

# The impact of organ donation specialists on consent rate in challenging organ donation conversations

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Discussing the possibility of organ and tissue donation with the family of a dying patient is important for optimising donation outcomes and for respecting the right of individuals and families to donate. These organ donation conversations (ODCs) bring together staff, family and the patient's own previously expressed donation decisions. In the Australian setting, an individual's own decision as expressed on the Australian Organ Donor Register (AODR) is a powerful determinant of organ donation.<sup>1</sup> Likewise, family members knowing a loved one's wishes is a positive predictor of consent.<sup>2</sup> Such characteristics make ODCs easier to conduct and more likely to result in organ donation.

In contrast, in some ODCs it can be more challenging to support families in making an informed and lasting donation decision. When families have a less clear sense of their loved one's wishes, they may be quite uncertain about whether "yes" or "no" is the right answer for them. In this setting, ODCs are significantly more complex and challenging. However, evidence suggests that, when families are provided with sufficient accurate information in a supportive manner by skilled, informed and trained staff, consent rates are higher.<sup>3</sup>

Given the above considerations, a validated grading system that allows intensive care unit (ICU) clinicians to prospectively predict which ODCs are more likely to be challenging has substantial utility. Such a tool may help guide the training and deployment of expert donation requestors with the aim of delivering better family understanding and, potentially, higher donation rates. Grading tools may also help define groups within the broader population where interventions can be assessed using a research framework. An ideal grading system i) would be simple to understand; ii) would be quick and easy for clinicians to apply prospectively; and iii) would identify groups with substantially different outcomes (in this case consent rates). We selected the two variables of AODR registration status and family-raised interest in donation, as these were thought to be easily identifiable by clinicians as well as being quite specific to the individual patient. Neither variable is a pure demonstration of individual patient decision. AODR status is dependent on

## ABSTRACT

**Background:** Consent rates for organ donation conversations (ODCs) vary. We hypothesised that a simple grading system could identify challenging ODCs. We further hypothesised that challenging ODCs would have higher consent rates when conducted by ODC specialists.

**Objectives:** We aimed to study the utility of a grading system for ODCs and test the hypothesis that any training effect would be associated with improved consent rates in ODCs graded as most challenging.

**Methods:** We stratified 2017 Australian DonatLife Audit aggregate consent and donation discussion data into four ODC grades based on Australian Organ Donor Register (AODR) status and person first raising the topic of organ donation. Grade I: "yes" present on AODR and family-raised organ donation; Grade II: "yes" present on AODR, and clinician-raised organ donation; Grade III: no registration on AODR but family-raised organ donation; and Grade IV: no registration on AODR, and clinician-raised organ donation.

**Results:** Grade I ODCs were uncommon 7.7% (109/1420), with a consent rate of 95.4% (104/109). Grade IV ODCs were frequent (60.4%, 857/1420), with a consent rate of 41.4% (355/857). However, in Grade IV ODCs, organ donation specialist consent rate was 53.5% (189/353), significantly greater than for other trained staff at 33.1% (88/266) ( $P < 0.005$ ; odds ratio [OR], 2.33; 95% CI, 1.68–3.24) or untrained requestors at 32.8% (78/238;  $P < 0.005$ ; OR, 2.36; 95% CI, 1.68–3.33).

**Conclusion:** The likelihood of consent can be predicted using readily available variables. This allows prospective identification of Grade IV ODCs, which carry low but potentially modifiable likelihood of consent. Involving donation specialists was associated with more consents for organ donation when applied retrospectively to Australian audit data.

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a potential donor having an Australian Medicare number, their own wishes, and, lastly, on whether the hospital staff have actively sought to check the AODR. Using AODR status tests both the individual and the health care system. Family-raised donation conversations rely on families having the opportunity to communicate with ICU staff. This may be diminished by distance, time of day, or access to interpreters. Using the variable of family-raised donation tests, to an extent, the degree of communication within families, which of course can vary greatly. We hypothesised that a simple ODC grading system could be developed which demonstrated a difference in the observed consent rate in the most challenging grade of ODC. Moreover, we hypothesised that the impact of a specialist-conducted ODC would be most apparent in ODCs with the greatest expected difficulty.

