

# PARLIAMENTARY INQUIRY QUESTION ON NOTICE

## Department of Health and Aged Care

### Parliament of Victoria - Legislative Assembly Legal and Social Issues Committee

#### Inquiry into increasing the number of registered organ and tissue donors

PDR Number: IQ23-000057

#### Increasing numbers of registered organ and tissue donors

##### Written

**Senator:** Ella George MP

##### Question:

1. Australian Organ Donor Register (AODR) statistics published by Services Australia distinguish between 'consent registrations' and 'intent registrations'. Why is it necessary to maintain a distinction between intent and consent registrations given that ultimately families must provide consent to organ or tissue donation?
2. Tony Holland, General Manager of DonateLife Victoria told the Committee at a public hearing, in relation to Victoria's low rate of organ donor registration on the AODR: This is the second-lowest rate in the country and below the national average of 36%. The reasons first for this are historical. At one point Victorians could sign up through a register managed by VicRoads when they received their drivers licence. We are not confident that these registrations were all carried over when the AODR was created in 2000.<sup>1</sup> How many Victorians were registered as organ and tissue donors through Victoria's drivers licence registration system at the time the Victorian data was uploaded to the AODR in 2000? How many were registered after the data transfer?
3. When will the draft National strategy for organ donation, retrieval and transplantation be finalised and what progress has been made on the Transition Action Plan, specifically Actions 1.5, 1.2, 4.1 and 4.22?
4. Appendix 1 (attachment A) summarises the different ways to register based on the Committee's research. Why do the registration options differ between the online form on the DonateLife website, printed form, MyGov and Express Plus Medicare app, in relation to the following information asked of registrants depending on the method used to register, and how are the differences reflected publicly in data reporting?
  - a. Ability to object to organ and tissue donation
  - b. Deciding which organs and tissue to donate
  - c. Reasons for registering as a donor

- d. Provision of Medicare number
5. Regarding the reasons for registering to be a donor; granular demographic data such as general ethnic group and location; and removing people from the register when they die:
- What data is collected?
  - What are the barriers to collecting this data?
  - How is the data publicly reported, analysed and used?
  - Can this data be provided specifically for Victoria?
6. What technology problems have people reported when trying to register on the AODR? What assistance is available in these situations?
7. The Australian Bone Marrow Donor Registry's website states that 'Australian governments restrict the number of donors that can join the registry, while Australian patients desperately need more local donors.'<sup>3</sup> There are also age restrictions to join the register as 'it costs a substantial amount of money to add each donor to the register.'<sup>4</sup> Does the Australian Government restrict the number of donors on the bone marrow donor registry, and what are the reasons for this? What analysis has been conducted on the costs associated with increasing the number of donors on the bone marrow register compared to the potential benefits for the health system and people who need a bone marrow transplant?

Footer:

1 DonatLife Victoria, Transcript of evidence, Monday 19 June 2023, p. 2

2 Issued in August 2022, the Transition Action Plan 'aims to consolidate and progress, under four priority areas, 12 actions which can be progressed over the next 12 months with no additional resourcing, including actions that will inform the Strategy and implementation approach.' Action 1.5: Consider options to improve donor registration to increase consent for donation; Action 1.2. Agree the role of the OTA; Action 4.1. Expand organ donation to transplantation data and reporting; Action 4.2. Expand deceased eye and tissue donation data and reporting.

3 <https://strengthtogive.org.au/about-abmdr/>

4 <https://strengthtogive.org.au/faqs/>

**Answer:**

1. *Australian Organ Donor Register (AODR) statistics published by Services Australia distinguish between 'consent registrations' and 'intent registrations'. Why is it necessary to maintain a distinction between intent and consent registrations given that ultimately families must provide consent to organ or tissue donation?*

- In 2005 all Australian Governments agreed that the Australian Organ Donor Registry (AODR) should operate as Australia's only national register of consent and that this must be 'informed consent'.
  - Registration of organ donation decisions that are not considered to meet the requirements of 'consent' are called 'intent' registrations.
  - The Department of Health and Aged Care (the department) confirms the Committee's understanding of 'intent' vs 'consent' registration channels as reflected in Appendix A, is correct.

