**ACT Mortality data**

ACT Registrar of Births, Deaths and Marriages

Australian Bureau of Statistics

Australian Coordinating Registry

## Background

All deaths for which a coronial inquiry is not required must be certified as to cause and date by a registered medical practitioner and the certificate registered by the Registrar of Births, Deaths and Marriages (RBDM) in each State and Territory. Deaths that are referred to a coroner are registered by the coroner at the conclusion of an inquiry into the circumstances of the death. The vast majority of non-coronial deaths are registered with the relevant RBDM within four weeks of the date of death; however coronial inquiries can take months or even years to conclude.

Details of all registered deaths are forwarded to the Australian Bureau of Statistics (ABS). The ABS then check and code the information.

## Australian Coordinating Registry Cause of Death Unit Record File

For deaths registered from 2006 onwards, the Epidemiology Section of ACT Health receives coded cause of death data from the Australian Coordinating Registry (ACR) for the Cause of Death Unit Record File (COD URF). Access to the COD URF is in accordance with the ACR terms and conditions of use and disclosure by the ACT Health Directorate..

Where information based on the COD URF data is used in any publication or report:

1. the information should be referenced as follows: “Source: Cause of Death Unit Record File held by ACT Health Directorate.”
2. the following acknowledgement should be included: “Acknowledgement: The Cause of Death Unit Record File (COD URF) is provided by the Australian Coordinating Registry for COD URF on behalf of Australian Registries of Births, Deaths and Marriages, Australian Coroners and the National Coronial Information System.”

## Record linkage of ACT RBDM and ABS/ACR data

Death registrations held by the RBDM contain full personal identifiers and the death registration number. The Australian Coodinating Registry (ACR) removes personal identifiers from the COD URF data each year once their annual mortality report is published, but retains the death registration number. Thus RBDM death registration data constitute personally identified but uncoded raw data, while the COD URF data have coded cause of death but with personal information removed. ACT COD URF data is supplied by the ACT Health Directorate in the same manner as other ACT Health Directorate administrative data sets.

## Tips for using mortality data in linkage studies

* Two datasets contain mortality information: RBDM death registration data and the ACR COD URF.
* The COD URF is based on year of reference of the death, rather than the year of the death. The reference year is the year in which the record was coded.
* RBDM death registration data are provided in raw, uncoded format. For this reason only date of birth, age at death, date of death and year of death are available for analysis.
* COD URF data are available later than the RBDM death registration data due to the time needed for coding and cleaning of the data.
* Death records available for linkage include deaths occurring in ACT and do not include deaths of ACT residents who die interstate. The Australian Institute of Health and Welfare holds the National Death Index, which can be used for research studies that require linkage of death records for ACT residents who die interstate.
* Death data is coded according to the ICD-10 International Version rather than the Australian Modification ICD-10-AM used in Australian hospitals. When there is an external cause of injury or poisoning, the external cause is provided as the underlying cause of death, not the injury itself.
* The date of birth is sometimes incorrect as it is reported by relatives to the funeral director at the time when the funeral is being arranged. The funeral director reports the personal details of the deceased to the RBDM. Particularly for older family members who have died, relatives generally report the birth day (day and month) correctly, but may inadvertently give an incorrect year of birth. For this reason age at death may be preferable for analysis purposes.

## Access to information on Aboriginal and Torres Strait Islander peoples

An application to the Aboriginal Health and Medical Research Council (AH&MRC) ethics committee should be made for research projects for which one or more of the following apply:

* The experience of Aboriginal people is an explicit focus of all or part of the research
* Data collection is explicitly directed at Aboriginal peoples
* Aboriginal peoples, as a group, are to be examined in the results
* The information has an impact on one or more Aboriginal communities
* Aboriginal health funds are a source of funding

Research that is not specifically directed at Aboriginal people or communities, such as for the total population or a sub-population (eg. rural NSW, people over 50 years old) can still potentially impact on Aboriginal people.

However, an application for such research need only be made to the Committee if *any* one of the following applies:

* Any of the five factors listed above are present; or
* Aboriginal people are known, or are likely, to be significantly over-represented in the group being studied (eg. compared to the 2.1% of the total NSW population as shown in the 2006 Census); or
* The Aboriginal experience of the medical condition being studied is known, or is likely, to be different from the overall population; or
* There are Aboriginal people who use the services being studied in distinctive ways, or who have distinctive barriers that limit their access to the services; or
* It is proposed to separately identify data relating to Aboriginal people in the results.

The AH&MRC ethics committee have some specific requirements, including evidence of community engagement in the research. Relevant documents can be found on the AH&MRC website at: <http://www.ahmrc.org.au>. If you are unsure whether an application to the AH&MRC Ethics Committee is required, please seek the advice of the Ethics Committee secretariat (T: 02 9212 4777).

## Delegated Data custodian

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## RBDM death registrations - variable information

| Variable [Variable name] | Description/Notes | Codes |
| --- | --- | --- |
| Date of birth  [birth\_date] | The date of birth of the individual.  Full date of birth is rarely released for data linkage projects; please ensure that you include detailed justification if you require full date of birth. |  |
| Date of death  [death\_date] | The date of death of the individual.  Full date of death is rarely released for data linkage projects; please ensure that you include detailed justification if you require full date of death. |  |
| Age at death in years  [age\_recode] | The age at death of the individual in years |  |
| Year of Registration  [registration\_year] | The year in which death was registered |  |

