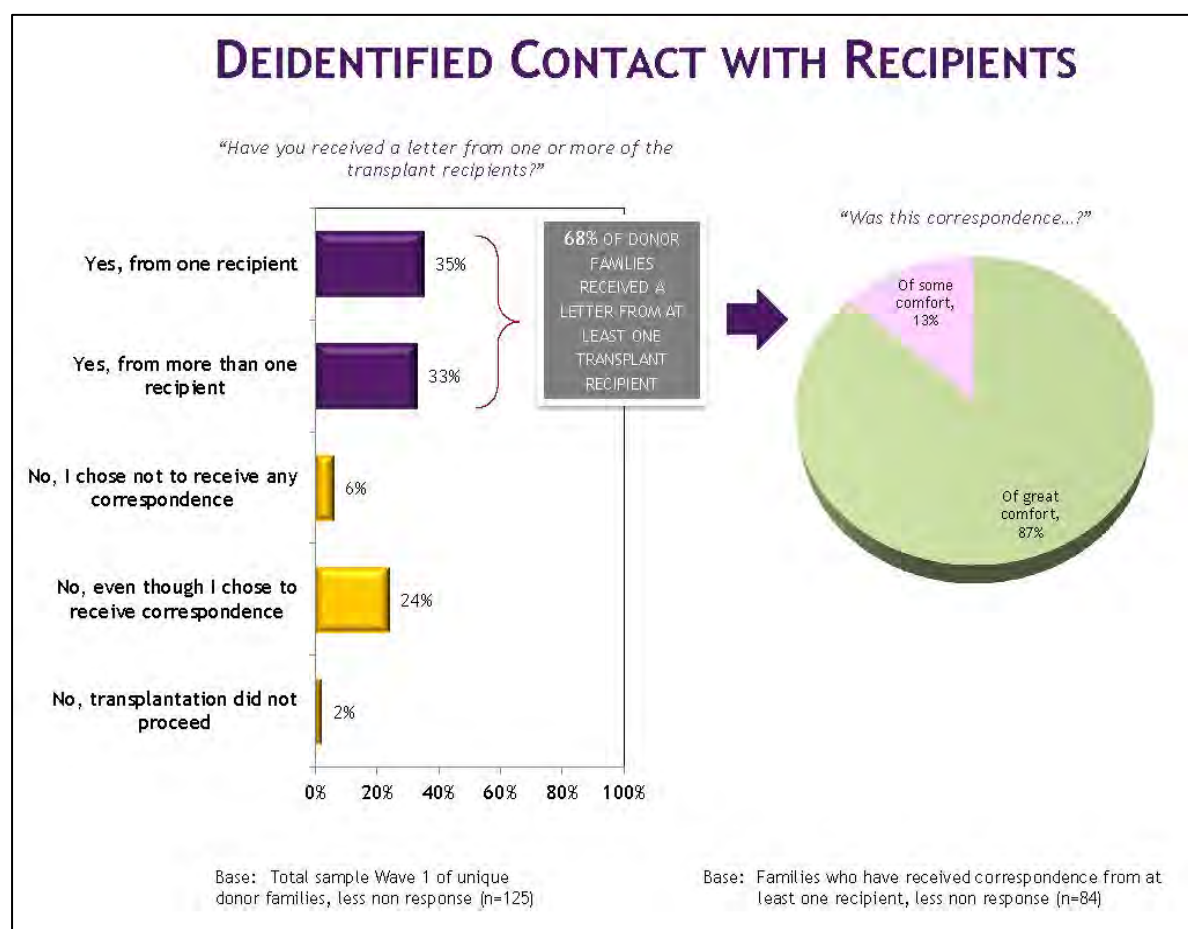


## 10.0 CONTACT WITH RECIPIENTS

Approximately seven in every ten donor families in 2010 and 2011 received a letter from at least one transplant recipient. This letter provided a great deal of comfort to these families.

One quarter of donor families in 2010 and 2011 (24%) have not received any correspondence from recipients, even though they chose to.

Figure 43: Contact with recipients



*"It made a big difference hearing from the recipients and knowing how much better their life has become through my husband's donation."*

2011

## 10.1 IMPACT OF NO CONTACT WITH TRANSPLANT RECIPIENTS

Family members who chose not to receive any correspondence from transplant recipients (6% of donor families) are generally comfortable with the decision they made.

*“Good. I know someone has received benefit, that’s enough.”*

2011

In some cases, family members fear the thought of the transplant being unsuccessful, and would rather hold onto the thought that the donations have benefited someone.

*“I do not want to know if the transplants were successful or not, as I want to think that the donations have all been useful.”*

2010

There are mixed feelings amongst families who chose to receive correspondence from transplant recipients but are yet to receive any (24% of donor families). Some are fine about it and say they respect the privacy of transplant recipients, while others are a little disappointed and sad and hope to hear from the recipients one day.

*“I do not expect it and as far as I am concerned, there is no need to. It is not about me – it is about the recipient being given hope and if they can use these organs/ tissues I wish them and their family well.”*

2011

*“I would have loved to hear how the person or persons got on and whether everything is still ok.”*

2010

For some donor families, not being acknowledged by at least one recipient family is disappointing and hurtful.

*“Very sad. I was hopeful that the recipient, any recipient, would contact us, with stories of hope and gratitude, but alas we haven’t received any – yet (staying positive).”*

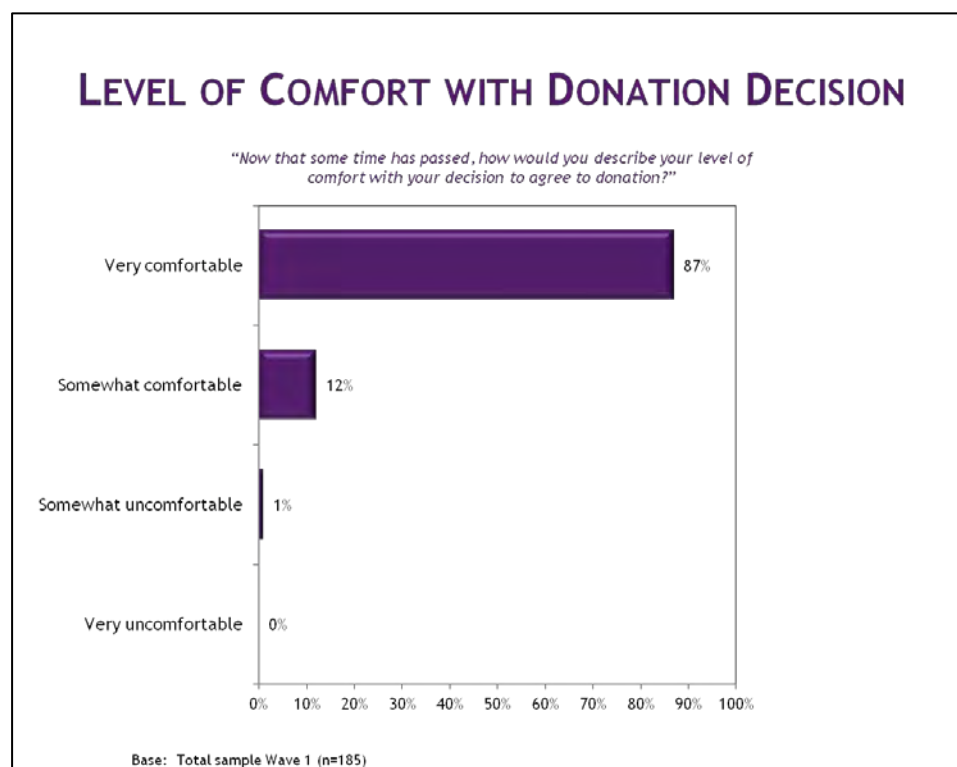
2011

## 11.0 ON REFLECTION

### 11.1 LEVEL OF COMFORT IN DECISION

For 99% of donor families, the decision to donate their family member's organs still sits well with them today; 87% very much so.

