

**ANZ
DATA**



**AUSTRALIA &
NEW ZEALAND**
LIVING KIDNEY DONATION
REGISTRY

Data Set Specification

Version 2.0

© Australia and New Zealand Dialysis and Transplant Registry 2016

We have made all reasonable efforts to identify and label data collected by Australian and New Zealand Renal and Transplant Units, who collectively are the rightful owners of their data. The Registry act as Custodian of the data and the analyses and reports generated from the data collected. You may distribute this work. However, you must attribute the ANZDATA Registry as the copyright holder of the work in compliance with our attribution policy available at www.anzdata.gov.au/copyright. Enquiries relating to copyright should be addressed to the Chair of Executive, ANZDATA Registry, South Australian Health and Medical Research Institute, (SAHMRI), PO Box 11060, Adelaide SA 5001.

Any enquiries about or comments on this publication should be directed to:

Registry General Manager
ANZDATA Registry
South Australian Health and Medical Research Institute
PO Box 11060
Adelaide SA 5001
Email: anzdata@anzdata.org.au
Phone: +62 8 8128 4747 Fax: +61 8 8128 4769

VERSION HISTORY

Version No.	Release date	Remarks	Prepared by	Approved by
1.0	2016/07/01	Introducing the new data dictionary for the online Living Kidney data entry module	M. Kandamby	Kylie Hurst
2.0	2019/12/10	Addition of new fields - <ul style="list-style-type: none">• LKDonorDetails Ethnicity1Code, Ethnicity1Other, Ethnicity2Code, Ethnicity2Other	M. Kandamby	Kylie Hurst

Australia and New Zealand Living Kidney Donation Registry Dataset

Identifying and definitional attributes

<i>Metadata item type:</i>	Data Set Specifications
<i>Registry Identifier:</i>	ANZDATA
<i>DSS type:</i>	Data Set Specification (DSS)
<i>Scope:</i>	The Australia and New Zealand Dialysis and Transplant Registry has been in operation since its inception in 1971 and stores data from 1964. The purpose of the Registry is to record, analyse and report on outcomes of treatment of those people with end stage kidney disease receiving renal replacement therapy treatment and of those such as haemodialysis, peritoneal dialysis and kidney transplantation.

Relational attributes

<i>Related Metadata references::</i>	See also Australia and New Zealand Dialysis & Transplant Registry (ANZDATA) Data Dictionary See also Australia and New Zealand Organ Donation (ANZOD) Data Dictionary
--------------------------------------	--

Accountability attributes

<i>Organisation/s responsible for providing data:</i>	Australian and New Zealand Renal and Transplant Units
<i>Accountability:</i>	ANZDATA

Collection and usage attributes

<i>Computation: description:</i>	As of 2004 the ANZDATA Registry has been collecting data on living kidney donors across Australia and New Zealand. This has been historically reported in the Annual Report in relation to living kidney transplantation. As at 2015 the Registry will be publishing a monthly report presenting a series of tables that describe living kidney donor activity by state and relationship to recipient. In time donor characteristics and follow up activity will also be reported in this new format.
<i>Comments:</i>	Data elements and statistical analyses have evolved over time and where indicated the status of a data element describes whether it is in current use or inactive.

List of metadata items

- Australia and New Zealand Living Kidney Donation Dataset 4
- Living Kidney Donor Details 6
- Living Kidney Yearly Follow up 11
- Living Kidney Other Comorbidities 14

Living Kidney Donor Details

Identifying and definitional attributes

<i>Metadata item type:</i>	Data set specifications
<i>DSS type:</i>	Data element cluster
<i>Table name:</i>	LKDonorDetails
<i>Historical table name:</i>	<i>PreTransplant</i>
<i>Registration status:</i>	<i>Active</i>
<i>Description:</i>	This data cluster contains data elements collected during the registration process for those living donors who were consented for kidney donation.