**Methods**

We developed an ODC grading system using two readily identified variables (each with only binary answers) to stratify all ODCs prospectively into one of four grades as described below:

- Grade I ODCs included cases where the donor was known to be registered “yes” in the AODR and the family raised the topic of organ donation.
- Grade II ODCs were those where the AODR status was known to be “yes” and the topic of organ donation was raised by clinicians.
- Grade III ODCs were those where the family raised organ donation but the AODR status was either unknown or the potential donor was not registered.
- Grade IV ODCs were those in which the topic of organ donation was raised by clinicians and the AODR status was either unknown or not registered.

Permission for this study was obtained from all Australian state and territory leads for the Organ and Tissue Authority and from the Austin Health Human Research Ethics Committee for a Quality Improvement Project (Austin HREC QI 33100).

The Organ and Tissue Authority provided a data extract from the 2017 DonatLife audit. The full DonatLife Audit dataset was originally entered contemporaneously by embedded donation staff in more than 70 hospitals

nationwide. The donation staff obtain data from hospitals of all deaths within a critical care environment and within 24 hours of discharge from ICU. All such deaths are carefully audited, especially those in whom donation was not considered or discussed. No deceased organ donation process can be completed without extensive involvement of donation specialist staff. Lastly, the electronic donor record dataset is verified externally by the Australia and New Zealand Organ Donation Registry (ANZOD). This allows considerable confidence that the dataset is a complete representation of all potential and actual donors. It includes detailed information regarding all ODCs with the families of potential donors. Such original data include professional role and donation conversation training status. The data analysis is tightly controlled by state and territory privacy legislation. Specifically, no identification of individuals, hospitals or jurisdictions is allowed.

The limited dataset approved for release and analysis included the following fields:

- AODR status (yes/no/not checked);
- donation raised by (family/staff);
- consent outcome for organ and tissue donation (yes/no);
- level of training of the family donation conversation (FDC) requestor (FDC trained yes/no); and
- donation specialist position (yes/no).

We defined the tier of training as one of three levels based on completion of FDC core training workshop and professional role (Table 1).

**Statistical analysis**

Continuous variables were expressed as median and interquartile range (IQR) and categorical variables as number with percentage. Differences in binomial distributions were assessed with  $\chi^2$  test and Fisher exact test. Differences in consent rate between the training tiers were tested using the Wilcoxon rank sum test, stratified by grade of ODC.

**Table 1. Tiers of training**

Tier of training	Definition	Description
Untrained	Has not completed the OTA FDC core workshop*	May include ED or ICU consultants, registrar, ICU nurses, social workers, other clinical staff
Trained	Completed the OTA FDC core workshop*	May include ED or ICU consultants, registrars, ICU nurses, social workers, other clinical staff who have completed the 2-day OTA FDC core workshop*
Specialist requestor	Employed in donation specialist position	May include consultant medical staff or senior nurses. Completed the 2-day FDC OTA core workshop* ± completed one-day FDC practical plus working in donation specialist role

ED = emergency department; FDC = family donation conversation; ICU = intensive care unit; OTA = Organ and Tissue Authority. \* The FDC core workshop has been compulsory for the College of Intensive Care Medicine of Australia and New Zealand Fellowship since 2014.

**Table 2. DonatLife Audit results, 2017**

	Number (%)
Total number of organ donation conversations	1420
Registered “yes” in AODR	335 (23.6%)
Not registered, AODR not checked, or registered “no”	1085 (73.4%)
Donation raised by family	314 (22%)
Donation raised by staff	1087 (73.4%)
Donation raised by family as a pre-emptive decline	13 (0.9%)
Not clearly documented who raised donation	6 (0.4%)
Consented to organ and tissue donation	826 (58%)
Declined consent for organ and tissue donation	594 (42%)
Untrained requestor	378 (26.6%)
Trained requestor	419 (29.5%)
Specialist requestor	623 (43.9%)

AODR = Australian Organ Donor Register.