Figure 44: Level of comfort with donation decision

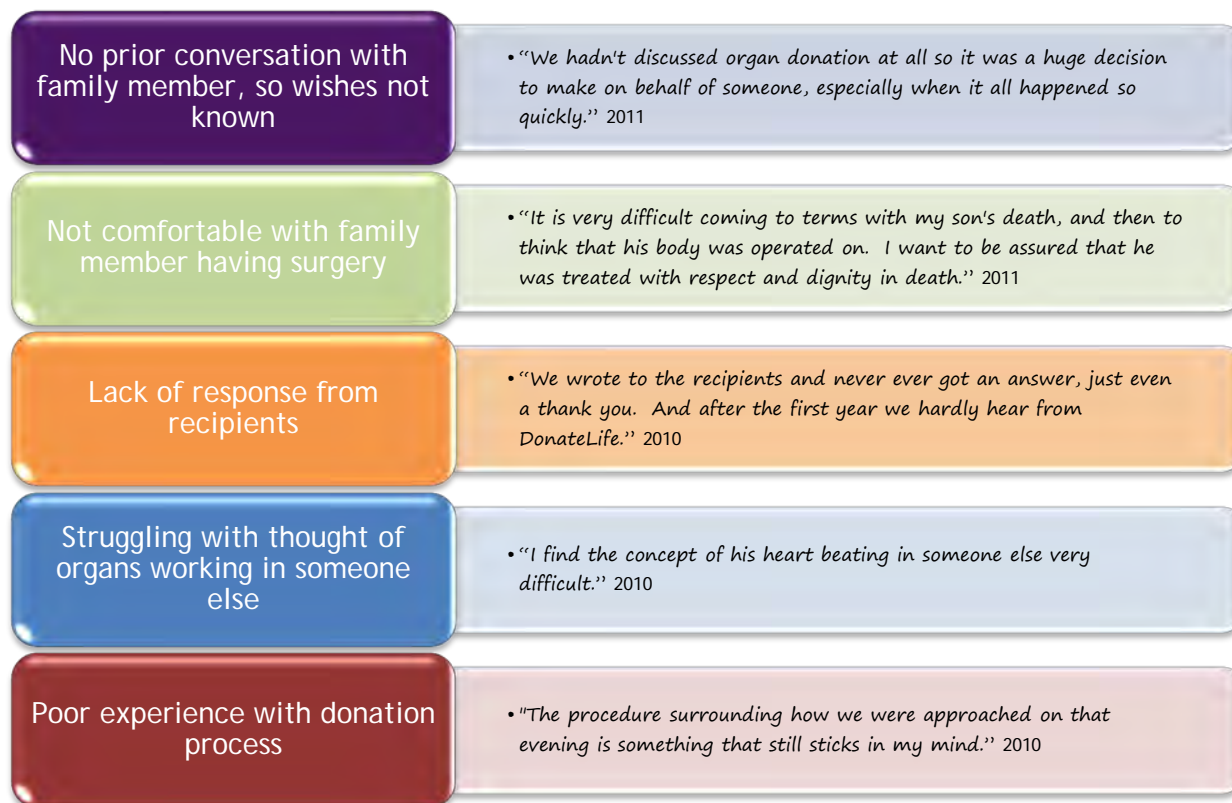


*"I feel entirely satisfied with the decision and even a little proud of it."*

2011

There are five key reasons for families being less than entirely comfortable with their donation decision. They are:

Figure 45: Key reasons for not feeling comfortable with donation decision

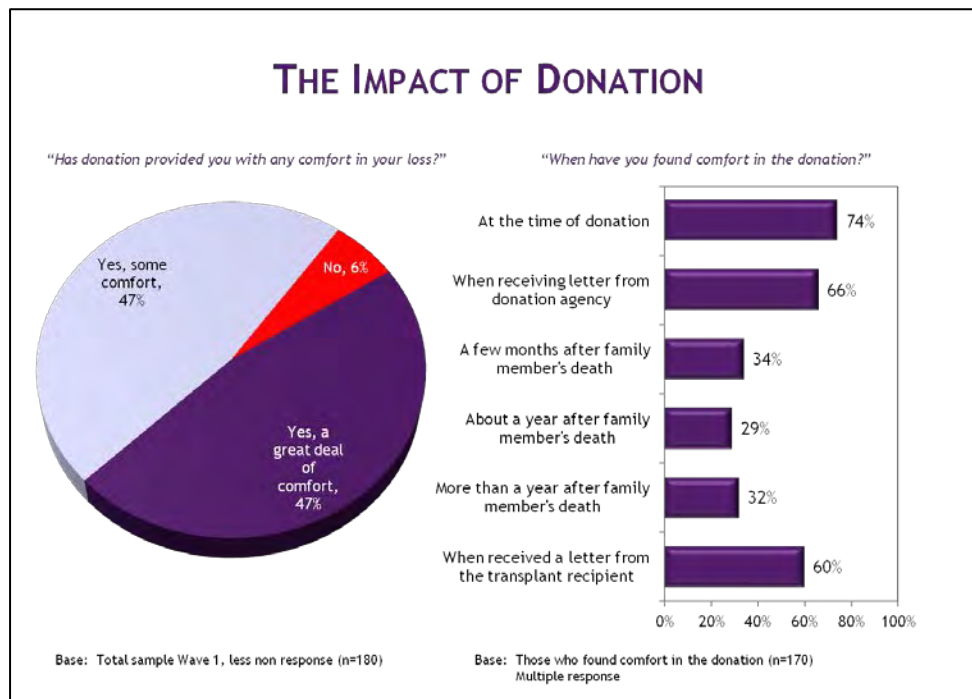


## 11.2 THE IMPACT OF DONATION

Organ donation provides a great deal of comfort in the days, weeks, months and years following a loved one's death. In addition, organ donation provides *immediate* solace (whilst at the hospital) to family members in both a *practical* and an *emotional* way. In fact, 74% of donor family members found comfort in donation *at the time of donation* (Figure 46).

