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: IQ23-000073

Follow up to responses to written questions on notice Inquiry into increasing the number of registered organ and tissue donors

Written

Senator: Ella George MP

Question:

Data transfer – response to question 2

DHAC states 'As at 19 September 2002, Victoria transmitted 402,930 records to the AODR'. Could DHAC please clarify:

- a) that 'transmitted' means that 402,930 records from Victoria were uploaded to the AODR and that that no subsequent records from Victoria were transmitted to the AODR (meaning 402,930 is the total number of records transmitted from Victoria to the AODR)
- b) if the transmitted records included both yes and no decisions, and if so, how many of each

Committee's table on registration methods – response to question 4

DHAC confirms that the table prepared by the Committee is correct. Further to this, could DHAC please clarify:

- a) why information on reasons for registering to be a donor is not collected through all registration options
- b) if the option to specify what to donate or object to donation is only through consent registrations, whether the phone line registration option is intent (as per the Committee's table) or consent; or whether the option to choose what to donate or object to donation is not available over the phone
- c) how a person that does not have a Medicare number registers to be a donor. For example, they are listed on a family Medicare card, meaning they do not have a personal Medicare number or they are not a citizen.

Data collection – response to question 5

DHAC confirms that Services Australia may be able to release data for Victoria.

The Committee would like to:

- a) request Victorian postcode data for AODR registrations for the purpose of reporting on registration rates and opportunities for improvement in regional and metropolitan areas
- b) confirm if the 'cumulative total number of registrations' as reported in Services Australia's annual report (p. 74) includes people who are now deceased, noting that a person is not removed from the AODR when they die.

Answer:

DHAC states 'As at 19 September 2002, Victoria transmitted 402,930 records to the AODR'. Could DHAC please clarify:

- a) that 'transmitted' means that 402,930 records from Victoria were uploaded to the AODR and that that no subsequent records from Victoria were transmitted to the AODR (meaning 402,930 is the total number of records transmitted from Victoria to the AODR)
- Over 2001 2002, multiple transmissions were sent to the AODR from Victoria Roads and the Victorian Transplant Promotion Council.
- The estimated range of total records transmitted by Victoria to the AODR is approximately 410,000 to 440,000.
- Records were quality checked, which included removal of duplicate records, prior to uploading to the AODR.
- Due to the historical nature of these transmissions, it is not practicable to provide a breakdown of transmitted versus uploaded records.
- b) if the transmitted records included both yes and no decisions, and if so, how many of each.
- Victoria only provided "yes" decisions in the transmissions.

DHAC confirms that the table prepared by the Committee is correct. Further to this, could DHAC please clarify:

a) why information on reasons for registering to be a donor is not collected through all registration options

- Most channels do not collect the reasons for registering, to ensure the registration process is as simple, efficient and streamlined as possible, thereby encouraging more people to register.
- Registration on the AODR and/or prior family knowledge of the intention to donate, results in a much higher rate of consent for donation by families. It is unclear if communicating the reasons behind a decision to donate would have any further impact, however collecting this information would make the registration process slower and more complex.

b) if the option to specify what to donate or object to donation is only through consent registrations, whether the phone line registration option is intent (as per the Committee's table) or consent; or whether the option to choose what to donate or object to donation is not available over the phone

- The Department of Health and Aged Care's (the department) previous response indicated that individuals who wish to record their selection of specific organs and tissues for donation need to do so through a 'consent' registration channel.
- For phone line registrations (which are 'intent' registrations), Services Australia are able to record an individual's choice over what to donate, or object to donation.
- Therefore, Services Australia records an individual's choice over what to donate, or object to donation, for both consent and intent registrations.

c) how a person that does not have a Medicare number registers to be a donor. For example, they are listed on a family Medicare card, meaning they do not have a personal Medicare number or they are not a citizen.

- If a person is on a family Medicare Card, then that is their Medicare Card number. The Individual Reference Number (IRN), which appears on the card, further identifies each person on the same card.
- If they do not have a Medicare Card number, for example they are not eligible for Medicare, they can register by:
 - completing an AODR Registration Form; or
 - calling the AODR Information Line on 1800 777 203.

DHAC confirms that Services Australia may be able to release data for Victoria. The Committee would like to:

- a) request Victorian postcode data for AODR registrations for the purpose of reporting on registration rates and opportunities for improvement in regional and metropolitan areas
 - Services Australia understands that the Organ and Tissue Authority (OTA) provided DonateLife Victoria with Local Government Area (LGA) level registration data, effective end 2022, to support DonateLife Week.
 - This data has been provided to the Committee in Attachment A.
 - The data should be considered to be estimates only. Postcodes crossing LGA boundaries have been apportioned, as outlined in the document.
- b) confirm if the 'cumulative total number of registrations' as reported in Services Australia's annual report (p. 74) includes people who are now deceased, noting that a person is not removed from the AODR when they die.
 - The Annual Report published by Services Australia outlines the total number of registrations in the AODR. This includes deceased people.

