

Victorian Parliamentary Inquiry into increasing the number of registered organ and tissue donors

Responses to questions on notice

16 August 2023

1. The Chair: What is the role of Victoria in supporting other jurisdictions in the organ donation program

Victoria is the only state that offers all five Nationally Funded Centres (NFC):

- Islet Cell Transplantation
- Paediatric heart transplantation
- Paediatric liver transplantation
- Paediatric lung and heart-lung transplantation
- Pancreas transplantation

NFCs deliver certain high cost, highly specialised health technologies with limited demand, to optimise access for all Australians regardless of geographical location.

Other jurisdictions access NFCs in Victoria. In 2022-23, 39 patients were treated at Victorian NFCs. Of those treated 23 patients were from Victoria and 16 patients from other states and New Zealand.

Table 1 contains more details on NFCs and number of patients

Table 1: NFCs and number of patients treated in Victoria from different states in 2021-22 and 2022-23

NFC	Health Service	Patients treated in Victoria			
		2021-22		2022-23	
		Total	State	Total	State
Islet Cell Transplantation	St Vincent Hospital (VIC) Royal Adelaide Hospital (SA) Westmead Hospital (NSW)	3	VIC (3)	2	VIC (2)
Paediatric heart transplantation	Royal Children's Hospital (VIC)	11	VIC (3) NSW (4) QLD (1) SA (2) O/S* (1)	13	VIC (3) NSW (6) WA (3) SA (1)

Paediatric liver transplantation	Royal Children’s Hospital (VIC) The Sydney Children’s Hospital Queensland Children’s Hospital	8	VIC (5) SA (2) TAS (1)	11	VIC (10) WA (1)
Paediatric lung and heart-lung transplantation	Alfred Hospital (VIC)	4	VIC (1) NSW (2) QLD (1)	3	QLD (2) NZ (1)
Pancreas transplantation	Monash Medical Centre (VIC) Westmead Hospital (NSW)	11	VIC (8) TAS (3)	10	VIC (8) TAS (2)

*Overseas

2. Cindy McLeish: Are you happy to provide us with a copy of that report?

Louise McKinlay: I cannot commit to that today, but I am certainly happy to take that on notice.

Annabelle Cleeland: Would you be able to share with us the recommendations, so we are not duplicating your work?

Louise McKinlay: I think I have said I will take on notice sharing the report, but if that is not the case, I am very happy to share the recommendations.

The Ngamaru Health Advisory Report – Review of organ donation and transplant services 2020 (the Review) commissioned by the Department of Health has not been released. The Review focused on services e.g., organ retrieval and transplantation rates, funding models and workforce requirements. The Terms of Reference of the Review explicitly excluded “programs to support and promote organ donations activities”. Consequently the 2020 Review is out of scope for this Inquiry.

Recommendations identified in Victoria are aligned with the Organ and Tissue Authority (OTA) Strategic Plan 2021-22 to 2023-24 and Victoria participates in this work via the Jurisdictional Organ and Tissue Steering Committee (JOTSC). Details below indicate work undertaken to date.

Objectives of national coordination and the implementation of the OTA Strategy:

- The OTA was established in 2009 to lead the delivery of the national program for organ and tissue donation. The OTA has existing knowledge and expertise in place to support an expanded role in retrieval and transplantation including:
 - community awareness and education programs
 - a clinical governance framework to support best practice care
 - data and analytics capability
 - expert advisory committees that facilitate advice from across state and territory governments, the clinical sector including organ donation, retrieval and transplantation clinicians, and the community sector.

Currently JOTSC is concentrating on the Priority Actions to support the National Eye and Tissue Sector Framework with the aim to collate priority actions to inform an Eye and Tissue Sector Framework Implementation Plan.

3. The Chair: Three out of four stem cell donations in Australia are sourced from overseas, is there anything that you would recommend in terms of increasing awareness around increasing registration for stem cell donors?

The national registry of Hematopoietic Progenitor Cell (HPC) donors is managed by the Australian Bone Marrow Donor Registry (ABDMR) under a contract with the Commonwealth and cost shared with jurisdictions.

There is increasing clinician and community concern regarding Australia's dependency on international donors and the need to increase local HPC donor recruitment. In 2021/-22, over 70% of HPC transplants in Australia used internationally sourced HPCs.

Australia is, and will continue to be, reliant on an international network of stem cell registries to identify matched donors for Australian patients. Bi-directional flow of stem cells between member countries will be necessary, even with anticipated increased Australian recruitment.

The selection by a clinician of the most appropriate HPC donor for their patient is primarily driven by patient's tissue-type (also known as the human leucocyte antigen (HLA) type) and availability of an appropriately matched donor, with the outcome of a HPC transplant being highly dependent on the degree of HLA matching.

The search for a donor for an Australian recipient is done sequentially with the identification and testing of any potential family/related donors, followed by searching for an unrelated Australian donor (ABMDR registrants). If a suitable domestic donor cannot be identified, then a search of overseas registries is performed.

This may result in HPCs being sourced from overseas rather than from the Australian registry. This phenomenon is commonplace across the globe, as no single country or geographical region is self-sufficient for its own adult donor HPC or Cord Blood Unit needs. (Cord Blood Unit are cells from umbilical cords. They are not used very often but there is a small subset of patients and conditions/certain hospitals that use this resource).

