Data Set Specification

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Australia and New Zealand Eye and Tissue Donation Registry Dataset

Identifying and definitional attributes

Metadata item type:	Data Set Specifications
Registry Identifier:	Eye and Tissue Donation
DSS type:	Data Set Specification (DSS)
Scope:	The Australia and New Zealand Organ Donation Registry has been in operation since its inception in 1989. The purpose of the Registry is to record and report on organ, eye and tissue donations in Australia and New Zealand. Data related to donation and transplantation activity is essential in identifying opportunities for improving care of donors, informing on quality of transplant organs and transplant recipient outcomes. The Registry began reporting on deceased and living donation of eye and tissue data collected from Australian Tissue banks in pilot project in 2012.

Relational attributes

Related Metadata references:	See also Australia and New Zealand Organ Donation Registry (ANZOD) Data Dictionary

Accountability attributes

Organisation/s responsible for providing data:	Participating Australian Eye and Tissue banks
Accountability:	ANZOD

Collection and usage attributes

Computation: description:	Tissue and eye data collected from Australian and New Zealand Tissue and Eye Banks
Comments:	Data collection for Australia began on **01.01.2013**

Usage of attributes:

Definitions

Cardiovascular tissue (cv)	Includes, but not limited to, heart valves, pericardium and annexed vessels.
Cornea	The cornea is the transparent anterior tissue of the eyeball consisting of many layers
Deceased solid organ and tissue donation	Identifies a donation event where one or more solid organs and tissues are retrieved from a deceased donor. Data has been crosschecked with the solid organ and tissue sector to ensure the donor has met the deceased solid organ and tissue donation criteria.
Deceased tissue donation	Identifies a donation event where one or more tissues are retrieved from a deceased donor and can comprise of pancreas islet cells, musculoskeletal tissue, cardiovascular tissue, skin tissue or eye tissue.
Donation date	The date of tissue retrieval from a donor for the purpose of transplantation to a recipient.
Donation event	A single retrieval event, within a calendar day, where a living donor can donate one or more musculoskeletal or cardiovascular tissues. Retrieval from deceased donors of solid organ, tissue and/or eyes that may occur on differing days but after the donor declaration of death date.
Eye only donor	A deceased donor where eye only retrieval has taken place. A donor is counted as an eye only donor if 2 whole eyes, 2 corneas only, one eye or one cornea only is retrieved. Outcomes of donated eye tissue are not limited to transplantation.
Eye and solid organ (and tissue) donor	A deceased donor where eye and solid organ retrieval has taken place. These donors may or may not have donated an additional tissue(s) e.g. musculoskeletal, cardiovascular or skin. Data has been crosschecked with the solid organ and tissue sector to confirm the donation event and donor classification.
Eye tissue donation	
Eye and tissue only donor	A deceased donor where eye and an additional tissue(s) e.g. musculoskeletal, Cardiovascular or skin has taken place. Data has been crosschecked with the tissue sector to confirm the donation event and donor classification. Unless otherwise specified all donors undergo retrieval of either whole eyes or both corneas. This means the number of eye tissue donations can be calculated by doubling the amount of total eye donors.
Eye tissue graft transplants	Corneal or scleral tissue transplanted into an eye tissue recipient within the reporting time period.
Eye tissue recipient	Unless otherwise specified the number of eye tissue recipients is equal to the number of eye tissue graft transplants (consistent with EBAANZ).
Living tissue donation	Identifies a donation event where one or more tissues are retrieved from a living donor. Living tissue is vastly comprised of donated femoral heads (bone) retrieved during hip replacement surgery. A living musculoskeletal donor can donate one femoral head during one donation event, two femoral heads during one donation event or one femoral head during two separate donation events.
Musculoskeletal tissue (ms)	Includes, but not limited to, bone, cartilage and tendon retrieved from areas such as the pelvis, arm and leg.
Notified tissue graft transplants	Number of tissue grafts supplied and confirmed by the hospital to the distributing tissue bank to have been transplanted. One tissue graft recipient may receive multiple graft transplants
Notified tissue graft recipients	The number of tissue graft recipients, confirmed by the hospital to the distributing bank, who receive one or more graft transplants during a single tissue transplant event

Pancreas islet (pi)	a multicellular structure within the pancreas that maintains normal blood glucose level within the body.
Sclera unit	A unit of the protective outer layer of the eyeball, used for transplantation during ocular surgery.
Skin tissue (sk)	Includes, but not limited to, split thickness skin (epidermis and upper part of the dermis), of varying size.
Tissue transplant event	A single tissue transplant event occurs when a tissue graft recipient receives 1 or more tissue grafts on a single occasion. This will be counted as one tissue graft recipient, one tissue transplant event
Tissue Graft Recipient	If a tissue graft recipient receives 1 or more tissue grafts during multiple tissue transplant events, this will be counted as one tissue graft recipient for each tissue transplant event.
Unique donor	A deceased or living donor who donates one or more tissue(s) during a single donation event.

| *Counting Methodology* | Each tissue and eye bank uses a Minimum Data Set Template (MDS) to provide the Registry de-identified donor information for each tissue type, as well as aggregate data for reporting of notified tissue graft transplants and notified tissue graft recipients. Data received undergoes reconciliation and cross checking between the solid organ sector (ANZOD), the eye sector (participating eye banks) and the tissue sector (participating tissue banks) to ensure accuracy at the time of reporting.

According to EBAANZ, since the end of 2011, the number of corneal transplants in Australia each year has exceeded the number of new patients requiring transplants each year. This means the current demand for corneal transplants in Australia is being met and should be noted when comparing 2016 corneal transplantation numbers to previous years published.