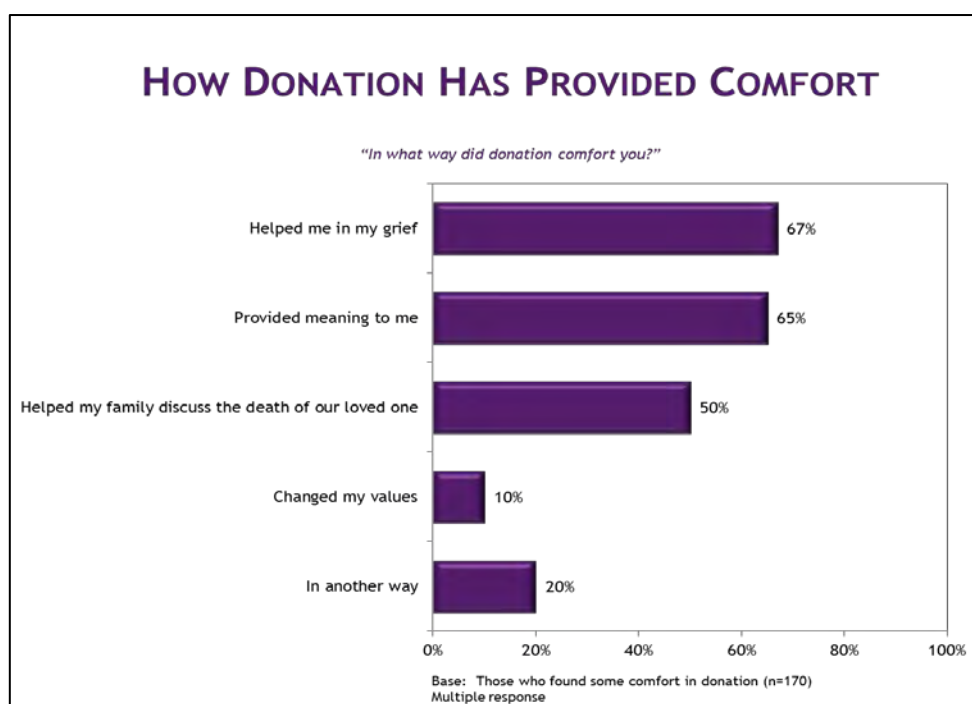
In terms of immediate solace, emotionally, family members take comfort from believing that their loved one is helping others; it is their last act and almost gives some purpose to their death. Practically, organ donation gives family members additional time to spend with their loved one while donation arrangements are being made.

Figure 46: The impact of donation



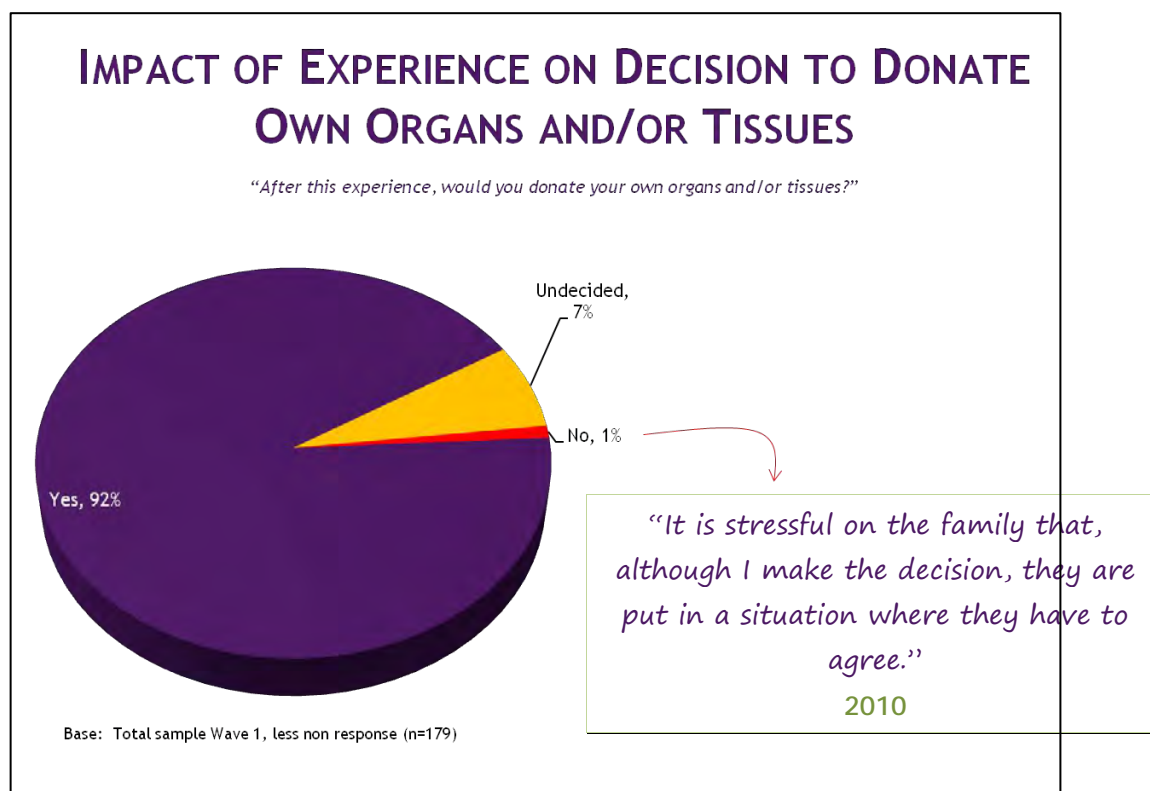
In terms of *how* donation helps, two thirds (67%) of donor family members who found comfort in donation feel that it helps them in their grief, and a further two thirds (65%) feel that donation provides meaning to them.

Figure 47: How donation has provided comfort



After the donation experience, 92% of donor family members would donate their own organs and/or tissues after death. One in 14 family members (7%) is undecided, while 1% would not consent to donation after death.

Figure 48: Impact of experience on decision to donate own organs and/or tissues



### 11.3 THE LITTLE THINGS THAT MATTER

Naturally the experience for families leading up to and during the process of a loved one's organ donation is a very distressing one. However, as discovered throughout the research and particularly during the face-to-face interviews with family members, certain gestures of hospital staff or donor coordinators can make a big difference to families.

