

Inquiry into increasing the number of registered organ and tissue donors

Questions taken on notice

Question:

‘Historically and even presently you can make a nuanced direction in that way, so particularly when it was considered a consent, you could write ‘I consent to all organs and tissues except’ for example, my heart or eyes or as the case may be. As we have made it more streamlined and tried to make it easier, the default is just you are in or out.

However, there is still that opportunity for people to use the other steps where you get a form or download a form and you kind of –

Gary Maas: Are there any stats on that?’ (pp. 11-12)

Response:

The breakdown of who has registered for ‘all’ and who has nominated specific organs sits with Services Australia and Donatelife Victoria does not have access to this information.

Prior to the national registry, individual State and Territory Organ Donation registries, such as the VicRoads registry, provided only a ‘yes’ for organ donation and did not allow for specific organs to be nominated.

Current registration methods:

Method	Decision options	Specific organ/tissue selection	
Online: Donatelifegov.au	Automatic ‘yes’	Automatic ‘yes to all’	Requires Medicare card details available
Online: Medicare App / myGov	<ul style="list-style-type: none"> - Yes - No - Update my preferences - Remove from AODR 	<ul style="list-style-type: none"> - Yes to all - specific organs/tissues can be selected 	
Paper: AODR form printed from website or OTA brochure	<ul style="list-style-type: none"> - Yes - No - Update my preferences - Remove from AODR 	<ul style="list-style-type: none"> - Yes to all - specific organs/tissues can be selected 	Form is sent to the AODR (Hobart) via reply paid postage.

When speaking to the public directly (for example, at community events), members are encouraged to select ALL as they don’t know what they will/won’t be able to donate at the time.

It is important to note that Next of Kin can and must consent to each organ at the time of donation and can choose not to consent to a particular organ. Next of kin can also override the patient’s AODR registered choice of organs they wish to donate.

Question:

'You note in your submission that when the VicRoads data was transferred to the Australian Organ Donor Register, AODR, the VicRoads donor register was decommissioned and now Victoria is rated at 23 per cent. You also note that South Australia is now the only state where you can register through the driver licence system and they have a registration currently of 72 per cent. A few questions on this: what was the Victorian registration rate when the VicRoads system was in place before 2009, if you are aware of that?' (p. 12)

Response:

DonateLife Victoria have not been able to source any information on what the registration rate was in Victoria under the VicRoads registry prior to moving to the AODR.

Question:

'... of the 1900 on a waitlist nationally, I believe, what portion do you believe would die waiting for an organ?' (p. 15)

Response:

This question is out of the remit of DonateLife Victoria. This information sits with the individual transplant units and collation from all units would be required for truly accurate information.

Appended to this response is Section 11 of the 2022 ANZOD Annual Report: Deceased Organ Transplant Waiting Lists. This provides information on deceased organ transplant lists up until 2021, including the number of deaths whilst in the waiting list.

Importantly, there are several limitations and caveats to this data which are covered thoroughly in the 'Waiting List Dynamics' section of the document (pg. 2). These include:

- Waiting list data is not a good indicator for actual demand for transplantation.
- Reasons for removal from the waitlist varies and can be due to improved function and health or become too sick for transplantation. Whether these patients subsequently return to the list, stay off the list or die is not currently captured within ANZDATA report.
- Any patients receiving a transplant overseas will not be captured in the report.

DonateLife Victoria strongly suggest you consider these caveats when interpreting this data.