- The department has AODR policy responsibility whilst Services Australia is responsible for the management and administration of the AODR. This is outlined in a Program Agreement between the department and Services Australia.
  - The Program Agreement states the consent and intent registrations by state, age and gender statistics to be published. This data is used to review and evaluate the effectiveness of each registration channel.
  - In practice, there is little difference between whether the donor registration is an intent or consent registration. When a DonateLife donor co-ordinator accesses the AODR, they check for a recorded donation decision. It is not discussed with the donor family whether the decision is intent or consent.
2. *Tony Holland, General Manager of DonateLife Victoria told the Committee at a public hearing, in relation to Victoria's low rate of organ donor registration on the AODR: This is the second-lowest rate in the country and below the national average of 36%. The reasons first for this are historical. At one point Victorians could sign up through a register managed by VicRoads when they received their drivers licence. We are not confident that these registrations were all carried over when the AODR was created in 2000.1*
- How many Victorians were registered as organ and tissue donors through Victoria's drivers licence registration system at the time the Victorian data was uploaded to the AODR in 2000? How many were registered after the data transfer?*
- As at 19 September 2002, Victoria transmitted 402,930 records to the AODR.
  - Victorian records were sent from two data sources, Victoria Roads and the Victorian Transplant Promotion Council. Data breaking down the figures for each source is not available.
3. *When will the draft National strategy for organ donation, retrieval and transplantation be finalised and what progress has been made on the Transition Action Plan, specifically Actions 1.5, 1.2, 4.1 and 4.22?*
- The draft *National Strategy for Organ Donation, Retrieval and Transplantation* (Strategy) was developed by the Jurisdictional Organ and Tissue Steering Committee (JOTSC), which comprises representation of the Commonwealth, OTA and state and territory governments.
  - The draft Strategy has been agreed by the JOTSC and will progress for agreement by Health CEOs and Health Ministers.
    - Planning of implementation activities to support the Strategy will occur throughout 2023/24.
  - *Transition Action Plan*
    - Action 1.2 – Agree the role of OTA
      - The role of the Organ and Tissue Authority (OTA) is being considered in ongoing discussions by the JOTSC. Any changes to the role of the OTA will need to be agreed by all Health Ministers.

- Action 1.5 – Consider options to improve donor registration to increase consent for donation
  - The Commonwealth, OTA and state and territory governments are currently investigating options to increase organ donor registrations, including through the use of driver licences, the AODR registration channel, as well as education and training of DonateLife Network staff. There is ongoing monitoring of international evidence, including countries that have recently changed their legislative framework.
- Action 4.1 – expand organ donation and transplantation data and reporting
  - The Organ and Tissue Authority have increased the breadth of data and the frequency of distribution for key hospital performance metrics across the DonateLife Network. Comprehensive hospital dashboards and analysis are provided quarterly for all hospitals.
- Action 4.2- expand deceased eye and tissue donation data and reporting
  - Through the Australian Eye and Tissue Donation Registry, the OTA are working with eye banks in each state to expand the data captured for potential and actual eye donors.

4. *Appendix 1 (attachment A) summarises the different ways to register based on the Committee’s research. Why do the registration options differ between the online form on the DonateLife website, printed form, MyGov and Express Plus Medicare app, in relation to the following information asked of registrants depending on the method used to register, and how are the differences reflected publicly in data reporting.*

- a. Ability to object to organ and tissue donation*
- b. Deciding which organs and tissue to donate*
- c. Reasons for registering as a donor*
- d. Provision of Medicare number*

- The Department confirms that the information the Committee has collated in Appendix 1 is correct.
- The MyGov and Express Plus Medicare app were developed based on the printed form. These registration channels are ‘consent’ registrations and include the ability for an individual to select specific organ and tissues for donation.
- The DonateLife registration channel was implemented as a quick, easy and direct method of donor registration. To promote efficiency, only fields required to authenticate identity were included, for validation through the interface to Services Australia in real time.
- Individuals who wish to record their selection of specific organs and tissues for donation need to do so through a ‘consent’ registration channel.
- Individuals who wish to record their objection to being an organ donor currently need to do so through channels that provide them with enough information to enable a full understanding of the decision they’re recording. This does not include intent registration channels (SA drivers’ licence, or the DonateLife online form).
  - In circumstances where no decision is recorded, the family are still approached for consent.

