

Cause of death unit record file

Frequently asked questions

1. What is the cause of death unit record file?

The cause of death unit record file (COD URF) is a dataset containing information relating to all deaths registered in Australia for a given reference year. The dataset does not contain names but has a number of attributes of an individual including the International Classification of Disease (currently version 10) codes relating to the causes of death, which are added by the Australian Bureau of Statistics (ABS).

The national dataset is a compilation of death records from each of the State and Territory Registries of Births, Deaths and Marriages (RBDMs) and from State and Chief Coroners through the National Coronial Information System (NCIS). Subsets of the national data will be available by individual or multiple jurisdictions.

The COD URF is used for demographic and health purposes. Research from this data provides significant information for the formulation and monitoring of health and other social policies. For a full list of the data items included in the COD URF refer to: "What data items are included in the COD URF?"

Note: The data available is coded to ICD-10, not ICD-10-AM.

2. Are deaths in the COD URF data set recorded by jurisdiction or usual residence?

The jurisdictional data available relates to deaths registered within that particular jurisdiction, and is not dependent on the place of usual residence. Therefore if a person who usually resides in Queensland (Qld) died in another jurisdiction, the record will not be available in the Qld COD URF outputs. If a person who usually resides in another jurisdiction died in Qld, the record will be available in the Qld COD URF outputs.

3. What and who are the data custodians?

Data custodians are the agencies which are responsible for the collection, use and disclosure of information in a dataset.

For the COD URF each jurisdictional State/Chief Coroner, as represented by the National Coronial Information System (NCIS), and the Registrars of each jurisdictional Registry of Births, Deaths and Marriages are the collective data custodians as they each contribute data to the national COD URF data set. These agencies collect the data from individuals under their respective legislation.

Data custodians may grant access to information they hold, but have an obligation to protect the persons to whom the information relates from unjustified intrusion on their privacy. Data custodians are sometimes referred to as data source agencies or data owners.

4. What is the Australian Coordinating Registry?

An Australian Coordinating Registry (ACR) is the jurisdictional Registry of Births, Deaths and Marriages that has been appointed by all Australian Registrars as the ACR to carry out a particular function. There are multiple coordinating Registries however the ACR appointed for COD URF is the Qld Registry of Births, Deaths and Marriages. In this role the ACR for COD URF has developed the necessary principles and processes for release of the COD URF data sets.

Note: The appointment of a coordinating registry does not void the responsibilities of each individual jurisdictional RBDM in regard to their respective RBDM legislation or other jurisdictional requirements.

5. What services/products will the ACR offer?

The ACR role is to facilitate access to predefined COD URF data products (ICD-10 coded). The ACR will only offer a small number of subsets/variations from the main COD URF data product. The ACR does not have the capacity to undertake data linkage with other data, nor provide summary outputs derived from the COD URF. Other approved on-providers of COD URF data may be able to offer these services. Refer to “Will the ACR offer a data linkage service?”

The products available from the ACR are the national COD URF:

- core data set, for reference years from 2006 onwards refer to “What is included in the COD URF “core” data set
- data linkage data sets for reference years from 2006 onwards .

Note:

The National data linkage data sets will only be supplied to approved data linkage agencies and will include two additional data items (registration number and full date of birth DD/MM/YYYY) to enable data linking.

Subsets of the above two data sets are available by data source and jurisdiction (e.g. NSW only or outputs that require RBDM data only or Coronial data only).

There can be multiple versions of each yearly data set according to their revision status. The different versions account for updates to the cause of death codes that have been made over time to Coronial data as additional information becomes available from the NCIS. For more information please refer to “Why are there multiple versions of the data?”

6. Can any of the data custodians release the COD URF or parts of it?

The data custodians have agreed to the national coordinated process offered through the ACR. Apart from the Qld Registry of Births, Deaths and Marriages, each data custodian only holds their own records from the COD URF data set. Individual RBDMs may be able to provide cause of death data which includes only textual cause of death information (un-coded), but they are not able to provide full COD URF data for their jurisdiction as the data held does not include the coded information for deaths reported to a coroner. The NCIS (referred to a Coroner) only holds records for those cases.

