



SECTION 11

Deceased Organ Transplant Waiting Lists

SUMMARY

This chapter brings together waiting list data for the various organs. This data is not directly collected by ANZOD, but has been provided by the relevant transplant outcome Registries. In many cases more detailed information is contained in the annual reports of the relevant transplant outcome Registries. There are, however, important general considerations in interpretation of waiting list data.

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Executive Summary

Since its inception in 1989 in Australia and 1993 in New Zealand, the Australian and New Zealand Organ Donation Registry (ANZOD) continues to record and report on organ donation within Australia and New Zealand.

Data related to organ donation and transplantation activity is essential in identifying opportunities for improving the care of donors, informing on the quality of transplant organs and transplant recipient outcomes.

One organ donor can benefit a number of recipients suffering from end stage organ disease. One donor could donate up to 9 organs including, kidneys (left and right), liver (split left and right), heart, lungs (left and right), pancreas and intestine, improving the lives of people wait listed for an organ transplant.

Of importance for this reporting period was the emergence of COVID-19 that spread across the world, with the first reported case in Australia on 25th January 2020. Rapid evolution of the pandemic saw precautionary steps taken by the transplant sector which effected the organ donation programs in Australia and New Zealand. During the peak emergence of COVID-19 (late-March through to mid-May 2020) the COVID-19 National Transplantation and Donation Rapid Response Taskforce was established, comprised of members from the Transplantation Society of Australia and New Zealand (TSANZ) and Organ Tissue Authority (OTA). Recommendations from the Taskforce saw transplant programs for kidney, pancreas and islets transplants suspended and restrictions placed on liver, heart, lung, pediatric and multi-organ transplant programs to consider only recipients likely to die within four months if not transplanted. This was subject to case-by-case review of donor-recipient characteristics at a unit level. Limitations on movement of organs between states was also observed during this period due to challenges faced including border closures, flight restrictions and COVID-19 restrictions.

Consideration of the effect of the COVID-19 pandemic should be given when analysing the data included in this chapter.

Suggested Citation

ANZOD Registry. 2021 Annual Report, Section 11: Deceased Organ Transplant Wait List. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2021. Available at: www.anzdata.org.au

Waiting List Dynamics

There are some important caveats to consider when interpreting the waiting list data presented in this report.

Firstly, waiting list data is not necessarily a good indicator of actual demand for transplantation. Due to the limited availability of organs for transplantations not all people with end stage organ disease are able to be treated with transplantation and therefore each organ waiting list employs criteria for listing in order to prioritise the use of organs.

There are many rules guiding eligibility for transplantation. For further information please see the Transplantation Society of Australia and New Zealand (TSANZ) website “Organ Allocation Guidelines”, www.tsanz.com.au

Secondly, the reasons for removal from the waiting list also vary. In some cases, an individual may die before receiving an organ. In other cases (particularly cardiothoracic and liver waiting lists) they may be removed due to improving health; conversely removal may reflect deteriorating health such that the risks of transplantation outweigh benefits. Data regarding whether these people subsequently return to the waiting list, remain off the list, or die without returning to the list is not consistently available across all organs at this stage.

Thirdly, the waiting list data refers only to people on the “active” waiting list who would be transplanted immediately if an organ were available. For some organs, there are groups of patients who have been assessed but not yet activated on the waiting list, or who are temporarily removed or made “inactive”. For example, patients may develop a medical problem that makes them temporarily or permanently unfit for transplantation.

Residents of Australia or New Zealand who have transplants performed abroad may not be reported to local transplant outcome Registries and may not impact on the wait list stock and flow.

For all organs, data is presented in a “stock and flow” format, examining the transitions on and off the waiting list over the period of a calendar year. It is possible those removed from the waiting list are subsequently re-listed. For organs that have criteria lead urgent listing for transplant (i.e. liver, heart) patients may be placed on the waiting list and removed very quickly and therefore point prevalent numbers do not represent the activity and readers should refer to the “made active” number to get an impression of overall activity.

The figures in the tables refer to the lists at 1 January and 31 December of each year.

