The impact of checking the Australian Organ Donor Register on family consent rates

TO THE EDITOR: Knowledge of the deceased’s wishes and the processes involved in requesting organ donation increases the likelihood of family consenting to donation.1 Australian research has found that many people who register consent for organ donation do not discuss it with family members.2 Others discuss their intentions with their family but choose not to register. Since the Australian Organ and Tissue Donation and Transplantation Authority was established in 2009, extensive resources have gone into raising awareness of organ donation, of which the costs of maintaining the Australian Organ Donor Register (AODR) represent a tiny fraction.

Decision-making methods, the number of people present when donation is requested, and family knowledge of their relative’s registered consent may all affect the likelihood of family consent.3,4 Checking the AODR is recommended before discussions with family about donation, but it is unknown how this influences a family’s decision.
We collated raw data from all 21 adult hospitals in Victoria contributing to the DonateLife Audit in 2010. From the 8797 deaths listed, we extracted data on all discussions about organ donation and analysed factors associated with family consent. Of the 294 cases where discussion about organ donation was documented, family consent was obtained in 168 (57%).

The AODR was checked in 147 (50%) of the cases involving discussion. The rate of family member consent for people registered as consenting on the AODR was 93%, compared with 70% for those who were not listed. When the AODR was not checked, the family consent rate was 39% (Box).

After adjusting for other factors associated with consent (“non-neurological cause of death” and “donation raised by family rather than medical staff”), checking the AODR was independently associated with family consent (odds ratio, 17.1 [95% CI, 6.6-44.4]; \( P < 0.001 \)), irrespective of the outcome of that check. Timing of the AODR check relative to the discussion about organ donation was not recorded and may limit interpretation of these results. It is unknown how many of these represent cases where the AODR was checked after consent was already obtained.

The association between checking the AODR and increasing likelihood of consent suggests a clear case for improving public awareness and use of the AODR through promotional activities. Further analysis of how and when the AODR is checked by clinicians in the requesting process is also needed. Other than the time and effort required, there appears to be little downside to checking the AODR before discussing organ donation with a family.

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3 Cook DA, Pilcher DV. Veto or vote? Do Australian families respect a dying person’s wishes by democratic consensus or by absence of objection? Mathematical modeling of consent for organ donation — insights into the decision-making process. Organs Tissues & Cells 2011; 14: 99-105

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**Family consent for organ donation, by Australian Organ Donor Register (AODR) check status**

<table>
<thead>
<tr>
<th>Outcome of AODR check</th>
<th>Deaths</th>
<th>Family consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent</td>
<td>28</td>
<td>26 (93%)</td>
</tr>
<tr>
<td>Refusal</td>
<td>1</td>
<td>1 (100%)</td>
</tr>
<tr>
<td>Not listed</td>
<td>118</td>
<td>83 (70%)</td>
</tr>
<tr>
<td>AODR not checked or unknown</td>
<td>128</td>
<td>50 (39%)</td>
</tr>
<tr>
<td>No data entered</td>
<td>19</td>
<td>8 (42%)</td>
</tr>
<tr>
<td>Total</td>
<td>294</td>
<td>168 (57%)</td>
</tr>
</tbody>
</table>

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"many people who register consent for organ donation do not discuss it with family members"

Stephens et al.