## ACR COD URF data - variable information

| Variable [Variable name] | Description/Notes | Codes |
| --- | --- | --- |
| Indigenous Status  [indigen] | Available from 2004. Indigenous Status is a measure of whether the deceased person has been identified as being of Aboriginal or Torres Strait Islander origin.  Approval of the Aboriginal Health and Medical Research Council (AH&MRC) may be required to obtain this variable (see page 3). | 1 = Aboriginal  2 = Torres Strait Islander  3 = Both Aboriginal and Torres Strait Islander  4 = Neither Aborginal nor Torres Strait Islander  9 = Not stated |
| Year of Registration  [reg\_year] | Year in which a death is registered by the relevant Registry of Births, Deaths and Marriages. |  |
| Reference Year  [ref\_year] | Year in which a registered death was coded. This variable determines what data items are available and the coding edition used to code the cause of death. |  |
| Date of death  [dthdte] | The date of death of the individual.  Full date of death is rarely released for data linkage projects; please ensure that you include detailed justification if you require full date of death. |  |
| Age at Death |  |  |
| Age in Years  [ageyrs] | Age in years. |  |
| Fractional age  (less than 1 year of age)  [age] | Age at death during the first year of life (0 years) is recorded in completed months, days, hours or minutes. If aged between 1 and 11 months, Age at Death is recorded in months. If aged between 1 and 28 days, Age at Death is recorded in days. If aged between 1 and 23 hours, Age at Death is recorded in hours. If aged less than an hour, Age at Death is recorded in minutes. If age is less than one minute, Age at Death is recorded in seconds. | 1-120 Age in years  201-211 Age in months with prefix of 2  299 Unknown months  301-327 Age in days with a prefix of 3  398 Unknown days  401-423 Age in hours with a prefix of 4  499 Unknown hours  500-559 Age in minutes with a prefix of 5  599 Unknown minutes  601-659 Age in seconds with a prefix of 6  699 Unknown seconds  999 Not stated |
| Place of Birth  [birthplace] | The country or state/territory (if born in Australia) in which the deceased person was born.  In 2009 the classification changed from Standard Australian Classification of Countries (SACC) 1998 (Revision 2.03) to the 2008 version of the SACC. Since 2012 the 2011 version of SACC has been used. | Coding has changed many times and is inconsistent. Use with care.  <http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/5D2485E6F15281E6CA2570B5007ACA80?opendocument> |
| Country of Birth  [sacc] | The country in which the deceased person was born, Australian states have been recoded to Australia. | <http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/5D2485E6F15281E6CA2570B5007ACA80?opendocument> |
| Period of Residence in Australia  [period\_residence] | Period of residence in Australia, in years. | 00-96 = 00-96 years of residence in Australia  97 = 97 or more years of residence in Australia  98 = Born in Australia (not applicable)  99 = Not stated |
| State/Territory of Usual Residence  [stateid] |  | 1 = New South Wales  2 = Victoria  3 = Queensland  4 = South Australia  5 = Western Australia  6 = Tasmania  7 = Northern Territory  8 = Australian Capital Territory  9 = Other Territories (Cocos (Keeling) Islands, Christmas Island, Jervis Bay Territory) |
| Sex  [sex] | The sex of the deceased person. | 1 = Male  2 = Female |
| Place of Occurrence of External Cause of Death  [place\_occurrence] | The place where the external cause of death occurred. | 0 = Home  1 = Residential Institution  2 = School  3 = Sports and athletics area  4 = Street and highway  5 = Trade and services  6 = Industrial and construction area  7 = Farm  8 = Other specified places  9 = Unspecified place  # = Place of occurrence not applicable |
| Underlying Cause of Death Diagnosis Code  [ucod] | Underlying cause is recorded as four digits. If a particular cause does not have a four digit code, the fourth character is filled as #. For example, in the ICD-10, Parkinson’s disease is coded as G20, however in the unit record file it is represented as G20#. | International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) |
| Contributing causes of death (ICD-10)  [RACS1-RACS20] | Up to 20 comorbidity codes. Original values as provided by the ACR. Please note that the codes do not have periods inserted, nor do they have the fourth characeter filled as # for 3-digit ICD 10 codes. | International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) |
| Geography |  |  |
| Australian Standard Geographic Classification (ASGC)  [URES\_9DIGIT\_SLA] | From 2006 to 2010. ASGC 9-digit code denoting where the deceased usually resided.  The geographic location is reported using a nine digit numeric code. This code is hierarchical and comprises a series of sub-codes indicating various levels of geography. The first digit of this code indicates the state or territory (S/T) of usual residence. Digits 2-3 show the Statistical Division (SD), digits 4-5 the Statistical Subdivision (SSD), and digits 6-9 show the Statistical Local Area (SLA). | http://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/1216.0?OpenDocument |
| Australian Statistical Geography Standard (ASGS)  [URES9\_SA2] | From 2009 onwards. ASGS 9-digit code denoting where the deceased usually resided.  The geographic location is reported using a nine digit numeric code (SA2). This code is hierarchical and comprises a series of sub-codes indicating various levels of geography. The first digit of this code indicates the state or territory (S/T) of usual residence. Digits 2-3 show the SA4, digits 4-5 show the SA3, and digits 6-9 show the SA2. The SA2 identifier is a 4-digit code, assigned in alphabetical order within an SA3 and numerically within an SA4. An SA2 code is only unique within an S/T if it is preceded by the S/T identifier. | http://www.abs.gov.au/ausstats/abs@.nsf/mf/1270.0.55.001 |
| COD URF revision status  [edition] | This is recorded as “Preliminary”, “Revised” or “Final”  See <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/3303.0Technical%20Note32013?opendocument&tabname=Notes&prodno=3303.0&issue=2013&num=&view>= for further information.  This variable will be included in all data releases. | f “Final”  r “Revised  p “Preliminary” |