Source or reference attributes

<i>Submitting Organisation:</i>	ANZOD Registry
---------------------------------	----------------

Metadata items in this Data Set Specifications

<i>Item</i>	<i>Metadata item</i>	<i>Obligation</i>	<i>Data Type</i>	<i>Reference</i>	<i>Variable label</i>	<i>Historical item</i>
1	LivingDonorId	Mandatory	int	No	Living Donor Id	
2	LivingDonorNumber	Mandatory	nvarchar(10)	No	Living Donor number	PreTransplant.DonNumber
3	StatusCode	Mandatory	nvarchar(10)	Yes	Donor status	
4	ReferringCentreCode	Optional	nvarchar(10)	Yes	Referring centre	PreTransplant.RefHosp
5	ReferringCentreMRN	Optional	nvarchar(10)	No	Referring centre MRN	PreTransplant.RefUnit
6	DonorSurname	Mandatory	nvarchar(50)	No	Donor surname	PreTransplant.DonSurname
7	DonorGivenNames	Mandatory	nvarchar(50)	No	Donor given name	PreTransplant.DonGivName
8	DateOfBirth	Mandatory	date	No	Date of birth	PreTransplant.DonDatBirth
9	GenderCode	Mandatory	nvarchar(10)	No	Gender	PreTransplant.DonSex
10	Ethnicity1Code	Optional	nvarchar(10)	Yes	Ethnicity 1 code	PreTransplant.DonRace
11	Ethnicity1Other	Optional	nvarchar(100)	No	Ethnicity 1 other	PreTransplant.DonRaceOthr
12	Ethnicity2Code	Optional	nvarchar(10)	Yes	Ethnicity 2 code	
13	Ethnicity2Other	Optional	nvarchar(100)	No	Ethnicity 2 other	
14	BirthCountryCode	Optional	nvarchar(10)	Yes	Birth country	PreTransplant.DonCountry
15	BirthCountryOther	Optional	nvarchar(100)	No	Birth country other	

16	DonorPostcode	Optional	int	No	Post code	PreTransplant.DonPostCode
17	RecipientAnzdataId	Optional	int	Yes	Recipient Anzdata Id	PreTransplant.Patient
18	RecipientRelationshipCode	Optional	nvarchar(10)	Yes	Relationship to recipient	PreTransplant.DonSource
19	RecipientRelationshipOther	Optional	nvarchar(50)	No	Relationship to recipient other	PreTransplant.DonSourceOthr
20	Height	Optional	decimal(4, 1)	No	Height	PreTransplant.DonHeight
21	Weight	Optional	decimal(4, 1)	No	Weight	PreTransplant.DonWeight
22	SmokingCode	Optional	nvarchar(10)	Yes	Smoking code	PreTransplant.DonSmoking
23	FamilyHistoryDiabetesCode	Optional	nvarchar(10)	Yes	Family history of diabetes (Y/N/U)	PreTransplant.DonFamily
24	DiabetesCode	Optional	nvarchar(10)	Yes	Diabetes code	PreTransplant.DonDiabetes
25	HypertensionCode	Optional	nvarchar(10)	Yes	Hypertension (Y/N)	PreTransplant.DonHt
26	NumberOfDrugsTaken	Optional	int	No	Number of drugs taken	PreTransplant.DonDrugs
27	BloodPressureSystolic	Optional	int	No	BP Systolic	PreTransplant.Systolic
28	BloodPressureDiastolic	Optional	int	No	BP Diastolic	PreTransplant.Diastolic
29	GlucoseToleranceTestCode	Optional	nvarchar(10)	Yes	Glucose tolerance test	PreTransplant.NoGTT
30	GttFastingBgl	Optional	decimal(4, 1)	No	GTT fasting blood glucose	PreTransplant.FastingBGL
31	Gtt2HrBgl	Optional	decimal(4, 1)	No	GTT2 hour blood glucose	PreTransplant.TwoHourBGL
32	HbA1cPercent	Optional	decimal(4, 1)	No	HbA1c percentage	-
33	HbA1cIFCC	Optional	int	No	HbA1cIFCC	-
34	SerumCreatinine	Optional	int	No	Serum creatinine	PreTransplant.DonSCreat
35	Urea	Optional	decimal(4, 1)	No	Urea	PreTransplant.DonUrea
36	MeasuredGfrMethodCode	Optional	nvarchar(10)	Yes	Measured GFR method	PreTransplant.Method
37	MeasuredGfrOther	Optional	nvarchar(50)	No	Measured GFR other	PreTransplant.MethodOthr
38	MeasuredGfr	Optional	decimal(5, 1)	No	Measured GFR	PreTransplant.DonGFR
39	ProteinResult24Hr	Optional	decimal(5, 2)	No	Protein result	PreTransplant.DonProtein
40	ProteinCreatinineRatio	Optional	decimal(5, 2)	No	Protein creatinine ratio	PreTransplant.DonPCR
41	AlbuminCreatinineRatio	Optional	decimal(5, 2)	No	Albumin creatinine ratio	PreTransplant.DonACR
42	OtherProteinMeasure	Optional	nvarchar(100)	No	Other protein measure	PreTransplant.ProteinOthr
43	PreTransplantComments	Optional	ntext	No	Pre transplant comments	PreTransplant.Comments
44	DonorCentreCode	Optional	nvarchar(10)	Yes	Donor centre	Operative.DonHosp