- The conversation with families is individualised and may include consent for specific organs.
  - The DonatLife form captures detail on what prompted registration. This information is not disseminated outside of the OTA.
  - All consent registrations require a Medicare number to verify identity and a signature.
    - The use of Medicare card details, in conjunction with demographic details, increases the likelihood that a unique match can be found and correctly recorded in the AODR. Sufficient information is required to ensure organ donor preferences are recorded correctly. Limiting information to demographic details, such as name and date of birth, risks multiple individuals being identified who have the same details.
  - Public reporting only reflects differences in consent vs intent. The Department and the OTA are provided with the breakdown of data per channel, but the data around selection of specific organs and tissues is not disseminated and is only used by transplant coordinators at the time of donation.
5. *Regarding the reasons for registering to be a donor; granular demographic data such as general ethnic group and location; and removing people from the register when they die:*
- a. *What data is collected?*
  - b. *What are the barriers to collecting this data?*
  - c. *How is the data publicly reported, analysed and used?*
  - d. *Can this data be provided specifically for Victoria?*
- The OTA publish overall registration figures and percentage of population registered at national and state levels in the OTA annual activity and performance reporting. With the approval of Services Australia, the OTA publishes LGA level registration data for external campaign activity on an ad-hoc basis to communication partners.
  - The AODR does not remove a donor from the register when they die. When Services Australia has been advised of a donor's date of death, once applied, this automatically prevents the donor record from being accessed for donation purposes.
  - Services Australia reports aggregated statistics on AODR registrations via the agency's website at [www.servicesaustralia.gov.au/australian-organ-donor-register-statistics](http://www.servicesaustralia.gov.au/australian-organ-donor-register-statistics). This provides data on the total number of intent and consent registrations, arranged by jurisdiction, age group, and gender.
  - Services Australia transmits the following de-identified data on a monthly basis to the Australian Organ and Tissue Authority:
    - De-identified Donor ID
    - Month and year of birth
    - Gender
    - Postcode
    - Intent/Consent
    - Donor Yes/No
    - Initial Registration Channel

- Services Australia may be able to release data to Victoria. Further information will be required to ensure a clear understanding of the scope of data sought and the ability to maintain the privacy of those registered on the AODR once the data has been released.

6. *What technology problems have people reported when trying to register on the AODR? What assistance is available in these situations?*

- Services Australia is not aware of any technical issues that prevent individuals from registering their organ donor preferences with the AODR.
- People requiring assistance can contact the Australian Organ Donor Register on 1800 777 203, Monday to Friday 8:30am to 5pm.

7. *The Australian Bone Marrow Donor Registry's website states that 'Australian governments restrict the number of donors that can join the registry, while Australian patients desperately need more local donors.' There are also age restrictions to join the register as 'it costs a substantial amount of money to add each donor to the register.' Does the Australian Government restrict the number of donors on the bone marrow donor registry, and what are the reasons for this? What analysis has been conducted on the costs associated with increasing the number of donors on the bone marrow register compared to the potential benefits for the health system and people who need a bone marrow transplant?*

- The Australian Government does not restrict the number of donors on the bone marrow donor registry. The Australian Bone Marrow Donor Registry (ABMDR) sets the eligibility criteria for donors based on the best clinical outcomes for HPC transplant patients. Research shows improved outcomes for patients with younger donors however, donors are encouraged to stay on the registry until they reach their 60th birthday.
- Currently, HPC donor recruitment activities occur through Australian Red Cross Lifeblood (Lifeblood), where individuals who volunteer as a blood donor are provided the option to also become a HPC donor. State and territory governments contract Lifeblood to recruit, screen and test HPC donors. In 2022-23, Lifeblood's funded recruitment target was 5,230 HPC donors. Lifeblood exceeded this target by approximately 80% and recruited 9,407 new donors to the registry.
- A cost benefit analysis of increasing the number of donors on the registry to the health system and patients requiring a HPC transplant has not been performed. However, Australian patients who require a HPC transplant have access to over 41 million HPC donors listed on international registries accredited by the World Marrow Donor Association (data as at 3 August 2023 from [www.wmda.info](http://www.wmda.info)).
- As Australia's population is relatively small and diverse, the HPC donor registry is unlikely to be able to provide a suitable donor match for every Australian requiring a transplant, hence patients are given the best chance to identify a donor through the ABMDR by also accessing international HPC registries. If a suitable international HPC donor is found, the Department provides financial assistance to approved patients to access internationally sourced HPC for transplants, *via* the Bone Marrow Transplant Program.