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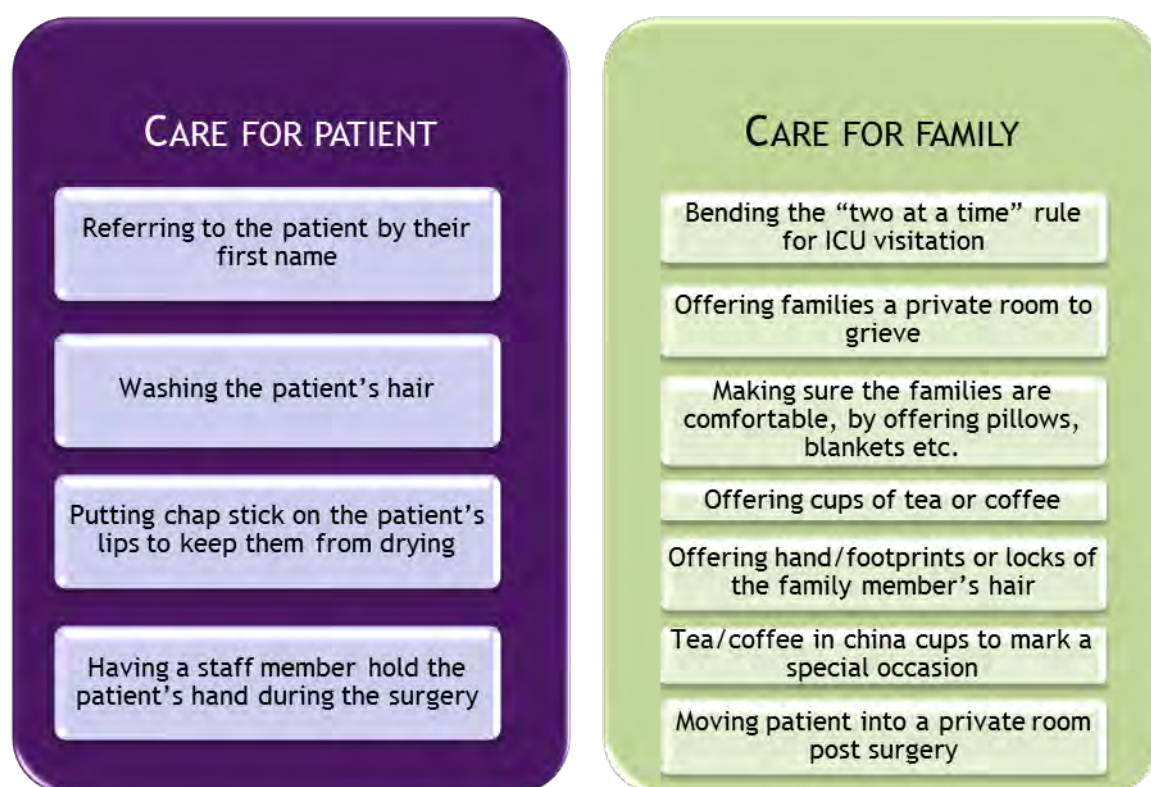
*The little things that staff do in demonstrating care and respect can have a profound effect on family members and can influence their whole donation experience.*

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Figure 49 shows some examples of 'the little things' that had a profound and positive impact on family members, whether they realised it at the time or upon reflection of the death of their loved one. These acts demonstrated an extra level of care and respect, either for the patient or for the patient's family.



Figure 49: Behaviours that have a positive impact on families



At the core, families long for their loved one to be treated with kindness and respect during their final hours and once donation surgery has taken place.

*“The staff continually referred to my brother by name throughout the whole process. At no time did I hear him referred to as ‘the patient’ or ‘the deceased’. This was very important to me as he was not a patient or the deceased, he was my brother and he had a name.”*

2010

Ensuring family members are as comfortable as they can be makes a distressing situation a little more bearable.

Allowing family members special moments with their loved one, or providing mementos of their loved one, such as locks of hair or hand/footprints, are very much treasured.

*“The DonateLife staff were amazing. All the additional things they did such as the handprint and locks of hair were an amazing addition and something that we cherish.”*

2011



## 12.0 MEETING THE NEEDS OF FAMILIES - SUMMARY

Family responses to the Wave 1 Donor Family Study provides guidance on the needs of families at each broad stage of the donation process.

Table 23: Meeting the needs of families

STAGES	EMOTIONAL STATE OF FAMILY	INFORMATION		
		NEEDS	DELIVERY	TIMING
1. AT THE HOSPITAL (PRIOR TO CONSENTING)	<ul style="list-style-type: none"> <li>Shock</li> <li>Confusion</li> <li>Distress</li> <li>Disbelief</li> </ul>	<ul style="list-style-type: none"> <li>Clarity of situation/ facts</li> <li>No false hope</li> <li>Compassion from staff</li> <li>Time to absorb information</li> <li>Private time with family member</li> </ul>	<ul style="list-style-type: none"> <li>Treat as individuals</li> <li>Understand family dynamic (next of kin and other family members)</li> <li>Simple language/ layman's terms</li> <li>Be aware of discussions other medical staff have had with family (to avoid conflicting information)</li> <li>Succinct &amp; sincere</li> </ul>	<ul style="list-style-type: none"> <li>As information becomes available</li> <li>Regular updates to family</li> </ul>
2. THE DONATION CONVERSATION	<ul style="list-style-type: none"> <li>Devastated</li> <li>Conflicted</li> <li>Pressured</li> </ul> <p>Sleep deprived, so emotions are heightened</p>	<ul style="list-style-type: none"> <li>Varying depth of information (it will depend on each family)</li> <li>Opportunities to ask questions</li> <li>Listened to/ heard</li> <li>Private time to discuss</li> </ul>	<p>SEEKING CONSENT</p> <ul style="list-style-type: none"> <li>Ensure families are 'on the same page' and have a full understanding of the situation</li> <li>Hospital staff (nurse or doctor) to raise the topic first (i.e. rather than DonateLife team)</li> <li>Provide a private room for discussion</li> <li>Verbal communication in layman's terms</li> <li>Seek permission for discussion with DonateLife</li> </ul> <p>THE DONATION CONVERSATION</p> <ul style="list-style-type: none"> <li>Written information to be provided</li> <li>Do not use the word "harvest"</li> <li>Be aware of the level of detail required / not required by each family</li> <li>Provide broad timeframe for donation decision and explain reasons for timeframe</li> </ul>	<ul style="list-style-type: none"> <li>Approximately 1 hour after delivery of the brain death or expected death news</li> </ul>
3. BEFORE	<ul style="list-style-type: none"> <li>Exhausted</li> </ul>	<ul style="list-style-type: none"> <li>Consistent approach to pre-</li> </ul>	<ul style="list-style-type: none"> <li>Experienced staff who are knowledgeable</li> </ul>	<ul style="list-style-type: none"> <li>As information</li> </ul>