45	DonorCentreMRN	Optional	nvarchar(10)	No	Donor centre MRN	-
46	TransplantCentreCode	Optional	nvarchar(10)	Yes	Transplant centre	Operative.TranHosp
47	TransplantCentreMRN	Optional	nvarchar(10)	No	Transplant centre MRN	Operative.TranUnit
48	DonationDate	Optional	datetime	No	Donation date	Operative.TxDate
49	Surgeon	Optional	nvarchar(50)	No	Surgeon	Operative.Surgeon
50	WhichKidneyCode	Optional	nvarchar(10)	Yes	Which kidney? (L/R)	Operative.Kidney
51	OperationTypeCode	Optional	nvarchar(10)	Yes	Operation type	Operative.Operation
52	ApproachCode	Optional	nvarchar(10)	Yes	Approach code	Operative.Approach
53	Arteries	Optional	int	No	Number of arteries	Operative.Arteries
54	NumberOfVeins	Optional	int	No	Number of veins	Operative.Veins
55	Ureters	Optional	int	No	Number of ureters	Operative.Ureters
56	OtherOperationDetails	Optional	ntext	No	Other operation details	Operative.DetailOthr
57	AdverseInfectionCode	Optional	nvarchar(10)	Yes	Adverse infection? (Y/N)	Operative.Infection
58	AdverseInfectionSiteCode	Optional	nvarchar(10)	Yes	Adverse infection site	Operative.Site
59	AdverseInfectionSiteOther	Optional	nvarchar(50)	No	Adverse infection site other	Operative.SiteOthr
60	UrineCultureCode	Optional	nvarchar(10)	Yes	Urine culture code	Operative.Culture
61	UrineInfectionCode	Optional	nvarchar(10)	Yes	Urine infection	Operative.UrineInf
62	OrganismCode	Optional	nvarchar(10)	Yes	Organism code	Operative.Organism
63	OrganismOther	Optional	nvarchar(50)	No	Organism other	Operative.OrgOthr
64	FurtherAdverseEventCode	Optional	nvarchar(10)	Yes	Further adverse event	Operative.Adverse
65	FurtherAdverseEventOther	Optional	nvarchar(100)	No	Further adverse event other	Operative.AdverseOthr
66	DaysInHospital	Optional	int	No	Days in hospital	Operative.HospDays
67	DischargeCreatinine	Optional	int	No	Creatinine at discharge	Operative.DisCreat
68	FollowUpCentreCode	Optional	nvarchar(10)	Yes	Follow up centre	-
69	FollowUpCentreMRN	Optional	nvarchar(10)	No	Follow up centre MRN	-
70	OperationComments	Optional	ntext	No	Operation comments	Operative.Comments
71	Physician	Optional	nvarchar(50)	No	Physician	-
72	CoMorbidityConditionOther	Optional	nvarchar(100)	No	Comorbidity condition other	-
73	CoMorbidityConditionOtherDM	Optional	nvarchar(150)	No	Comorbidity condition other DM	-
74	PreRolloverStatusCode	Optional	nvarchar(10)	Yes	Rollover status code	-