In the tables presented in this chapter, the rows describe:

- Number on the active list at the beginning of each year
- Number added to the active list during the year - “made active”
- Number removed from the active list during the year
- Number of deceased donor (DD) transplants to people on the waiting list
- Number of living donor (LD) transplants to people on the waiting list
- Number of transplants performed outside Australia / New Zealand to people on the waiting list
- Number who died while on the active waiting list
- Number on the active waiting list at the end of the year

Kidney Waiting List

Data for these waiting lists are derived from the National Organ Matching Service (NOMS) and OrganMatch (OM), combined with material from the ANZDATA Registry. The National Organ Matching Service (NOMS) transitioned to OrganMatch (OM) end March 2019. The deceased donor kidney waiting list does not include recipients who receive pre-emptive transplants, a transplant before dialysis treatment is required. In some case people on the deceased donor (DD) kidney waiting lists may receive a kidney from a living donor (LD). Although the majority of living kidney donor recipients are pre-emptive and not included on the waiting list. A patient is deemed fit for transplantation and activated on the deceased donor transplant list but a living donor kidney can be made available prior to a deceased donor transplant taking place. These two groups are illustrated separately.

Data is currently only available for Australia. Negotiations are continuing to include New Zealand data in future reports.

Further material is available in the ANZDATA Annual Report at www.anzdata.org.au

Table 11.1 Deceased Donor Kidney Only Waiting List - Stock and Flow, 2015–2020¹

	Event	2015	2016	2017	2018	2019	2020
Australia	Active start of year	1099	1049	944	961	988	1126
	Made active	757	817	954	1017	1094	903
	Taken off list	139	129	136	139	125	194
	DD graft	633	758	761	816	793	634
	LD graft	33	34	34	29	33	31
	Overseas graft	0	1	1	0	0	0
	Died on list	2	0	5	6	5	3
	Active end of year	1049	944	961	988	1126	1163

Data may differ to that previously published as data is updated in subsequent years in NOMS/OM and ANZDATA

Liver Waiting List

This table includes the waiting lists for both Australia and New Zealand. For liver transplantation, the waiting list is extracted from the Australia and New Zealand Liver and Intestinal Transplant Registry (ANZLITR) Annual Report, based on returns from transplanting centres. More detailed analyses can be found in the Report, at <http://www.anzltr.org/>.

Table 11.2 Deceased Donor Liver Waiting List Activity, 2014–2020¹

	Event	2015	2016	2017	2018	2019	2020
Australia	Active start of year	190	187	140	147	137	136
	Made active	337	337	345	362	360	330
	Taken off list	54	61	43	46	42	50
	DD graft	267	312	281	320	309	277
	LD graft	2	2	2	0	1	1
	Died on List	18	9	12	6	9	7
	Active end of year	186	140	147	137	136	131
New Zealand	Active start of year	21	24	23	28	35	33
	Made active	61	70	72	65	65	55
	Taken off list	7	11	26	8	8	14
	DD graft	45	55	52	47	54	54
	LD graft	3	4	3	2	4	0
	Died on list	3	4	2	1	1	2
	Active end of year	24	24	24	35	33	18

¹Data may differ to that previously published as data is updated in subsequent years in ANZLITR.

Cardiothoracic Organ Waiting List

Waiting lists for heart transplants: lung transplants and heart-lung transplants are collated by the Australia and New Zealand Cardiothoracic Organ Transplant Registry (ANZCOTR), based on reports from transplant units. The ANZCOTR ceased functions in June 2020 and national Australian data has not been accessible since 2019. At the time of publishing this report the Australian Commonwealth Government agency, the Organ and Tissue Authority (OTA) with support from the chairs of the Transplant Society of Australia and New Zealand (TSANZ) lung and heart transplant advisory committees and the President of TSANZ, agreed to scope the requirements to undertake the development and ongoing delivery of a contemporary Australia and New Zealand Cardiothoracic Organ Transplant Registry.

The data in the tables below were supplied by the ANZCOTR previously and include both Australia and New Zealand waiting list data. Further material for each organ is available in the ANZCOTR Annual Report at <http://www.anzcotr.org.au/>.