STAGES	EMOTIONAL STATE OF FAMILY	INFORMATION		
		NEEDS	DELIVERY	TIMING
DONATION SURGERY	<ul style="list-style-type: none"> <li>Anxious</li> <li>Somewhat accepting</li> </ul> <p>Can start to feel:</p> <ul style="list-style-type: none"> <li>Nervous</li> <li>Overwhelmed</li> <li>Doubtful of decision</li> <li>Distressed</li> <li>Abandoned</li> </ul>	<ul style="list-style-type: none"> <li>consent</li> <li>Informed of what is involved and why</li> <li>Acknowledgement of contribution</li> <li>To be kept informed (even when no news)</li> <li>Realistic about likely outcomes</li> <li>"Sitting" time with family member</li> <li>Sufficient time to say goodbyes</li> </ul>	<ul style="list-style-type: none"> <li>about processes, but can sense when things become too difficult</li> <li>Efficient</li> <li>Informative</li> <li>Offer an "out" in non-judgemental way</li> </ul>	<ul style="list-style-type: none"> <li>becomes available</li> <li>Regular updates to family</li> </ul>
4. AFTER DONATION SURGERY	<ul style="list-style-type: none"> <li>Sad</li> <li>Exhausted</li> <li>Proud of family member</li> </ul>	<ul style="list-style-type: none"> <li>Offer to spend time with family member post-surgery</li> <li>Realistic expectations regarding physical appearance of family member</li> <li>Outcomes of surgery (successful or not)</li> </ul>	<ul style="list-style-type: none"> <li>Clear information about what may be expected (e.g. physical changes in family member)</li> <li>Private room, tastefully decorated (i.e. not "cold") to spend time with family member post-surgery</li> </ul>	<ul style="list-style-type: none"> <li>Outcome of surgery to be delivered to family members immediately post-surgery</li> </ul>
5. FOLLOW-UP SERVICES	Range of different feelings from calm and accepting, to disappointed and upset	<ul style="list-style-type: none"> <li>Know what services are available</li> <li>All family members to be included / offered support</li> <li>Outline of how the services can help and what is involved</li> <li>Outcomes for transplant recipients</li> </ul>	<ul style="list-style-type: none"> <li>Genuine</li> <li>Tailored to individual needs</li> <li>Ongoing (unless requested otherwise)</li> <li>Consistent delivery</li> <li>Use donor's first name in discussions with family members</li> </ul>	<ul style="list-style-type: none"> <li>As required by individual family members</li> </ul>
APPROACH ACROSS ALL STAGES: COMPASSIONATE   RESPECTFUL   EMPATHETIC   CARING   CONSIDERATE   SENSITIVE   PROFESSIONAL				

# Glossary of Key Terms

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

TERM	DEFINITION
<b>Australasian Transplant Coordinators Association (ATCA)</b>	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.
<b>Brain Death Testing</b>	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.
<b>DonateLife agencies</b>	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.
<b>Donation after brain death (BD)</b>	When organ donation occurs after brain death has been determined and before cessation of circulation.
<b>Donation after circulatory death (DCD)</b>	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).
<b>Donor Family Support Coordinator (DFSC)</b>	Support Coordinators provide counselling, coordinate and assist in the provision of support to donor families.
<b>Donor Family Support Implementation Group (DFSIG)</b>	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.
<b>Family</b>	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).
<b>Hospital staff</b>	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 of participants; interviews are audio-taped for later transcription and analysis.
National Ethics Application Form (NEAF)	An online tool for researchers of all disciplines to complete research ethics proposals for submission to HRECs and to assist HRECs to consistently and efficiently assess these proposals.
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.
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.
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.
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

### Family Experiences of Organ and Tissue Donation A National Family Survey

This survey is designed to help staff involved in organ and tissue donation provide the best possible service to the families of organ and tissue donors. Your responses to the questions in this survey will assist in this review process.

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 details of the study have been given to you in the letter of invitation and the Participant Information Statement.

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.

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 or Silvia Munoz at Proof on 07 3839 4446 or email [rhonda@proofresearch.com.au](mailto:rhonda@proofresearch.com.au).

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

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

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

Yours sincerely



Rhonda McLaren  
Director  
Proof Research



Tel. 07 3839 4446 | Mob. 0419 706 801 | Email. [Rhonda@proofresearch.com.au](mailto:Rhonda@proofresearch.com.au) | Web. [www.proofresearch.com.au](http://www.proofresearch.com.au)  
Street. 549 Queen Street, Brisbane QLD 4000 | Mail. P.O. Box 6987, Upper Mount Gravatt QLD 4122 | ACN. 158 630 481

## SECTION 1 - YOUR FAMILY MEMBER AND THE DECISION TO DONATE

We'd like to understand more 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. How old was your family member when he/ she died? \_\_\_\_\_ years

3. When did your family member die? \_\_\_\_\_ month \_\_\_\_\_ year

4. 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

5. Had you discussed donation with your family member at any time prior to being asked to consider donation? (Please tick ☒ one box only)

Yes, we discussed it and I knew their 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

6. 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

7. 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 (✍ _____)	<input type="checkbox"/> 10

8. 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 Q10
Somewhat comfortable	<input type="checkbox"/> 2		
Somewhat uncomfortable	<input type="checkbox"/> 3		
Very uncomfortable	<input type="checkbox"/> 4		

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

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

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## SECTION 2 - AT THE HOSPITAL

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

11. 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

12. 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	<input type="checkbox"/> 1
To some extent	<input type="checkbox"/> 2
Not at all	<input type="checkbox"/> 3

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

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14. 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"/>

15. 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

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

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Please only answer Q17-21 if your family member was determined to have brain death.

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

} → **GO TO Q20**

18. If you answered 'yes' to Q17. Did you choose to be present during the brain death testing? (Please tick ☒ one box only)

Yes ☐ 1

No ☐ 2

→ **GO TO Q21**

19. If you answered 'yes' to Q18. 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 Q21**

20. If you answered 'no' or 'not sure' to Q17. Would it have helped you to have the option of being present during the brain death testing?

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

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

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### SECTION 3 - DISCUSSING ORGAN AND TISSUE DONATION

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

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

Doctor

☐ 1

Nurse

☐ 2

Donor coordinator

☐ 3

Family member/ close friend

☐ 4

Other (*relationship to you:* \_\_\_\_\_)

☐ 5

I raised it myself

☐ 6

Can't remember

☐ 9

→ GO TO Q28

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

Before I was told of my family member's brain death or expected death

☐ 1

At the same time as I was told of my family member's brain death or expected death

☐ 2

Within an hour of being told of my family member's brain death or expected death

☐ 3

More than 1 hour after being told of my family member's brain death or expected death

☐ 4

Can't remember

☐ 9

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

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

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26. Do you remember whether any of the staff were organ and tissue donation (DonateLife Network) staff? (Please tick ☒ one box only)

Yes they were ☐ 1

No they weren't ☐ 2

Can't remember ☐ 3

27. 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

28. 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"/>

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

Yes ☐ 1  
 No ☐ 2 → GO TO Q31  
 Not sure ☐ 3 → GO TO Q31

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

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### Consenting to organ and/or tissue donation

31. Did you meet with the donor coordinator or donation nurse or doctor? (Please tick ☒ one box only)

Yes ☐ 1  
 No ☐ 2 → GO TO Q34  
 Not sure ☐ 3 → GO TO Q34

32. Which of these statements best describes your understanding of the donation process after speaking with the donor coordinator/ donation 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

33. 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

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

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

35. 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 Q39  
 I can't recall ☐ 4 → GO TO Q39