7. What is the COD URF used for?

There are many applications for COD URF data, including:

- population based health research and policy development, monitoring or evaluation
- investigation of potential projects i.e. testing hypotheses and pilot studies
- follow-up and comparison of different treatment regimes
- morbidity studies and outcomes of specific diseases.

8. Am I eligible to access the COD URF?

The COD URF data set contains data of a sensitive nature at the individual record level. As such the data sets are only available to approved applicants for approved uses. Approved users and uses are determined by the data custodians (or their appointed delegate) and must meet the eligibility requirements through an application process administered by the Australian Coordinating Registry.

Allowable uses are research or statistical purposes, with approval only granted if the application is consistent with the following data access principles:

- purpose of data access is in the public interest, which includes research that benefits the community
- where deemed necessary each project has been approved by a Human Research Ethics Committee(s) registered with the National Health and Medical Research Council (NHMRC) which are constituted and operated in accordance with NHMRC guidelines.

For further information regarding ethical approvals please refer to <https://www.nhmrc.gov.au/guidelines-publications/e72> (**National Statement on Ethical Conduct in Human Research (2007)**)

- data released must be appropriately managed by approved users to protect individuals from unreasonable intrusion on their privacy.

Approved data users must be able to satisfy the data custodians of the following:

- use of the data has strong merit, as determined by assessment of uses being in the public interest
- benefits of using the COD URF data will outweigh any privacy risks.
- applicant will manage the data appropriately to ensure that it is used for the purposes as specified in the application
- each project and/or use in a master linkage file has been approved by a Human Research Ethics Committee(s) registered with the National Health and Medical Research Council (NHMRC) which are constituted and operated in accordance with NHMRC guidelines. For further information please refer to <https://www.nhmrc.gov.au/>.

The applicant must apply strict protocols to ensure the confidentiality of the information, have appropriate data security measures, and wherever possible, undertake the research using de-identified data.

The COD URF is not to be used for administrative or compliance purposes, though other RBDM data may be available for purposes other than research and statistics. Please contact the ACR alternative products and services.

Researchers will not be given access to the COD URF where it is deemed that a more viable mechanism or data source more appropriate to meet the needs of the research purpose is available e.g. the researcher will not be given access to unit record data if their research work can be undertaken using summary information.

9. Are there any restrictions on how I use, store or output data from the COD URF?

Yes, there are restrictions on how the COD URF can be used, stored or published.

These restrictions are provided to ensure that the data custodians meet their obligations in relation to providing access to their data. This includes ensuring agreed data management principles have been met and that they have full transparency and awareness of the users and uses of their data.

The main restrictions on using the COD URF are included in the Applicant declaration. The declaration covers use, disclosure and security arrangements. By signing this declaration, the Applicant is binding all staff within the agency/project to adhere to the restrictions stipulated in the declaration. Upon approval of the application, additional strictures could be imposed to mitigate data custodian risks. These would be outlined upon notification of application outcomes.

There are specific confidentiality guidelines set out in the COD URF Application Guide. These rules must be adhered to by all applicants and data users including any third party data users.

Approved applicants are not permitted to onward provide data, for fee or otherwise at the unit record level to any other agency or external party without data custodian approval.

Any agency wishing to be granted an exemption or exception from any of the confidentiality rules or other terms and conditions will need to provide a written request that gives a detailed explanation of the exemptions sought and outlines any references or supporting information which should be considered by the ACR and delegate when assessing any such request.

A breach of these conditions may result in future non-supply of this data to you/your agency.

10. Who should complete an application for COD URF?

In recognition that a number of researchers within an agency may have a need to use COD URF data, the application forms have been designed to be completed by applicant agencies, rather than individuals. This limits the need to obtain agency details for each individual data use/project. An application can also be used by individual researchers applying for COD URF.

In some cases agencies may be asked to complete multiple applications where the data uses or data management arrangements differ greatly within one agency.

For most applicant agencies the persons completing the application should be from the area within the agency that routinely manages data. The application allows for the agency to nominate a central access and coordination point to manage the COD URF data sets or for the agency to nominate multiple areas within the organisation if copies of the data will be stored or managed by multiple areas.