**Grades of organ donation conversation**

The most frequent type of ODC was Grade IV, with 857 conversations (60.4%) — more than all the three other grades of ODC combined (Table 3). Grade II and Grade III had similar numbers, with 230 (16.2%) and 224 (15.8%) respectively. The least common grade of ODC was Grade I, with only 109 ODCs (7.7%). Consent was observed significantly less in Grade IV ODCs with a consent rate of 41.4% (355/857;  $P < 0.0001$ ).

**Requests by tier of training**

Donation specialists were the most frequent requestor, with 623 ODCs (43.9%), while FDC-trained requestors were involved in 419 ODCs (29.5%) (Table 4). The remaining 378 ODCs (26.6%) were conducted by untrained staff alone. The level of training was not consistent across the four different grades

Odds ratios were determined to compare each of the three training tiers against the other two tiers for all four grades of ODC. A two-sided  $P < 0.05$  was considered statistically significant.

**Results**

**Registration status and raising of organ donation**

There were 1420 documented ODCs nationwide in the calendar year 2017 (Table 2). Most were either not registered or not checked, with only 23.6% of patients (335/1420) known to be registered as “yes” in the AODR.

The topic of organ donation was raised by the patient’s family in only 22% of cases (314/1420). An additional 13 families (0.9%) raised the topic of organ donation, specifically to express a clear pre-emptive decline. In a small number of cases (6/1420, 0.4%), there was no clear documentation of who had raised organ donation.

of ODC. Untrained requestors made up 26.6% of ODCs overall. There was no significant difference ( $P = 0.07$ ) in their distribution, with a range of 19.6% in Grade II ODCs up to 29.4% in Grade I ODCs.

Trained requestors participated in 29.5% of ODCs overall. There was a significant difference in their distribution ( $P = 0.02$ ), with higher participation in Grade III and Grade IV ODCs (33.5% and 31% respectively) and lower participation in Grade I and Grade II ODCs (21.1% and 23.9% respectively).

**Table 3. Distribution of organ donation conversation (ODC) grades and observed consent rates**

Grade of ODC	Number of ODCs (%)	Consent for organ donation (%)
Grade I	109 (7.7%)	104 (95.4%)
Grade II	230 (16.2%)	191 (83.0%)
Grade III	224 (15.8%)	176 (78.6%)
Grade IV	857 (60.4%)	355 (41.4%)*

\*  $P < 0.0001$ .

**Table 4. Distribution of staff by training tier and grade of organ donation conversation (ODC)**

	n (%)	Grade I ODC	Grade II ODC	Grade III ODC	Grade IV ODC	P
Untrained	378/1420 (26.6%)	32 (29.4%)	45 (19.6%)	63 (28.1%)	238 (27.8%)	0.07
Trained	419/1420 (29.5%)	23 (21.1%)	55 (23.9%)	75 (33.5%)	266 (31%)	0.02
Specialist	623/1420 (43.9%)	54 (49.5%)	130 (56.5%)	86 (38.4%)	353 (41.2%)	0.0001

Specialist requestors participated in 43.9% of ODCs overall. Specialist requestors were significantly more likely ( $P = 0.0001$ ) to be found when medical staff raised the issue of organ donation (130 donation specialist-led ODCs were Grade II and 353 were Grade IV).

### Consent for organ donation

The overall consent rate was 60.3%, with 826 families supporting organ donation and 594 declining (Table 5). Consent was most frequent in Grade I ODCs, with an observed consent rate of 95.4% (104/109). Grade II and Grade III ODCs had consent rates of 83.0% (191/230) and 78.6% (176/224) respectively. Consent was observed significantly less in Grade IV ODCs, with a consent rate of 41.4% (355/857;  $P < 0.0001$ ).

The largest relative and absolute differences in consent rates between training tiers were demonstrated with specialist requestors in Grade IV ODCs. Both untrained and trained requestors had similar consent rates with 32.8% and 33.1% respectively. However, the consent rate for specialist requestors in Grade IV ODCs was 53.5%.

The odds ratios for consent by tier of training differed for each grade of ODC (Table 6). The effect of training was significantly different in the two grades of ODC raised by staff: Grade II ( $P = 0.01$ ) and Grade IV ( $P < 0.005$ ).