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

Yes, in detail ☐ 1  
 Yes, skimmed through it ☐ 2  
 No ☐ 3 → GO TO Q39

37. When did you read the information about donation? *(Please tick ☒ one box only)*

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

38. Was the written information useful? *(Please tick ☒ one box only)*

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

39. 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

40. What further comments would like to make? ✍

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41. 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

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

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### The donation process

43. 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

44. 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

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

Too detailed ☐ 1  
☐ 4

Too broad ☐ 2

Too brief ☐ 3

Just right

46. 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

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

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### After the donation surgery

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

Yes ☐ 1

No ☐ 2 → GO TO Q50

Not sure ☐ 3 → GO TO Q50

49. If you answered 'yes' to Q48. Did you spend time with your family member after the donation surgery? *(Please tick ☒ one box only)*

Yes ☐ 1

No ☐ 2

50. If you answered 'no' or 'not sure' to Q48. Would you have wanted the opportunity to spend time with your family member after donation surgery? *(Please tick ☒ one box only)*

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

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

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## SECTION 4 - FOLLOWING DONATION

### Follow up services from the hospital and the organ and tissue donation agencies

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

53. Have you received any ongoing contact from any of the following staff?

Social worker

Yes ☐ 1

No ☐ 2

Donor coordinator/ donation nurse or doctor

Yes ☐ 1

No ☐ 2

Donor Family Support Coordinator

Yes ☐ 1

No ☐ 2

Chaplain

Yes ☐ 1

No ☐ 2

54. If you ticked 'yes' to any in Q53. To what extent did you find this ongoing contact helpful?  
(Please tick ☒ one box only)

To a great extent ☐ 1

To some extent ☐ 2

Not at all ☐ 3

→ Why? \_\_\_\_\_

→ GO TO Q57

55. In what way was the ongoing contact helpful?

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56. If you ticked 'no' to all in Q53. 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

57. To help hospitals and organ and tissue donation agencies provide the best service, please tick ☒ the boxes indicating the services you received, those you found helpful and those you would have liked to receive:

	Received	Service helpful		Would have liked to receive
		Yes	No	
a) A follow up phone call from the donor coordinator/ donation nurse or doctor	<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"/>
c) Follow up from the donor family support coordinator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Information about bereavement support services in your area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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

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

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### Your feelings about organ and tissue donation

60. 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 Q63**

61. 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

62. 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

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

Yes      ☐ 1      →      **GO TO Q65**  
 No      ☐ 2  
 Undecided      ☐ 3

64. Please share your reasons for feeling this way. *✍*

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## Support provided

65. Below is a list of things which you may or may not have found helpful. Please indicate by ticking the box which best reflects your feelings.

	Definitely helpful 3	Somewhat helpful 2	Not helpful 1	N/A 9
a) The initial follow up phone call from the donation agency informing you of the outcome and how many people had been helped	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) The <u>content</u> of the letter from the donation agency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) The "In Reflection" book written for donor families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) The follow-up contact by telephone from the donation agency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) 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"/>
f) Annual Service of Remembrance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Contact with recipients

66. Have you received a letter from one or more of the transplant recipients? (Please tick ☒ one box only)

- ☐ 1 Yes, from one recipient  
☐ 2 Yes, from more than one recipient  
☐ 3 No, I chose not to receive any correspondence → GO TO Q68  
☐ 4 No, even though I chose to receive correspondence → GO TO Q68  
☐ 5 No, transplantation did not proceed → GO TO Q69

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

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

68. If you answered 'no' to Q66. How do you feel about not receiving any correspondence from the transplant recipients to date? ✍

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

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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 in the addressed pre-paid envelope provided, to:

PROOF RESEARCH, REPLY PAID 85405  
UPPER MOUNT GRAVATT QLD 4122



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

**NSW:** *DonateLife NSW*  
Alison Barnwell  
02 8566 1705

**ACT:** *DonateLife ACT*  
Sean Dicks  
02 6174 5625

**NT:** *DonateLife NT*  
Andrea James  
08 8944 1396

**QLD:** *DonateLife Qld*  
Diane Murphy  
07 3176 2350

**SA:** *DonateLife SA*  
Lesley Sheffield  
08 8207 7117

**VIC:** *DonateLife Vic*  
Michelle Skinner  
03 8317 7411

**TAS:** *DonateLife Tas*  
Verity Shugg  
03 6222 7806

**WA:** *DonateLife WA*  
David Easton  
08 9222 8557

## 2.0 QUESTIONNAIRE - FAMILIES WHO DECLINED DONATION

### Family Experiences of Organ and Tissue Donation A National Family Survey

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 we hope that this research will provide some insight into the reasons why people decline donation.

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 details of the study have been given to you in the letter of invitation and the Participant Information Statement.

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.

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 or Silvia Munoz at Proof on 07 3839 4446 or email [rhonda@proofresearch.com.au](mailto:rhonda@proofresearch.com.au).

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

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

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

Yours sincerely



Rhonda McLaren  
Director  
Proof Research



Tel. 07 3839 4446 | Mob. 0419 706 801 | Email. [Rhonda@proofresearch.com.au](mailto:Rhonda@proofresearch.com.au) | Web. [www.proofresearch.com.au](http://www.proofresearch.com.au)  
Street. 549 Queen Street, Brisbane QLD 4000 | Mail. PO Box 6987, Upper Mount Gravatt QLD 4122 | ACN. 158 630 481

## SECTION 1 - YOUR FAMILY MEMBER AND THE DECISION TO DONATE

We'd like to understand more about your family and the family member who died in hospital.

1. What relationship are you to the person who died in hospital? *(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 <i>(please specify)</i> _____ | <input type="checkbox"/> 5 |

2. How old was your family member when he/ she died? \_\_\_\_\_ years

3. When did your family member die? \_\_\_\_\_ month \_\_\_\_\_ year

4. 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 |

5. 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 |

6. Had you discussed donation with your family member at any time prior to being asked to consider donation? *(Please tick ☒ one box only)*

- |   |                            |
|---|----------------------------|
| Yes, we discussed it and I knew their 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 |

7. 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 easier         | <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 |

8. 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 |

9. 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 Q11 |
| Somewhat comfortable   | <input type="checkbox"/> 2 |   |           |
| Somewhat uncomfortable | <input type="checkbox"/> 3 |   |           |
| Very uncomfortable     | <input type="checkbox"/> 4 |   |           |

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

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

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## SECTION 2 - AT THE HOSPITAL

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

12. 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

13. 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

14. Please add any other comments you wish to make about your time at the hospital. ✍

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15. 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"/>

16. 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

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

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Please only answer Q18-22 if your family member was determined to have brain death.

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

} → GO TO Q21

19. If you answered 'yes' to Q18. Did you choose to be present during the brain death testing? (Please tick ☒ one box only)

Yes ☐ 1

No ☐ 2

→ GO TO Q22

20. If you answered 'yes' to Q19. 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 Q22

21. If you answered 'no' or 'not sure' to Q18. Would it have helped you to have the option of being present during the brain death testing?