Throughout the application process the applicant agency must nominate an “Applicant”. The Applicant must be someone in the agency who has the authority to act on behalf of the agency (e.g. Senior Manager/Chief Information Officer). The Applicant must declare their authority to make assurances on behalf of the agency requesting the data; to bind the agency, including all individuals specified in the application, to the terms of this agreement.

The Applicant must take responsibility for the confidentiality assurances of all individuals in the agency that use COD URF data.

In addition to the Applicant, the application will collect details of a Primary contact person (for the ACR to liaise with), the data manager (who will control access to the data), and the person who will take receipt of the COD URF data. These may be the same person in some instances.

For agencies with multiple COD URF data use/project uses the application includes a data use/project register which must detail all data uses/projects undertaken using the COD URF and provide details on all Chief/Principal Investigators managing each data use/project.

Note **exceptions for universities:**

The data custodians have requested that due to the high level of segregation between areas within a University, applications for COD URF should be at the Research/School/Institute (or equivalent) level and the data Applicant should be the head of the Research/School or Institute.

11. Why are there three different COD URF applications?

There are three ACR application forms for access to COD URF data. These are:

1. Application for Cause of Death Unit Record File for General Requests
2. Application for Cause of Death Unit Record File for Data Linkage
3. Repeat Request and/or Supplementary Project Use Application for Cause of Death Unit Record File.

The first General Request application is used to apply for COD URF data sets which will not be subject to data linkage activities.

Data custodians have deemed data linkage activities as a higher risk and therefore the second application caters for the collection of additional information about data linkage activities. Data linkage application forms will only be provided to agencies that meet specific eligibility criteria.

For more information refer to “How can I become an approved Data linkage agency for COD URF?” Data linkage agencies that intend to also undertake other data uses/projects that do not require data linkage will only need to complete the Data linkage application form, but will be required to record all data uses/projects (data linkage and non-data linkage) within the supplied data use/project register.

A Repeat Request / Supplementary application form will only be available to limited agencies that have previously been approved to use COD URF data. This application was designed to streamline the application process by enabling the data user to specify changes to an original application or to request data for additional reference periods without the need to complete a full application. The ACR will advise applicants if they are eligible for this application type.

12. What is the data use/project register?

There are two different data uses/project registers associated with the COD URF application processes:

1. Data Use/Project Register for General Applications
2. Data Use/Project Register for Data Linkage Applications.

A data use/project register is a spreadsheet that accompanies the COD URF applications where there is more than one data use/project being undertaken by an agency. The ACR will supply the applicable data use/project register when they send you the relevant COD URF application. You will also be sent an application guide to assist in completion of your application.

The Data Use/Project Register collects detailed information relating to each data use/project use for which the Applicant intends to use COD URF data. The information collected includes details of the Principal Investigator, the research hypothesis, the proposed public benefit, duration and retention of data, details of the intended use and outputs, any approvals granted in relation to the project such as the ethical approval(s) granted in relation to the project/s or consent.

In addition, the Data Use/Project Register for Data Linkage Applications includes details of the datasets that will be linked with the COD URF, and captures details of any data linkage services that will be offered by the data Applicant to third party data users.

Each Applicant must provide details of all data uses/projects by completing the Data Use/Project Register. Omission of any data uses/projects may result in a new application for COD URF being required and further fees imposed.

13. How will the data use/project register be used?

The data use/project register will provide information for the data custodians to determine approval for each data use/project listed in the application. It must contain sufficient details to enable the data custodians to assess each data use/project to ensure any privacy concerns are outweighed by public benefit.

Note: Approval for use of the COD URF will be assessed and provided on a Project/Use basis. Therefore there is no guarantee that all proposed data uses/projects will be given approval. In some cases the data custodians may provide approval for provision of the COD URF data set to an applicant, but prohibit it from being used for specific data uses/projects.

14. Why does the COD URF application require such detail?

The COD URF is a sensitive data set and disclosure of the information contained in the COD URF can only occur if the legislative requirements governing the data are met. As far as practical, the data custodian must protect the persons to whom the information relates from unjustified intrusion on their privacy. Provision can only occur when the data custodians are satisfied that the use of the data is in the public interest.

The application form has been designed to ensure that all information relevant to the data custodians making a determination regarding disclosure is collected. These include the requirement for the data custodians to ensure that release of information is in the public interest and that they meet all privacy requirements. To make this assessment the data custodians

require transparency of all uses of the data, including details of all applicants and for all data uses/projects.