75	LastValidatedDate	Optional	datetime	No	Record validated date	-
76	CreatedByUser	Mandatory	nvarchar(25)	No	Created user	-
77	CreatedDate	Mandatory	datetime	No	Created date	-
78	ModifiedByUser	Optional	nvarchar(25)	No	Modified user	-
79	ModifiedDate	Optional	datetime	No	Modified date	-

Relational attributes

Related metadata references:

AnzdataPatients
CodeAdverseEventSite
CodeCountryOfBirth
CodeFurtherAdverseEvents
CodeLKDiabetesType
CodeLKDonorStatus
CodeLKOrganism
CodeMeasuredGFR
CodeOperationApproach
CodeOperationType
CodeRacialEthnicOrigin
CodeRelationshipToRecipient
CodeSmoking
CodeWhichKidney
CodeYesNo
CodeYesNoUnknown
CommonCentres

Collection and usage attributes

Guide for use:

Data is collected in real-time or at the end of each month.

Implementation start date

01/04/2015

Comments:

This data cluster replaces the historical tables 'PreTransplant' and 'Operative' of the legacy 'ORACLE' database.

Fields added to the table from April 2010

DonACR

Fields added to the table from 2015

FollowUpCentreCode, FollowUpCentreMRN, DonorCentreMRN, HbA1cPercent, HbA1cIFCC

Method of collection changed from April 2010

DonHeight - range restricted to between 100-220 (not previously restricted)

DonWeight - Range restricted to between 40-180 (not previously restricted)

DonSmoking - U=Unknown removed

DonDrugs - Changed from 1-20 to 1-5

Diastolic - Range changed from 40-110

FastingBgl - Changed from NUMBER (2)

twoHourBgl - Changed from NUMBER (2)

DonScreat - Changed from (mmol/l) to (μ mol/L)

DonUrea - Range changed from 0-20.0 to 0.5-20.0

Method - New Code C added for 24 hour Creatinine Clearance (from 1st April 2010)

DonGfr - Changed from (ml/min) to (mL/min)

DonProtein - Changed from (g/day) to (mg/day)

Measurements prior to this change are a mix of mg/day and g/day and difficult to interpret

Range added 0-500 or null

DonPcr - Changed from NUMBER (4,1) to NUMBER (4,2)

Range changed from 0-20 to 0-100

Arteries - range added

Veins - Range added

HospDays - Range added

DisCreat - Now collected in (μ mol/L) NOT (mmol/l), Range added

Ethnicity1Code, Ethnicity1Other, Ethnicity2Code, Ethnicity2Other fields started collecting data from 2019-01-01.

Fields added for internal use only -

CreatedDate, CreatedByUser, ModifiedDate, ModifiedByUser, StatusCode, LastValidateDate

Living Kidney Yearly Follow up

Identifying and definitional attributes

Metadata item type:	Data set specifications
DSS type:	Data element cluster
Table name:	LKYearlyFollowup
Historical table/s:	Longterm
Registration status:	Active
Description:	This data cluster contains data elements relating to a donor's yearly follow up details.