In February 2023, Health Ministers approved the release of \$1 million to increase Haemopoietic Progenitor Cell (HPC) donor recruitment through both blood testing and cheek (buccal) swabbing. These funds will be used to increase recruitment to the registry, including targeted recruitment of ethnic groups under-represented in the register.

Work is ongoing at a national level to provide recommendations and advice to all governments on HPC donor recruitment reform as part of the implementation of the National Haemopoietic Progenitor Cell Framework.

4. Cindy McLeish: When registration data was uploaded, Victorian data was not all uploaded to the Commonwealth. Are there any issues in the processes that we have that impact the registrations? Every 10 years I seem to drop off every time the system changes, and no-one contacts me to ask about privacy, to say, 'This is happening', at all. Is that not something you have heard of at all?

Annabelle Cleeland: How many people were lost in that data transfer and how many people have since been notified that they may not actually be registered when they think they are.

We are not aware of any current issues with uploading new donor registrations into the Australian Organ Donor Register (AODR). The AODR is hosted and managed by Services Australia and the registered donors' details are not shared with States/Territories.

Individuals can register to become a donor online through Express Plus Medicare app, myGov or DonateLife website or filling in the Australian Organ Donor register form.

Prior to year 2000, Victorians were able to sign up as organ donors on a registry managed by VicRoads. In year 2000, AODR was established as the national register to record organ and tissue donation decision of donors. Thus, the VicRoads data was transferred to the AODR, and VicRoads register was eventually decommissioned. DonateLife Victoria is running advertising campaigns through social media, sporting events and public posters to encourage Victorians to revisit their donor registration status and update their details.

5. **Cindy McLeish: How much does the Victorian Government contribute to or give the organ donation process, other than through the provision of the hospital staff?**

Under the Hospital Participation Agreement hospital specialist staff are paid by the Organ and Tissue Authority (OTA) through a three-year agreement with the department. In addition, Victoria provides funding to Health Services for shortfalls that are not covered by the OTA based on actual acquittal.

In 2022-23, the Victorian government provided \$13,860,690 to Australian Red Cross Lifeblood (ARC). The funding was allocated to the following services through the ARC:

- \$4,594,580 to DonateLife Victoria
- \$475,650 to Blood Matters
- \$300,059 to Bone Marrow Donor centre
- \$8,490,401 to Victorian Transplantation Immunogenetic Service for tissue typing

6. **Chris Couzens: What policies does DH have in place to address inequality in accessing kidney transplants for First Nations people in Victoria, given they are some of the lowest recipients? Is there any work being done around that?**

Victoria has Aboriginal Hospital Liaison Officers (AHLOs) in hospitals to support Aboriginal patients, families, community members and hospital staff. There is no clear role expectation for an AHLO to be involved in discussions in relation to organ donation. However, the role of a AHLO could be a mechanism to better support tissue donation in the indigenous population.

The DonateLife Victoria specialised nursing workforce all participate in hospital cultural awareness and sensitivity programs. In addition – further ongoing education is in this year's workplan.

7. **Annabelle Cleeland: So, you're understanding with DonateLife's role in the awareness, was there a registration increase element to their performance measurements?**

DonateLife Victoria has quarterly operational meetings with the department. The number of new registrations is specifically reported. Other KPIs reported are:

- Donation activity: number of organ donors, referral rate, donation specialist nurse coordinator/nurse donation specialist in Family Donation Conversation (FDC), Consent rate, AODR check – Specialist staff check in relation to family discussions.
- Media and Communication report:
 - number of new registrations in each quarter and progress towards annual target
 - media coverage and activity: Online, TV, Radio, Prints, special event
 - registration pathway breakdown, e.g., VicRoads, Service Victoria App, Senior Card and convenience advertising

- Education and Training, e.g.: workshops (core Family Donation Conversation, Practical Family Donation Conversation, Introduction to Donation and Transplantation and Preoperative workshop) DSCs/NDS training programs, university presentations and DSNC home health service presentation.
 - Business and operations:
 - Donation specialist staffing profile
 - Health Services Executive engagement
 - Current business cases.
 - DonateLife Victoria key projects update, e.g.: Network Professional Success Program, training simulation, incident management system and good-to-great initiative.
8. Do you have any insights from your analysis of inpatient data that you could share with the Committee with regard to who becomes an organ donor in Victoria? just on data generally, are you aware of any gaps in data collection with regard to organ and tissue donations and looking at who is likely to register and how we can get more people registering?

In 2022, there were 454 deceased donors in Australia. 60% male, 15% below the age of 25 years while 15% above the age of 65 years. 73% were Australian Non-indigenous and 3% were Australian Indigenous, 24% - Other.

We do not have access to demographic information of registered donors. That information is collected and held by Services Australia and is not shared with any jurisdiction. From the available data, we know that the number of female registered donors is almost twice more than the male registered donors.

9. Chris Crewther: Are you liaising with VicRoads on potentially including information about organ donation on their new digital licence system?

Request to refer to the Department of Transport and Planning including a contact for the Inquiry for those that have dropped off including data loss – Action completed.