Yes ☐ 1                      No ☐ 2                      Not sure ☐ 3

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

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### SECTION 3 - DISCUSSING ORGAN AND TISSUE DONATION

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

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

Doctor ☐ 1  
 Nurse ☐ 2  
 Donor coordinator ☐ 3  
 Family member/ close friend ☐ 4 → GO TO Q29  
 Other person (Relationship to you: \_\_\_\_\_) ☐ 5  
 I raised it myself ☐ 6 → GO TO Q29  
 Can't remember ☐ 9

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

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

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

Yes ☐ 1                      No ☐ 2                      Not sure ☐ 3

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

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27. Do you remember whether any of the staff were organ and tissue donation (DonateLife Network) staff? *(Please tick ☒ one box only)*

Yes they were ☐ 1      No they weren't ☐ 2      Can't remember ☐ 3

28. 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

29. 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"/>

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

Yes ☐ 1  
 No ☐ 2 → **GO TO Q32**  
 Not sure ☐ 3 → **GO TO Q32**

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

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#### Declining organ and/or tissue donation

32. Did you meet with the donor coordinator or donation nurse or doctor? *(Please tick ☒ one box only)*

Yes ☐ 1  
 No ☐ 2 → **GO TO Q34**  
 Not sure ☐ 3 → **GO TO Q34**

33. Which of these statements best describes your understanding of the donation process after speaking with the donor coordinator/ donation 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

34. 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 Q38  
 I can't recall ☐ 4 → GO TO Q38

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

Yes, in detail ☐ 1  
 Yes, skimmed through it ☐ 2  
 No ☐ 3 → GO TO Q38

36. When did you read the information about donation? *(Please tick ☒ one box only)*

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

37. Was the written information useful? *(Please tick ☒ one box only)*

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

38. 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

39. Are there any further comments you would like to make about this time? ✍

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40. 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

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

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## SECTION 4 - FOLLOW UP SERVICES

### Follow up services from the hospital and the organ and tissue donation agencies

42. 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 Q44  
No ☐ 2  
Not sure ☐ 3

43. If you answered 'no' or 'not sure' to Q42. Would you have liked somebody to contact you? ✍

Yes ☐ 1  
No ☐ 2 } GO TO Q47  
Not sure ☐ 3

44. If you answered 'yes' to Q42. From whom did you receive contact? *(Please tick ☒ all that apply)*

Social worker ☐ 1  
Organ donation agency ☐ 2  
Donor Family Support Coordinator ☐ 3  
Chaplain ☐ 4  
Other ( ) ☐ 5

45. 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 Q47

46. In what way was the contact helpful? ✍

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47. 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 organ donor agency ☐ 1  
Information about bereavement support services in your area ☐ 2  
A follow up visit/ phone call from the donor family support coordinator ☐ 3

48. What other services do you feel could be offered to better support family members? ✍

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## Your feelings about organ and tissue donation

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

Yes ☐ 1

No ☐ 2

Not sure ☐ 3

50. Please tell us why you feel this way. ✍

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51. 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?

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*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 as soon as possible in the addressed pre-paid envelope provided, to:*

PROOF RESEARCH  
REPLY PAID 85405  
UPPER MT GRAVATT QLD 4122

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

**NSW:** *DonateLife NSW*  
Alison Barnwell  
02 8566 1705

**ACT:** *DonateLife ACT*  
Sean Dicks  
02 6174 5625

**NT:** *DonateLife NT*  
Andrea James  
08 8944 1396

**QLD:** *DonateLife Qld*  
Diane Murphy  
07 3176 2350

**SA:** *DonateLife SA*  
Lesley Sheffield  
08 8207 7117

**VIC:** *DonateLife Vic*  
Michelle Skinner  
03 8317 7411

**TAS:** *DonateLife Tas*  
Verity Shugg  
03 6222 7806

**WA:** *DonateLife WA*  
David Easton  
08 9222 8557

### 3.0 PARTICIPANT INFORMATION STATEMENT AND CONSENT FORMS

THIS INFORMATION IS FOR YOU TO KEEP

#### PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

**Project Title: Survey of Family Experiences of Organ and Tissue Donation**

**Principal Researcher: Rhonda McLaren (Director, Proof Research)**

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This Participant Information Statement and Consent Form is 8 pages long. Please make sure you have all the pages.

#### 1. Your Consent

You are invited to take part in this research project entitled *Survey of Family Experiences of Organ and Tissue Donation*.

This Participant Information Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it. You do not have to take part in this research project and there will be no repercussions if you choose not to. Please read this Participant Information Statement carefully. Feel free to ask questions about any information in the Statement.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form you are acknowledging that you understand the information outlined in this Participant Information Statement and that you give your consent to participate in this research project.

#### 2. Description of the Project

The overall purpose of this project is to run a national survey with families across Australia who have consented or declined the donation of organs and/or tissues in a hospital setting. The research aims to capture the experiences of families during the process, from initial family donation conversations through to follow up support after a family decision has been made.

The Organ and Tissue Authority has commissioned Proof Research Pty Ltd for this important research project. Information collected from this survey will be kept confidential, accessible only by study staff. The Organ and Tissue Authority was established on 1 January 2009 as part of the Australian Government's National Reform Agenda, A World's Best Practice Approach to Organ and

Tissue Donation for Transplantation to create a nationally consistent and coordinated approach to organ and tissue donation and transplantation.

All families in Australia who consented to or declined donation during 2010 and 2011 are invited to participate.

This national survey has been carried out every four years since 1996, and each time, the findings have been critical to identifying gaps and improving services for families to better support them during such difficult circumstances. The Organ and Tissue Authority is committed to the ongoing improvement of support services available to families. This survey is therefore important to determine if current processes and mechanisms are supporting families sufficiently, and to identify what aspects of services need to be improved.

You are invited to participate in this research project and share your views and experiences.

Participation in this project will involve:

- Completing a questionnaire which will be available in paper-based form (and posted to you) or online.

AND/OR

- Taking part in an interview discussion with a senior qualified researcher.

Please note that all responses you provide in the questionnaire or discussions will remain confidential and no results will be released that may identify individuals. With your permission, interviews will be recorded for analysis purposes.

### **3. Benefits for families and the wider community**

This research provides families an opportunity to share their experiences and provide feedback in regards to what services they found beneficial to them and those that were not beneficial and could be improved or introduced.

The findings will be used by the Organ and Tissue Authority to address gaps and improve the donor support services and processes provided. The researchers acknowledge that you may not receive any direct or personal benefit from your participation in this study. If you and your family are still in contact with the Organ and Tissue Authority then you may experience some helpful changes in services received. Hopefully your contribution will also help to improve these important and sensitive services for other families faced with decisions concerning organ donation in the future.