It is acknowledged that service provision in the living tissue donation sector by BAA and associated member banks occurs in addition to the Australian Organ and Tissue Authority's (OTA) \national reform programme to improve organ and tissue donation and transplantation outcomes in Australia". |
| *The Registry declares:* | - All donations of eye tissue have come from deceased donors.

- Eye donors include those who have donated 2 whole eyes, 2 corneas or one whole eye or one cornea.
- Eye donations are not limited to the outcome of transplantation.

- Eye and Tissue Graft Transplants and Transplant Recipient data includes transplant events that have occurred in a different jurisdiction to where the tissue was donated.

- Graft Transplants and Transplant Recipient data may or may not be a direct outcome of tissue donations reported for the quarter, as tissue can be stored for a period of time before the graft is transplanted.

- Outcome data does not capture tissue that has been supplied for transplant but not yet notified as transplanted to the distributing tissue bank. |

List of metadata items

TissueDonors

Identifying and definitional attributes

Metadata item type:	Data set specifications
DSS type:	Data element cluster
Table name:	**TissueDonors**
Registration status:	Active
Description:	This data cluster contains data elements collected during the registration process for those donors who were consented for tissue donation.

Source or reference attributes

Submitting Organisation:	ANZOD Registry

Metadata items in this Data Set Specifications

Item	Metadata item	Obligation	Data Type	Reference	Variable label
1	BankDonorNumber	Mandatory	nvarchar(10)	No	Bank Donor ID
2	DateOfBirth	Mandatory	date	No	Donor's date of birth
3	Gender	Mandatory	nvarchar(10)	No	Donor's sex
4	DateOfDonation	Mandatory	date	No	Date of donation
5	DonorType	Mandatory	nvarchar(10)	No	Donor is live or deceased at the time of donation
6	DonorCategory	Mandatory	nvarchar(10)	No	Donor category
7	PlaceOfRetrieval	Mandatory	nvarchar(10)	No	Geographical state where the donation happened
8	TissueType	Mandatory	nvarchar(10)	No	Type of tissue

Collection and usage attributes

Guide for use:	Data is collected in real-time or at the end of each month.
Implementation start date	**01/01/2013**
Comments:	

TissueTransplants

Identifying and definitional attributes

Metadata item type:	Data set specifications
DSS type:	Data element cluster
Table name:	**TissueTransplants**
Registration status:	Active
Description:	Describes number of recipients notified to the bank who receive one or more graft implants during a single transplant event.

Source or reference attributes

Submitting Organisation:	ANZOD Registry

Metadata items in this Data Set Specifications

Item	Metadata item	Obligation	Data Type	Reference	Variable label
1	BankName	Mandatory	nvarchar(10)	No	Name of the bank
2	BankJurisdication	Mandatory	nvarchar(10)	No	State of the bank
3	DonationYear	Mandatory	int	No	Year of donation
4	DonationMonth	Mandatory	int	No	Month of donation
5	TissueGrafts	Mandatory	int	No	No of tissue grafts implanted
6	TissueRecipients	Mandatory	int	No	No of grafts implanted in to recipients

Collection and usage attributes

Guide for use:	Data is collected in real-time or at the end of each month.
Implementation start date	**01/01/2013**
Comments:	

EyeDonors

Identifying and definitional attributes

Metadata item type:	Data set specifications
DSS type:	Data element cluster
Table name:	**AnzodDonors**
Historical table name:	*OrganDonor, Consent*
Registration status:	*Active*
Description:	This data cluster contains data elements collected during the registration process for those donors who were consented for organ donation.

Source or reference attributes

Submitting Organisation:	ANZOD Registry

Metadata items in this Data Set Specifications

Item	Metadata item	Obligation	Data Type	Reference	Variable label
1	BankDonorNumber	Mandatory	nvarchar(10)	No	Bank Donor ID
2	LocalDonorId	Mandatory	nvarchar(10)	No	Local tissue bank Id
3	DateOfBirth	Optional	date	No	Donor's date of birth
4	Gender	Optional	nvarchar(10)	No	Donor's sex
5	DateOfDonation	Mandatory	date	No	Date of donation
6	EDRNumber	Mandatory	nvarchar(10)	No	Unique identification number assigned by the DonateLife network to the donor
7	DonorCategory	Mandatory	nvarchar(10)	No	Donor category
8	PlaceOfRetrieval	Mandatory	nvarchar(10)	No	Geographical state where the donation happened
9	AdditionalInformation	Optional	nvarchar(50)	No	Additional Information

Collection and usage attributes

Guide for use:	Data is collected in real-time or at the end of each month.
Implementation start date	**01/01/2013**

EyeTransplants

Identifying and definitional attributes

Metadata item type:	Data set specifications
DSS type:	Data element cluster
Table name:	**EyeTransplants**
Registration status:	Active
Description:	Describes the number of corneas and sclera transplanted within the reporting time period.
	This number includes corneas and sclera that have been imported and transplanted by the banks.

Source or reference attributes

Submitting Organisation:	ANZOD Registry

Metadata items in this Data Set Specifications

Item	Metadata item	Obligation	Data Type	Reference	Variable label
1	BankName	Mandatory	nvarchar(10)	No	Name of the bank
2	BankJurisdication	Mandatory	nvarchar(10)	No	State of the bank
3	DonationYear	Mandatory	int	No	Year of donation
4	DonationMonth	Mandatory	int	No	Month of donation
5	ConeasTransplanted	Mandatory	int	No	No of Coneas transplanted
6	ScleraTransplanted	Mandatory	int	No	No of Sclera transplanted

Collection and usage attributes

Guide for use:	Data is collected in real-time or at the end of each month.
Implementation start date	**01/01/2013**
Comments:	