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## Appendix 1: Different ways to register on the Australian Organ Donor Register

	DonateLife online form <sup>a</sup>	Printed form <sup>b</sup>	MyGov website, if Medicare linked	ExpressPlus Medicare app, if MyGov linked	Drivers licence (SA only) <sup>c</sup>	Phone number <sup>d</sup>
<b>Details required to verify identity</b>	Medicare number	Medicare number OR address, date of birth	N/A - app can be used if Medicare and MyGov linked	N/A - app can be used if Medicare and MyGov linked	Licence details, already linked	Medicare OR address, contact information (email, address) used to find Medicare number
<b>Asks for date of birth</b>	Y	Y	Assume information linked	Assume information linked	Assume information linked	Assume information linked
<b>Asks for gender</b>	Assume information linked	Y	Assume information linked	Assume information linked	Assume information linked	Assume information linked
<b>Asks for postcode</b>	Y	Y (full address)	Assume information linked	Assume information linked	Assume information linked	Assume information linked
<b>Option to choose which organs and tissue to donate</b>	N	Y	Y	Y	N	Y
<b>Ability to record objection, change decision or be removed from register</b>	N	Y	Y	Y	N	Y
<b>Consent or intent registration</b>	Intent <sup>5</sup>	Consent for people aged 18 yrs and above, intent for 16-18 yrs <sup>6</sup>	Consent for people aged 18 yrs and above, intent for 16-18 yrs	Consent for people aged 18 yrs and above, intent for 16-18 yrs	Intent	Intent – phone operator checks it's okay to continue with intent, notes signature required for consent
<b>Asks whether decision discussed with friends and family</b>	N	Y	Unknown	Unknown	N	N
<b>Asks what prompted registration</b>	Y	N	Unknown	Unknown	N	N
<b>Digital donor card available</b>	N	N	N	Y	N	N
<b>Hard copy donor card available</b>	Unknown	Y	Y	Y	N	Y – but phone operator asks you to go online

- Available at [www.donatelife.gov.au/register-donor-today](http://www.donatelife.gov.au/register-donor-today). An individual can check their registration status via the online form but appears to be automatically enrolled upon checking.
- Available at <https://www.servicesaustralia.gov.au/nh007df>. The form can be printed, collected from a service centre, or posted after calling the AODR phone line. It can be submitted at a service centre, or by fax or post. If a Medicare number is provided, the form is used to keep details up to date.<sup>7</sup> Individuals with no Medicare number or who are not Australian citizens can register to be a donor by completing the paper form or calling the AODR phone line.<sup>8</sup>
- [Correspondence from South Australia Department for Health and Wellbeing](#) to the Legal and Social Issues Committee, 19 July 2023: 'SA is currently the only jurisdiction in which a person's interest in organ and/or tissue donation after death (intention) is captured through drivers licence arrangements. SA residents are prompted to answer an optional question about their interest in registering to become an organ donor as part of both online and manual drivers licence application and renewal processes.

The Department for Health and Wellbeing (SA) recently identified that the organ donation question required standardisation across the manual and online drivers licence application and renewal platforms. Drivers licence

<sup>5</sup> Services Australia, Annual report 2021-22, p. 74

<sup>6</sup> Services Australia, Annual report 2021-22, p. 74

<sup>7</sup> <https://www.servicesaustralia.gov.au/how-to-register-australian-organ-donor?context=22331>

<sup>8</sup> <https://www.donatelife.gov.au/register-donor-today#donthavecard>



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registrations are managed by the SA Department for Infrastructure and Transport (DIT), and we have been working collaboratively with DIT to ensure the current agreed organ donation registration question is consistently updated across all platforms. We expect this process to be completed shortly.

If a person answers YES to the optional organ donation registration question they are informed that an organ donor indicator will be shown on any photo permit or licence issued and recorded on the drivers licence database managed by DIT. Licensees are informed that their details will be provided to the 'Australian Organ Donor Register' (AODR) who may contact them for further details. Information held on the drivers licence database is transferred via encrypted file by officers in DIT to the AODR, monthly. Details provided to the AODR are Client/Licence Number, Full Name, Address, DOB, Gender, and 'Y' Organ Donor Indicator (all licence holders who have indicated YES since the last file was generated).

It is our understanding that drivers licence registrants are identified on the AODR as having registered their 'intent' to become an organ/tissue donor after death. Answering YES to the drivers licence organ donation question records a person's intention to become an organ donor, but does not complete the AODR registration process. A person is still required to complete their full registration on the AODR ...'

- d. Note that this information was collected during a test call to the AODR number.