15. Why are there multiple versions of COD URF data?

In line with the Australian Bureau of Statistics, the COD URF revisions process for COD URF data is subject to three iterations.

Revisions are made to Coronial data, where investigations of death remain open, for up to three years. This means that there will be multiple data sets available spanning three years - e.g. From April 2016, data will be available for 2018 Preliminary, 2017 Revised, 2006-2016 Final.

Once each revision iteration has been completed only data considered “Final” will be available - e.g. 2016 revised data sets are not available once 2016 Final data sets are available.

Please note, you will not be automatically granted access to Final data if you apply for Preliminary or Revised data. If you require the revised versions of the data you must re-apply using the “Supplementary COD URF Data Application” and pay the applicable fees. If your use of the data changes between applications, you may be required to complete a new full COD URF application.

For more details regarding the revisions process for Cause of Death data refer to the ABS website on www.abs.gov.au.

16. What if I need data sets further back than 2006?

COD URF data sets prior to 2006 are not available from the ACR or any other source in unit record format. The quality of data sets prior to 2006 and the format has been deemed unsuitable for use.

For more details regarding summary data for earlier periods is available through both the ABS website on www.abs.gov.au and the Australian Institute of Health and Welfare (AIHW) website on www.aihw.gov.au.

17. What if I already hold COD URF data sets (prior to 2006 from the ABS) and would like to use the data for new projects?

Prior to the ACR process, COD URF data was distributed by the ABS on behalf of the data custodians. If you have previously received COD URF data from the ABS, the agreement and terms specified for use of the data still apply. If your agreement requires you to provide additional or updated information regarding uses of the data or outputs to the ABS, this will still be required and requests should be directed to the health and vitals team at the ABS by email to Health_and_Vitals_WDB@abs.gov.au.

18. Can overseas researchers and agencies be approved to receive the COD URF?

Not at this time. The governance arrangements for COD URF data through the ACR enable Australian coded cause of death data at the unit record level to be released to researchers and agencies within Australia. As a result, the release of data at the unit record level to overseas researchers and/or agencies is not available at this time. Overseas researchers/agencies interested in Australian cause of death information may be able to

access summary information through the AIHW www.aihw.gov.au or the ABS www.abs.gov.au.

19. What happens if my application is not approved?

The ACR aims to assist all eligible applicants to obtain COD URF data for research or statistical purposes that meet the data custodians' access principles.

Before providing an agency with a COD URF application the ACR will hold initial eligibility discussions with COD URF applicants. At this stage the ACR may suggest other options for obtaining cause of death data.

The ACR will undertake an initial compliance check of all submitted applications to ensure all necessary questions and documentation is included before the applications are assessed by the data custodians or their delegates. The ACR will manage further correspondence between the data custodians and the data applicants where additional information is required and provide notification of application outcomes.

Note: Approval for use of the COD URF will be assessed and provided on a Project/Use basis. Therefore there is no guarantee that all proposed data uses/projects will be given approval.

Depending on the reasons for non-approval, the ACR will provide feedback to the applicant and where possible offer alternative solutions.

20. Will the ACR offer a data linkage service?

No. The ACR is not a data linkage agency. There are a number of data linkage agencies within Australia who have been approved to hold COD URF data sets for data linkage purposes. A number of these data linkage agencies upon approval from the data custodians will be able to provide data linkage services to third parties which include COD URF data items.

Currently the AIHW has the approval and ability to undertake data linkage with the COD URF data sets and therefore the ACR would recommend data users requiring this service to seek further information from the AIHW website on www.aihw.gov.au.

21. Will the COD URF data set contain coronial data?

Yes, unless otherwise requested the COD URF includes data from all deaths registered in Australia, including both Registry data and Coronial data. The COD URF application process incorporates requests to access both Coronial and Registry data through the single application process.

Note: Any individual or agency wishing to **on-provide** any part of the COD URF data that contains Coronial data (including provision of data linkage services to other agencies) will need to apply to be an on-provider of Coronial information. This approval can only be granted by the National Coronial Information System (NCIS) through application. For more information please refer to the NCIS website on <http://www.ncis.org.au> and <http://www.ncis.org.au/how-to-access-data-on-the-ncis/#a3>.