Source or reference attributes

Submitting Organisation:	ANZOD Registry
--------------------------	----------------

Metadata items in this Data Set Specifications

Item	Metadata item	Obligation	Data Type	Reference	Variable Label	Historical item
1	FollowUpId	Mandatory	int	No	Follow up Id	
2	LivingDonorId	Mandatory	int	Yes	Living donor Id	
3	FollowUpNumber	Mandatory	int	No	Follow up sequence	
4	FollowUpDate	Optional	date	No	Follow up date	LongTerm.FollowDate
5	FollowUpCentreCode	Optional	nvarchar(10)	Yes	Follow up centre	LongTerm.CurrHosp
6	FollowUpCentreMRN	Optional	nvarchar(10)	No	Follow up centre MRN	LongTerm.CurrUnit
7	FollowUpPhysician	Optional	nvarchar(100)	No	Physician	LongTerm.Physician
8	DonorAliveCode	Optional	nvarchar(10)	Yes	Donor alive? (Y/N)	LongTerm.Alive
9	DateOfDeath	Conditional	date	No	Death date	LongTerm.DatDeath
10	CauseOfDeathCode	Conditional	nvarchar(10)	Yes	Cause of death	LongTerm.CausDeth
11	CauseOfDeathOther	Conditional	nvarchar(100)	No	Cause of death other	LongTerm.DethOthr
12	BloodPressureSystolic	Optional	int	No	BP Systolic	LongTerm.Systolic
13	BloodPressureDiastolic	Optional	int	No	BP Diastolic	LongTerm.Diastolic
14	SerumCreatinine	Optional	int	No	Serum Creatinine	LongTerm.Donscreat

15	ProteinCreatinineRatio	Optional	decimal(4, 2)	No	Protein Creatinine ratio	LongTerm.DonPCR
16	AlbuminCreatinineRatio	Optional	decimal(4, 2)	No	Albumin Creatinine ratio	LongTerm.DonACR
17	OtherProteinName	Optional	nvarchar(100)	No	Other protein name	LongTerm.ProteinOthr
18	HypertensionCode	Optional	nvarchar(10)	Yes	Hypertension	LongTerm.DonHT
19	NumberOfDrugsTaken	Optional	int	No	Number of drugs	LongTerm.DonDrugs
20	SmokingCode	Optional	nvarchar(10)	Yes	Smoking code	LongTerm.Cig
21	DiabetesCode	Optional	nvarchar(10)	Yes	Diabetes code	LongTerm.DonDiabetes
22	RenalProblemsCode	Optional	nvarchar(10)	Yes	Renal problems code	LongTerm.Renal
23	RenalProblemsText	Optional	nvarchar(100)	No	Renal problems text	LongTerm.Problems
24	VascularEventCode	Optional	nvarchar(10)	Yes	Vascular event code	LongTerm.Event
25	VascularEvent1Date	Optional	date	No	Vascular event date	LongTerm.FirstDate
26	VascularEvent1Code	Optional	nvarchar(10)	Yes	Vascular event 1 code	LongTerm.VasEvent1
27	VascularEvent1Other	Optional	nvarchar(100)	No	Vascular event 1 other	LongTerm.VasOthr1
28	VascularEvent2Date	Optional	date	No	Vascular event 2 date	LongTerm.SecondDate
29	VascularEvent2Code	Optional	nvarchar(10)	Yes	Vascular event 2 code	LongTerm.VasEvent2
30	VascularEvent2Other	Optional	nvarchar(100)	No	Vascular event 2 other	LongTerm.VasOthr2
31	PregnancyCode	Optional	nvarchar(10)	Yes	Pregnancy code	LongTerm.Pregnancy
32	PregnancyOutcomeCode	Optional	nvarchar(10)	Yes	Pregnancy outcome code	LongTerm.Outcome
33	PregnancyOutcomeDate	Optional	date	No	Pregnancy outcome date	LongTerm.OutcomeDate
34	WeeksPregnant	Optional	decimal(4, 1)	No	Weeks pregnant	LongTerm.WeeksPreg
35	Comments	Optional	ntext	No	Comments	LongTerm.Comments
40	FollowUpStatusCode	Optional	nvarchar(10)	Yes	Follow up status code	
41	LastValidatedDate	Optional	datetime	No	Last validated date	
42	FollowUpDate	Optional	int	No	Follow up date	
43	FollowUpCentreCode	Optional	int	Yes	Follow up centre code	
36	CreatedByUser	Mandatory	nvarchar(25)	No	Created user	
37	CreatedDate	Mandatory	datetime	No	Created date	
38	ModifiedByUser	Optional	nvarchar(25)	No	Modified user	
39	ModifiedDate	Optional	datetime	No	Modified date	