Heart

Table 11.3 Deceased Donor Heart Waiting List Activity, 2014–2020¹

Event		2014	2015	2016	2017	2018	2019	2020
Australia	Active start of year	48	60	44	44	72	N/A	N/A
	Made active	127	98	142	143	153	N/A	N/A
	Taken off list	32	15	13	14	20	N/A	N/A
	DD graft	78	93	124	92	121	N/A	N/A
	LD graft ²	0	0	1	1	0	N/A	N/A
	Died on list	5	5	4	8	8	N/A	N/A
	Active end of year	60	44	44	72	74	N/A	N/A
New Zealand	Active start of year	10	8	13	14	8	N/A	N/A
	Made active	18	19	18	20	23	N/A	N/A
	Taken off list	3	4	4	2	0	N/A	N/A
	DD graft	17	10	11	24	20	N/A	N/A
	LD graft	0	0	0	0	0	N/A	N/A
	Died on list	0	0	2	0	1	N/A	N/A
	Active end of year	8	13	14	8	10	N/A	N/A

¹Data may differ to that previously published as data is updated in subsequent years in ANZCOTR.

²Hearts from a living donor are identified as a domino transplant. A procedure in which the heart is removed from one transplant candidate and immediately transplanted into a second patient, with the first patient receiving a new organ from a deceased donor.

N/A - Not Accessible

Lung

Table 11.4 Deceased Donor Lung Waiting List Activity, 2014–2020¹

Event		2014	2015	2016	2017	2018	2019	2020
Australia	Active start of year	96	111	85	77	100	N/A	N/A
	Made active	223	211	234 ¹	252	245	N/A	N/A
	Taken off list	29	33	32 ¹	10	12	N/A	N/A
	DD graft	166	195	199	210	222	N/A	N/A
	Died on list	14	9	11	9	14	N/A	N/A
	Active end of year	110	85	77	100	97	N/A	N/A
New Zealand	Active start of year	13	13	5	8	8	N/A	N/A
	Made active	18	19	24	23	33	N/A	N/A
	Taken off list	0	4	2	3	0	N/A	N/A
	DD graft	17	23	17	0	28	N/A	N/A
	Died on list	1	0	2	0	1	N/A	N/A
	Active end of year	13	5	8	8	12	N/A	N/A

¹Data may differ to that previously published as data is updated in subsequent years in ANZCOTR.

N/A - Not Accessible

Pancreas Waiting List

Data for the pancreas transplant waiting list is derived from data supplied by hospitals to the Australian and New Zealand Islets and Pancreas Transplant Registry (ANZIPTR). It includes both people waiting for a combined kidney-pancreas transplant (the majority) and those waiting for a pancreas transplant alone. It does not include people waiting for pancreas islet cell transplants.

Registry data is dynamic and corrections and updates are made continually. Since 2017, ANZIPTR has undergone extensive data-audit and worked to compile data from all transplant centers into a central database to facilitate real-time data entry. This process of data checking and cleaning has meant changes as some historical data have been superseded.

Table 11.5 Deceased Donor Pancreas Transplant Waiting List Activity, 2014–2020¹

	Event	2014	2015	2016	2017	2018	2019	2020
Australia	Active start of year	9	18	30	49	71	39	48
	Made active	54	60	74	81	32	57	57
	Taken off list	2	1	3	9	11	1	7
	DD graft	43	57	42	48	50	42	47
	Died on List	0	0	0	2	3	5	2
	Active end of year	18 ¹	30	49	71	39	48	49
New Zealand	Active start of year	7	4	4	4	5	1	3
	Made active	3	4	7	6	4	6	6
	Taken off list	3	1	3	2	2	4	1
	DD graft	2	3	4	2	6	0	2
	Died on list	1	0	0	1	0	0	0
	Active end of year	4	4	4	5	1	3	6

¹Data may differ to that previously published as data is updated in subsequent years in ANZIPTR.

Intestine Waiting List

Data for the intestine transplant waiting list is derived from data supplied by hospitals to the Australian and New Zealand Liver and Intestinal Transplant Registry (ANZLITR). It includes both people waiting for a combined organ and intestine transplant (the majority) and those waiting for an intestine only transplant.

Table 11.6 Deceased Donor Intestine Waiting List Activity, 2014– 2020¹

	Event	2015	2016	2017	2018	2019	2020
Australia	Active start of year	4	5	4	3	1	3
	Made active	2	0	1	0	2	1
	Taken off list	0	0	0	1	0	0
	DD graft	1	1	1	1	0	1
	Died on list	0	0	1	0	0	0
	Active end of year	5	4	3	1	3	3

¹Data may differ to that previously published as data is updated in subsequent years in ANZLITR.