#### 4. Potential Risks

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 a dedicated DonateLife Donor Family Support Coordinator in your State or Territory:

**NSW:** *DonateLife NSW*  
Alison Barnwell  
02 8566 1705

**ACT:** *DonateLife ACT*  
Sean Dicks  
02 6174 5625

**NT:** *DonateLife NT*  
Andrea James  
08 8944 1396

**QLD:** *DonateLife Qld*  
Diane Murphy  
07 3176 2350

**SA:** *DonateLife SA*  
Lesley Sheffield  
08 8207 7117

**VIC:** *DonateLife Vic*  
Michelle Skinner  
03 8317 7411

**TAS:** *DonateLife Tas*  
Verity Shugg  
03 6222 7806

**WA:** *DonateLife WA*  
David Easton  
08 9222 8557

## 5. Confidentiality and Disclosure of Information

Any information obtained in connection with this project and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law.

Proof Research Pty Ltd will be responsible for collecting and analysing your responses in the questionnaire and interview discussions to ensure the confidentiality of the answers. By providing consent to participate, you consent for your responses to be provided to Proof Research Pty Ltd. No survey results that may identify individuals will be released.

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 nor collected in the questionnaire.

Your responses will be collated together with those of other families, and the results of the research will be reported to the Organ and Tissue Authority in aggregate. At no point will the results of individual responses be reported.

If any information is published as a result of this research, your information will be provided in such a way that you cannot be identified.

## 6. Results of Project

If you would like to receive information regarding the results of the research project, including any published material, please contact the principal researcher at Proof Research, Rhonda McLaren. Her contact details are provided below in point 7.

## 7. Further Information or Any Problems

If you require further information or have any concerns about this project, you can contact Rhonda McLaren or Silvia Munoz at Proof Research on:

Rhonda McLaren  
(Director, Proof Research)  
[rhonda@proofresearch.com.au](mailto:rhonda@proofresearch.com.au)  
PH: 07 3839 4446/ 0419 706 801

Silvia Munoz  
(Senior Project Manager, Proof Research)  
[silvia@proofresearch.com.au](mailto:silvia@proofresearch.com.au)  
PH: 07 3839 4446

If you have any concerns or complaints on the ethical conduct of this research, please contact:

All States / Territories	The Secretariat Departmental Ethics Committee Department of Health and Ageing GPO Box 9848 MDP 132 CANBERRA ACT 2601 Email: <a href="mailto:ethics@health.gov.au">ethics@health.gov.au</a>
ACT	Research Office Level 6, Building 10 Canberra Hospital PO Box 11 Woden ACT 2606 Email: <a href="mailto:acthealth-hrec@act.gov.uk">acthealth-hrec@act.gov.uk</a>
Northern Territory	The Secretariat Central Australian Human Research Ethics Committee (CAHREC) Centre for Remote Health PO Box 4066 Alice Springs NT 0871 Email: <a href="mailto:cahrec@fliniers.edu.au">cahrec@fliniers.edu.au</a>

## 8. Other Issues

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 on (02) 6198 9881.

## 9. Participation is Voluntary

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.



A member of the research team will be available so that you can ask any questions you have about the research project before deciding. You can ask for any information you want. Only sign the Consent Form once you have had a chance to ask your questions and have received satisfactory answers. Before deciding whether or not to take part, you may wish to discuss the project with other family members.

#### 10. Ethical Guidelines

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 the Departmental Ethics Committee.

PLEASE COMPLETE BOTH CONSENT FORMS ON THE FOLLOWING PAGES.



## CONSENT FORM A (SURVEY)

### SURVEY OF FAMILY EXPERIENCES OF ORGAN AND TISSUE DONATION

1. The survey should take approximately 15 minutes to complete. Based on the information provided, would you like to participate in the survey?

Yes ☐ → Thank you. Please complete the remainder of this form.

No ☐ → Please return this form in the reply paid envelope provided.

Please note you do not have to return the survey form to us if you do not wish to participate.

2. How many family members, including yourself, would like to participate? \_\_\_\_\_ family members

Each family member may nominate how they would like to participate:

- By completing a paper questionnaire sent in the mail
- By completing the questionnaire online

Both methods will be anonymous (i.e. your responses will not be linked to your name, email address or any other identifying information). Proof Research will be responsible for collecting and analysing responses to the survey. Your responses will be grouped together with the responses of others. Raw data will be stored on a secure server in Brisbane, with access granted only to senior researchers of Proof Research.

Paper questionnaires will be sent to your home address for you to distribute to family members. Each questionnaire will be accompanied by a reply-paid envelope for ease of return. Should you prefer to complete the questionnaire online, please provide your email address for Proof Research to email you a link to the survey.

Please nominate how each family member would like to take part. In addition, each family member wishing to take part will need to provide their consent by signing and dating below

Name 1: _____	Paper <input type="checkbox"/>	Online <input type="checkbox"/>	Sign: _____	Date: _____
Name 2: _____	Paper <input type="checkbox"/>	Online <input type="checkbox"/>	Sign: _____	Date: _____
Name 3: _____	Paper <input type="checkbox"/>	Online <input type="checkbox"/>	Sign: _____	Date: _____
Name 4: _____	Paper <input type="checkbox"/>	Online <input type="checkbox"/>	Sign: _____	Date: _____
Name 5: _____	Paper <input type="checkbox"/>	Online <input type="checkbox"/>	Sign: _____	Date: _____
Name 6: _____	Paper <input type="checkbox"/>	Online <input type="checkbox"/>	Sign: _____	Date: _____

Please include the email address of each family member who wishes to complete the survey online.

Family member 1:	Name _____	email _____
Family member 2:	Name _____	email _____
Family member 3:	Name _____	email _____
Family member 4:	Name _____	email _____
Family member 5:	Name _____	email _____
Family member 6:	Name _____	email _____

**PARTICIPATION IS VOLUNTARY**

**CONSENT FORM B (PERSONAL INTERVIEW)**  
**SURVEY OF FAMILY EXPERIENCES OF ORGAN AND TISSUE DONATION**

In addition to the survey, we will be inviting a small number of families to participate in a one-on-one interview discussion with a researcher from Proof Research. Your feedback will be anonymous and will be used by donation agencies to ensure they provide the best possible service and support to families.

The interview will last for approximately 1 hour and will be conducted at a time and place suitable to you. With your permission, interviews will be recorded for the purposes of analysis. Families will be randomly selected to take part in this stage of the research.

**Would you like to participate?**

- ☐ Yes  
☐ No  
☐ I am unsure and would like to be contacted to learn more about this.

Please provide the following details:

Your Name: \_\_\_\_\_

Preferred method to be contacted:

- ☐ Phone *(please insert)* \_\_\_\_\_  
☐ Email *(please insert)* \_\_\_\_\_  
☐ Other *(please insert)* \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**THANK YOU FOR COMPLETING CONSENT FORM A AND B.**

**PLEASE RETURN THEM TO THE DONATELIFE NETWORK DONOR FAMILY SUPPORT CO-ORDINATOR IN YOUR  
STATE/TERRITORY.**

**PLEASE USE THE *REPLY PAID ADDRESS ENVELOPE* PROVIDED.**

*INSERT DONOR ID REFERENCE*