22. Do I need to inform the ACR of any changes to personnel working on the cleansing of administrative records?

The following data items are included in the COD URF core data set:

Mortality identifier
Reference year
State/territory of registration
Indigenous Status
Age at death
Period of residence in Australia
State/territory of usual residence
Statistical area level 2 of usual residence (SA2)
Gender (sex)
Underlying cause of death
Certifier type
Source of cause of death data
Entity axis data
Record axis data
Record axis count
Date Of Death
Registration date
Coroner case status flag
Birth year
Place of birth
**Meshblock
Data set status
Local government area
Notes:

**The Meshblock field is not currently supplied, and data set status refers to the reference year e.g. Preliminary, Revised or Final

1. This is the current list of data items. Over time some items have undergone change (e.g. International Classification of Disease coding changes and Geographic classification changes). Further information on data items and historical data items will be available in a COD URF user guide which will be provided to approved data users upon release of the data.
2. Applicants will be able to apply for national COD URF core data sets or jurisdictional subsets of this national data set, dependent on the scope of their research project(s).

23. What is included in the COD URF data linkers data set?

Approved COD URF data linkage agencies will be able to request both the COD URF core data set and the COD URF Data Linkers data set to append to the corresponding COD URF core data sets. The Data Linkers data sets contain the following data items:

Mortality ID
Registration Number
DOB (Multiple strings – birth day, birth month, birth year)

24. How can I become an approved data linkage agency for COD URF?

Only a small number of agencies will be approved to use the COD URF for data linkage purposes. These agencies must have demonstrated expertise in data linkage and be able to satisfy the detailed requirements of the data custodians to ensure that the data custodians meet their obligations under respective RBDM, privacy and other legislative requirements.

Due to the sensitivity of the data the only agencies permitted to become COD URF data linkage agencies will be:

- Data Integrating Authorities: as appointed by the Cross Portfolio Statistical Integration Committee (CPSIC).
- Data linkage agencies: agencies set up for the main purpose of facilitating data linkage.
- Health agencies: Where these agencies can demonstrate that data linkage is a core component of their work and they have data linkage expertise.

The data custodians may consider granting other agencies outside of the above the ability to undertake data linkage using COD URF, on a case by case basis.

25. Is there a fee for the COD URF?

Yes. The fee for the COD URF has been determined on a cost recovery basis. The fee does not include charges for the data itself, but does include charges to recover the costs of dissemination of the COD URF to data users. This includes quality checks that need to be performed by each of the data custodians at various stages of the project and the costs associated with running and maintaining the ACR processes.

The current fees for COD URF applications can be found in the COD URF Application Guide. These fees will be reviewed annually.

26. Why do I need to pay for the COD URF?

To ensure that the data is fit for research purposes the data custodians have invested a significant amount of resources to develop and maintain the release processes. The cost for these activities is outside of the funding allocated to the various data custodians and without charging for these services the data custodians will not be able to maintain data quality or release the data to users.

27. How will I be able to pay for the COD URF data?

Once your application has been approved an invoice will be generated. This invoice will provide details of the payment options. These include BPay, Electronic Funds Transfer (EFT) or payment by Credit Card.

Note: No cheques will be accepted.

28. Will there be any discounts applied to COD URF data?

No. As the fees have been set on a cost recovery model no discounts can be applied. The ACR suggests that these fees are taken into consideration when seeking funding for research proposals.

29. How is the ACR funded?

The ACR operates on a cost recovery model. A portion of the fees collected from data users for the COD URF will be used to offset the costs of the administrative functions of the ACR. This includes application processes, administration of the national agreements, liaison with all stakeholders including data custodians and data users and any system costs required for storage, and extraction the COD URF data. The COD URF fees include provisions for money to be returned to each of the Registry data custodians to manage their costs associated with the product, such as review and assessment of applications or input data quality checks.

30. Is the COD URF data set the same data set the ABS used to release?

Yes, the product is the same. The ABS obtains data from the NCIS and each registry to produce a range of statistics. In addition to the statistical publications the ABS previously managed Unit Record File releases on behalf of the collective data custodians, however a review in 2007 determined that the provisions for the ABS to release unit record data sourced from other agencies is not within the legislative remit of the ABS and would need to be managed by the data custodians.