Number of registered donors by LGA for Victoria

Data is for all registrations up until

NB: the end of 2022

Postcodes are captured at the time of registration and may no longer reflect the residence of the registrant

Registrations by LGA are created from postcodes provided as part of the registration process. Where postcodes cross multiple LGAs the registrations are weighted and assigned by the amount of the postcode within the LGA (eg if 85% of the postcode is within the LGA 1 and 15% in LGA 2, 85% of registrations will be assigned to that LGA 1 and 15% to LGA 2). More info can be found on the ASGS correspondences website.

*ABS Regional population by age and sex, 2020. Estimated resident population by age, Local Government Areas – 30 June 2020

State	LGA	Total Registrations	Est 2020 population aged 16 or older*	Estimated people registered in LGA
VIC	Alpine (S)	3546	10752	33%
VIC	Ararat (RC)	2441	9934	25%
VIC	Ballarat (C)	26427	88544	30%
VIC	Banyule (C)	30443	106503	29%
VIC	Bass Coast (S)	10263	30955	33%
VIC	Baw Baw (S)	12799	43437	29%
VIC	Bayside (C)	25232	86586	29%
VIC	Benalla (RC)	3712	11742	32%
VIC	Boroondara (C)	37972	150854	25%
VIC	Brimbank (C)	16646	168503	10%
VIC	Buloke (S)	1312	5039	26%
VIC	Campaspe (S)	9712	30510	32%
VIC	Cardinia (S)	20731	87947	24%
VIC	Casey (C)	43642	277156	16%
VIC	Central Goldfields (S)	2932	10941	27%
VIC	Colac-Otway (S)	5617	17560	32%
VIC	Corangamite (S)	3598	12891	28%
VIC	Darebin (C)	30523	139855	22%
VIC	East Gippsland (S)	11534	39503	29%

\ // C	Fundada (C)	24245	444025	270/
VIC	Frankston (C)	31215	114835	27%
VIC	Gannawarra (S)	2203	8627	26%
VIC	Glen Eira (C)	27610	128605	21%
VIC	Glenelg (S)	5329	16234	33%
VIC	Golden Plains (S)	5661	18580	30%
VIC	Greater Bendigo (C)	28061	95316	29%
VIC	Greater Coolean (C)	12953	136491	9%
VIC	Greater Geelong (C)	70104	213858	33%
VIC	Greater Shepparton (C)	14183	52558	27%
VIC	Hepburn (S)	4163	13483	31%
VIC	Hindmarsh (S)	1132	4636	24%
VIC	Hobsons Bay (C)	18526	78987	23%
VIC	Horsham (RC)	3880	15830	25%
VIC	Hume (C)	23601	183745	13%
VIC	Indigo (S)	5482	13679	40%
VIC	Kingston (C) (Vic.)	32141	136130	24%
VIC	Knox (C)	31508	134442	23%
VIC	Latrobe (C) (Vic.)	17004	61294	28%
VIC	Loddon (S)	1598	6234	26%
VIC	Macedon Ranges (S)	13542	39617	34%
VIC	Manningham (C)	20059	106401	19%
VIC	Mansfield (S)	2505	7667	33%
VIC	Maribyrnong (C)	16645	79540	21%
VIC	Maroondah (C)	26892	95750	28%
VIC	Melbourne (C)	22236	172221	13%
VIC	Melton (C)	16951	128214	13%
VIC	Mildura (RC)	9988	44523	22%
VIC	Mitchell (S)	9615	37098	26%
VIC	Moira (S)	7575	24480	31%
VIC	Monash (C)	28140	171541	16%
VIC	Moonee Valley (C)	23587	108910	22%
VIC	Moorabool (S)	7834	28218	28%
VIC	Moreland (C)	33333	157533	21%
VIC	Mornington Peninsula (S)	45000	138062	33%
VIC	Mount Alexander (S)	5659	16824	34%
VIC	Moyne (S)	3986	13396	30%
VIC	Murrindindi (S)	4193	12217	34%
VIC	Nillumbik (S)	18020	51779	35%
VIC	Northern Grampians (S)	2497	9514	26%
VIC	Port Phillip (C)	27328	102297	27%
VIC	Pyrenees (S)	1802	6322	29%
VIC	Queenscliffe (B)	1408	2653	53%
VIC	South Gippsland (S)	7598	24469	31%
VIC	Southern Grampians (S)	3742	13124	29%
VIC	Stonnington (C)	25316	104006	24%
VIC	Strathbogie (S)	2922	9225	32%
VIC	Surf Coast (S)	10872	27224	40%
VIC	Swan Hill (RC)	4207	16303	26%
VIC	Towong (S)	1678	5031	33%
VIC	Unincorporated Vic	278	776	36%

VIC	Wangaratta (RC)	8114	23499	35%
VIC	Warrnambool (C)	8253	28766	29%
VIC	Wellington (S)	9594	36346	26%
VIC	West Wimmera (S)	862	3104	28%
VIC	Whitehorse (C)	31700	149653	21%
VIC	Whittlesea (C)	24092	183378	13%
VIC	Wodonga (C)	11475	33170	35%
VIC	Wyndham (C)	25782	207180	12%
VIC	Yarra (C)	26008	91520	28%
VIC	Yarra Ranges (S)	39130	127844	31%
VIC	Yarriambiack (S)	1358	5403	25%