Relational attributes

Related metadata references:

CodeAnzdataCauseOfDeath
CodeLKDiabetesType
CodeLKFollowUpStatus
CodeSmoking
CodeVascularEvent
CodeYesNo
CommonCentres
LKDonorDetails

Collection and usage attributes

Guide for use:

Data is collected at commencement of organ donation and recorded at the end of each month.

Implementation start date

01/03/2014

Comments:

This data cluster replaces some or all data elements in the historical tables 'Longterm' of the legacy ORACLE' database.

Fields for internal use only -

FollowUpStatusCode , LastValidatedDate , FollowUpDate, FollowUpCentreCode
CreatedByUser, CreatedDate, ModifiedByUser, ModifiedDate

Fields added to the table from 2010 -

DonACR - *To avoid confusion between PCR and ACR*

Method of collection changed from April 2010

DonScreat - *Changed from (mmol/l) to (μmol/L), Range changed from 20-200 to 20-400*

DonPCR - *Changed from NUMBER (4,1) to NUMBER (4,2), Range changed from 0-20 to 0-100*

DonDrugs - *Range changed from 1-20 to 1-5*

Living Kidney Other Comorbidities

Identifying and definitional attributes

<i>Metadata item type:</i>	Data set specifications
<i>DSS type:</i>	Data element cluster
<i>Table name:</i>	LKOtherComorbidities
<i>Historical table/s:</i>	<i>PreTransplant</i>
<i>Registration status:</i>	<i>Active</i>
<i>Description:</i>	This data cluster contains data elements relating to all other comorbid conditions diagnosed either as pre-existing, present and/or arising of the living donor. Data is coded in accordance with the ICD-10 codes.

Source or reference attributes

<i>Submitting Organisation:</i>	ANZOD Registry
---------------------------------	----------------

Metadata items in this Data Set Specifications

<i>Item</i>	<i>Metadata item</i>	<i>Obligation</i>	<i>Data Type</i>	<i>Reference</i>	<i>Variable Label</i>	<i>Historical item</i>
1	OtherComorbidId	Mandatory	int	No	Other Comorbid Id	
2	LivingDonorId	Mandatory	int	Yes	Living Donor Id	
3	ComorbidConditionCode	Mandatory	nvarchar(10)	Yes	Comorbid condition code	PreTransplant.CoMorbidOthr
4	CreatedByUser	Mandatory	nvarchar(25)	No	Created user	
5	CreatedDate	Mandatory	datetime	No	Created date	
6	ModifiedByUser	Optional	nvarchar(25)	No	Modified user	
7	ModifiedDate	Optional	datetime	No	Modified date	

Relational attributes

Related metadata references:

CodeOtherCoMorbidityConditions

Collection and usage attributes

Guide for use:

Data is collected at commencement of renal replacement therapy, in real-time, and at the end a survey period.

Implementation start date

01/03/2014

Comments:

This data cluster replaces some or all data elements in the historical table 'Pretransplant' of the legacy 'ORACLE' database.

Fields for internal use only -

CreatedByUser, CreatedDate, ModifiedByUser, ModifiedDate