In recognition of the high value of the COD URF data set, the data custodians agreed to make the COD URF data available through an Australian Coordinating Registry approach. This agreement has led to increased visibility of the wide variety of uses of the Registry and Coroner data and has resulted in increased emphasis on the need to develop capability and adopt best practice for data management. The benefits of this new arrangement are providing the data custodians with the transparency required to meet their legislative requirements and the capacity to offer additional services. For data users this new process also provides better accessibility through a single access point and data that is nationally consistent.

Any reference to the ABS being the data custodians for COD URF is incorrect and any documentation about COD URF should reflect the Registries and NCIS as the COD URF data custodians.

31. How do I acknowledge the data custodians in publications?

Acknowledging the data custodians in publications is part of the terms and conditions of using COD URF data and undertakings signed to by COD URF Applicant. The acknowledgment may vary according to the individual project, but here is an example:

Acknowledgement: Standard Project

The authors wish to thank the Registries of Births, Deaths and Marriages, the Coroners and the National Coronial Information System for enabling COD URF data to be used for this publication.

Where COD URF data has been obtained from a data linkage agency approved to on-provide the information, additional acknowledgements may be required.

32. Do I need to inform the ACR of any changes to personnel working on my approved data use/project?

Only the names of the principal investigator for each data use/project are collected by the ACR through the data use/project register that accompanies the COD URF application. Any changes to the principal investigator/s or the agency "Applicant" must be provided to the ACR by an email to bdm.codurf@justice.qld.gov.au.

If additional personnel work on the data use/project or project teams change, no information needs to be provided unless the additional personnel are from an agency that differs from the agency stated in the original application or are subject to different confidentiality or access arrangements. In these cases please contact the ACR by email at bdm.codurf@justice.qld.gov.au for further advice.

33. There is something wrong with my data, who do I contact?

The first point of contact will be the ACR through bdm.codurf@justice.qld.gov.au, the ACR may need to refer enquiries to the original data custodians or to the ABS.

Please be aware that we will not be investigating individual records, as the COD URF data sets are not designed for interrogation of individual records.

Data users who obtain COD URF data and other data from any of the Registries of Births, Deaths and Marriages should not cross reference or data link this information unless they have an approval to do so. In these cases small discrepancies may arise between the data sets due to differences in the timing of data extraction, noting that the COD URF data is a snapshot of data from the data custodians at a point in time, whereas the Registry databases may be subject to continual updates or corrections.

34. Why can't I access the extra data items in the data linkers COD URF?

There are some variables contained in the data collections which are deemed to be identifiable or potentially identifiable (e.g. full date of birth, address). The National Health and Medical Research Council (NHMRC) National Statement states that the public benefit of using personal health information must outweigh the risk to privacy; therefore wherever possible only non-identifiable data can be released for medical and health research.

For the Data Linkers COD URF, Registration and Full Date of Birth information is included to enable data linkage, but is not to be used for other purposes or able to be published in any format. As soon as these identifiers are no longer required, they must be destroyed by the applicant.

35. What am I allowed to release in publications?

No information that will directly or indirectly identify individuals should be released in publications. All outputs using COD URF data need to be subject to a quality assurance process to ensure they comply with the COD URF data confidentiality rules that have been agreed to by the data custodians. A copy of these rules can be found in the COD URF application guide.

In particular, there are specific confidentialisation techniques that should be completed for any outputs that contain small cell sizes, or where there is a small population size.

All draft abstracts, manuscripts and/or papers should be reviewed and approved by the ACR prior to publishing.

36. I have discovered a breach in protocol, what do I do?

Please contact the ACR for advice by email at bdm.codurf@justice.qld.gov.au.

37. How will my data be delivered?

Currently the data sets are encrypted and supplied via email to the person nominated to receive the data in the COD URF application. Once the COD URF data sets have been received by the applicant agency the nominated recipient should contact the ACR by telephone to receive the encryption key. The data files and encryption key must never be stored together.

Note: the ACR will only send data to official agency email addresses and after approval has been granted and payment has been received.