**Table 5. Consent rates by training tier and grade of organ donation conversation (ODC)**

Grade of ODC	Training tier	Consent rate
I	Untrained	29/32 (90.6%)
	Trained	22/23 (95.7%)
	Specialist	53/54 (98.1%)
	All tiers	104/109 (95.4%)
II	Untrained	35/45 (77.8%)
	Trained	39/55 (70.9%)
	Specialist	117/130 (90.0%)
	All tiers	191/230 (83.0%)
III	Untrained	47/63 (74.6%)
	Trained	61/75 (81.3%)
	Specialist	68/96 (79.1%)
	All tiers	176/224 (78.6%)
IV	Untrained	78/238 (32.8%)
	Trained	88/266 (33.1%)
	Specialist	189/353 (53.5%)
	All tiers	355/857 (41.4%)

## Discussion

### Key findings

We tested a four-level grading system for ODCs on a complete national dataset from 2017. We found that Grade IV ODCs were more numerous than all others grades combined and were associated with significantly lower consent rates. Moreover, we found that different levels of requestor training were unevenly distributed throughout the grades of ODC, such that specialist requestors were significantly more likely to be present in staff-initiated donation requests (Grade II and Grade IV). These same grades had significantly higher consent rates for specialist requestors over their untrained and trained colleagues. Finally, we found that the most numerous ODCs (Grade IV) were associated with the lowest consent rate in both trained and untrained staff. However, they also carried the strongest evidence of higher consent rates with specialist requestors.

### Relationship with previous studies

There are many predictors of family and patient support for organ and tissue donation that are beyond the capacity of the critical care clinician to influence.<sup>2</sup> These include, socio-economic status,<sup>4</sup> age,<sup>5</sup> ethnicity<sup>6</sup> and cultural and religious practices.<sup>7</sup> However, some predictive factors are more modifiable: number of family and staff involved in family discussions,<sup>1</sup> timing of discussions,<sup>1</sup> advance checking of any registry,<sup>8</sup> and the professional roles of hospital staff involved in discussions.<sup>1</sup> Both registry status<sup>1,6,8</sup> and family-initiated conversations<sup>9</sup> have been examined as powerful predictors of successful ODCs.

Nevertheless, to date, all literature seeking to understand ODCs and how to achieve optimal consent results have assessed a broad population (all comers). To our knowledge, ours is the first description of a simple stratification system using two clear patient-related predictors that can help focus attention on the group where change is most likely. Such stratification can be applied prospectively by a clinician embarking on an ODC, or retrospectively by administrators and researchers seeking to evaluate process changes. Importantly, our findings did not demonstrate a clearly graduated level of difficulty that increased predictably with each step in grade. Rather, we identified two distinct populations, with Grade I, Grade II and Grade III ODCs likely to result in consent, and Grade IV ODCs being far less certain. The pronounced difference in consent results in Grade IV ODCs between donation specialists

**Table 6. Odds ratio for training effect by grade of organ donation conversation (ODC)**

Grade of ODC	Effect	Odds ratio (95% CI)	P*
I	Training grade		0.33
	Trained v untrained	2.28 (0.22–23.39)	
	Specialist v untrained	5.48 (0.55–55.13)	
	Specialist v trained	2.41 (0.14–40.26)	
II	Training grade		0.01
	Trained v untrained	0.70 (0.28–1.73)	
	Specialist v untrained	2.57 (1.04–6.37)	
	Specialist v trained	3.69 (1.63–8.36)	
III	Training grade		0.63
	Trained v untrained	1.48 (0.66–3.34)	
	Specialist v untrained	1.29 (0.60–2.78)	
	Specialist v trained	0.87 (0.40–1.89)	
IV	Training grade		< 0.005
	Trained v untrained	1.01 (0.70–1.47)	
	Specialist v untrained	2.36 (1.68–3.33)	
	Specialist v trained	2.33 (1.68–3.24)	

\*  $\chi^2$ 

### Strengths and limitations

The strengths of this study include the conceptual simplicity of the two-variable, four-grade model and the large, complete dataset supplied by the Organ and Tissue Authority (and verified by ANZOD). The observed consent rates demonstrate that Grade IV ODCs were clearly different from the rest of the population. Further highlighting the potential importance of such stratification, the Grade IV ODCs were also associated with different consent rates by level of training. This provides a targeted understanding of the positive impact specialist donation requestors may have on ODCs.

