

# **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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#### **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 pass away 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 available at this stage, consistently across all organs.

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 for urgent transplant (i.e. liver, heart, lung) 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 idea 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 from National Organ Matching Service (NOMS), combined with material from the ANZDATA Registry. Some people in the deceased donor (DD) kidney waiting lists may receive a kidney from a living donor (LD), though the majority of living kidney donor recipients are not on the waiting lists. 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 also 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, 2014 - 20181

	Event	2014	2015	2016	2017	2018
	Active start of year	1076	1145	1071	954	965
	Made active	854	767	824	963	1014
	Taken off list	148	156	135	145	147
A	DD graft	572	633	759	751	811
Australia	LD graft	56	42	37	45	33
	Overseas graft	0	2	1	1	0
	Died on list	9	8	9	10	6
	Active end of year	1145	1071	954	965	982

<sup>&</sup>lt;sup>1</sup>Data may differ to that previously published as data is updated in subsequent years in NOMS 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 Transplant Registry (ANZLTR) 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, 2014-2018

Country	Event	2014	2015	2016	2017	2018
	Active start of year	152	190	187	140	147
	Made active	342	337	337	345	362
	Taken off list	54	54	61	43	46
Australia	DD graft	234	267	312	281	320
	LD graft	1	2	2	2	0
	Died on List	16	18	9	12	6
	Active end of year	189	186	140	147	137
	Active start of year	19	21	24	23	28
	Made active	56	61	70	72	65
	Taken off list	14	7	11	26	8
New Zealand	DD graft	38	45	55	52	47
	LD graft	5	3	4	3	2
	Died on list	2	3	4	2	1
	Active end of year	18	24	24	24	35

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

#### **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 data in the tables are supplied by the ANZCOTR, and include both Australia and New Zealand waiting list data. Further material for each organ is available in the ANZCOTR Annual Report at <a href="http://www.anzcotr.org.au/">http://www.anzcotr.org.au/</a>.

#### Heart

Table 11.3 Deceased Donor Heart Waiting List Activity, 2014 - 20181

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

<sup>&</sup>lt;sup>2</sup>Hearts 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.

#### Lung

Table 11.4 Deceased Donor Lung Waiting List Activity, 2014 - 2018<sup>1</sup>

	Event	2014	2015	2016	2017	2018
	Active start of year	96	111	85	77	100
	Made active	223	211	234 <sup>1</sup>	252	245
Augtrolia	Taken off list	29	33	32¹	10	12
Australia	DD graft	166	195	199	210	222
	Died on list	14	9	11	9	14
	Active end of year	110	85	77	100	97
	Active start of year	13	13	5	8	8
	Made active	18	19	24	23	33
	Taken off list	0	4	2	3	0
New Zealand	DD graft	17	23	17	0	28
	Died on list	1	0	2	0	1
	Active end of year	13	5	8	8	12

<sup>&</sup>lt;sup>1</sup>Data may differ to that previously published as data is updated in subsequent years in ANZCOTR.

#### **Pancreas Waiting List**

Data for the pancreas transplant waiting list is derived from data supplied by hospitals to the Australian and New Zealand Pancreas and Islets Transplant Registry (ANZPITR). 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. For this reason, those comparing current and previous years may notice differences particularly for waitlist activity.

Table 11.5 Deceased Donor Pancreas Transplant Waiting List Activity, 2014 - 2018

Country	Event	2014	2015	2016	2017	2018
	Active start of year	9	18	30	49	71
	Made active	54	60	74	81	32
Australia	Taken off list	2	1	3	9	11
Australia	DD graft	43	57	42	48	50
	Died on List	0	0	0	2	3
	Active end of year	18¹	30	49	71	39
	Active start of year	7	4	4	4	5
	Made active	3	4	7	6	4
New Zealand	Taken off list	3	1	3	2	2
New Zealand	DD graft	2	3	4	2	6
	Died on list	1	0	0	1	0
	Active end of year	4	4	4	5	1

<sup>&</sup>lt;sup>1</sup>Data 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 Transplant Registry. 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 - 2018

	Event	2014	2015	2016	2017	2018
	Active start of year	4	4	5	4	3
	Made active	0	2	0	1	0
Australia	Taken off list	0	0	0	0	1
	DD graft	0	1	1	1	1
	Died on list	0	0	0	1	0
	Active end of year	4	5	4	3	1