The major limitation of the study is its retrospective nature. Repeated patterns over time would certainly help in inferring a repeatable phenomenon. Additional confidence in the associations we observed requires a prospective evaluation.

There are multiple potential sources of bias that we were unable to eliminate in this retrospective observational dataset. No ODCs were conducted with any randomisation of participants. It is possible that low rates of AODR checking (as observed in this study) significantly underestimate the population of potential donors who have registered their

donation decision in the AODR with or without discussing these with loved ones. The data entry for this dataset was completed by nursing donation specialists, not independent data collection staff. ODCs involving donation specialists may be more likely to be contemporaneously and accurately captured. ODCs excluding donation specialists were only able to be documented based on the medical record or on clinical staff recollections (both fallible).

The DonateLife Audit is the most complete dataset describing donation conversations. As all cases that proceed to donation involve a DonateLife staff member, we can be confident that all true consents are captured. We cannot, however, exclude that some episodes of donation being considered and dismissed are not captured in this dataset. We cannot independently verify that audit data accurately captured the very first conversation regarding organ and tissue donation between staff and family (ie, informal, undocumented bedside or corridor conversations with one or more family members). In addition, the true individual patient organ donation decision may be misrepresented (ie, when the AODR is not checked by staff before ODC and registration is not available to potential paediatric donors < 16 years old). Finally, the findings of this study

and all other requestors suggest the possibility that the likelihood of consent can be modified in this group.

### Study implications

Four stage grading systems to predict procedural difficulty are well established in critical care.<sup>9</sup> They can have a range of practical and research applications. Most notably they serve to identify the most challenging of possible clinical interactions. Family meetings are among some of the most important procedures undertaken in the ICU, and our findings imply that consent rates can be increased with specific training or job roles.<sup>10</sup> Moreover, our study implies that knowledge that a patient is not registered and that donation with a grieving family is imminent should prompt consideration of referral to a donation specialist.

Finally, our findings also imply that researchers and administrators can use the grading system to evaluate a wide range of possible process evolutions in ODCs including timing, location, language and participants involved. Metrics to measure effective ODCs are needed to help drive process improvement.<sup>8</sup> Our grading system allows the identification of Grade IV ODCs as a valuable subgroup for closer attention.

are likely valid in countries such as Australia, where an opt-in registration model is used. In countries with opt-out or presumed consent, the influence of a positive registration status may be substantially less than that seen in Australia. The findings may not apply to systems with different conversation training or ODC requesting models.

Further evaluation over time is desirable in future research. This study evaluated national data from 2017. There has not as yet been any coordinated evaluation of subsequent national data. The interpretation of multiple different privacy legislations in the different states and territories is a limiting factor to such research. As a single jurisdiction, DonateLife Victoria has evaluated the raw 2018 and 2019 data (without further statistical analysis) using this grading system. This has informed constructive communication with ICU clinicians, donation specialists, and hospital executives, with widespread acceptance. In both subsequent years, Grade IV conversations remain the most common ODC and maintain the lowest consent rate. The consent outcomes observed by level of training in these subsequent years in Victoria appear similar to the national 2017 results. Future prospective studies, either at a state or national level, are recommended to evaluate further the characteristics of requestors and their consent results, especially in Grade IV ODCs.

## Conclusion

Identifying and assessing a subgroup of organ donation consent discussions with highly modifiable outcomes can be done simply. When applied retrospectively, it is possible to assess associations with process changes such as the use of specialist requestors. Prospective studies are required before the strength of any such associations can be confidently supported. When applied before an ODC by clinicians, such a grading system may help encourage the participation of specialist donation requestors in these conversations. Making such changes in who makes the requests appears to be associated with a significantly increased consent rate, which could translate to increased donation for transplantation. ICU clinicians seeking to embark on the very important procedure of discussing organ and tissue donation should strongly consider collaborating with a donation specialist, particularly, if they are heading into a known Grade IV ODC.

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## Competing interests

None declared.

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