

# National Death Index (NDI), Data Quality Statement

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# National Death Index (NDI), Data Quality Statement

## Identifying and definitional attributes

<b>Metadata item type:</b>	Data Quality Statement
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## Data quality

### Data quality statement summary:

- Deaths occurring in Australia are registered and maintained by the Registrars of Births, Deaths and Marriages in each state and territory. These registration details are then provided to the AIHW and are assumed to be as correct as possible. The AIHW has no ability to confirm the correctness and completeness of these data.
- It is expected that some death registration details may contain errors and some information that is critical might be missing. The AIHW uses a probabilistic data linking technique to link researchers' data to the NDI. Consequently, the linkage result is an indication or index of death, rather than an absolute fact of death.
- Incorrect linkages can result because of errors or incorrect details in personal information supplied when deaths are registered. Examples of such errors are: the changed surname when women marry is not provided; given names are transposed, incorrectly spelt, or partly replaced by nicknames; the date of birth is wrong, the birth day of an elderly relative might be known, but not the year of birth.
- Linkages are tailored to the needs of the researcher, in terms of the matching tightness.

## Description

The National Death Index (NDI) is a database, housed at the Australian Institute of Health and Welfare (AIHW), which contains records of all deaths occurring in Australia since 1980. The data are obtained from the Registrars of Births, Deaths and Marriages in each state and territory. The Index is designed to facilitate the conduct of epidemiological studies and its use is strictly confined to medical research.

Researchers undertaking such studies need to follow up groups of persons who, for example, take part in clinical trials, or who have suffered from particular diseases, or are known to have been exposed to specific hazards, in order to determine whether death has occurred, and if so to analyse the survival rate and causes of death.

Each Registry records only those deaths that occur in its own state or territory, and if a person dies in a state or territory other than the one in which the circumstances being studied were experienced, without the NDI the researchers would have to contact every Registry to determine whether or not a death has been registered.

**Institutional environment:** The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the [Australian Institute of Health and Welfare Act 1987](#) to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent statutory authority established in 1987, governed by a management [Board](#), and accountable to the Australian Parliament through the Health and Ageing portfolio.

The AIHW aims to improve the health and wellbeing of Australians through better health and welfare information and statistics. It collects and reports information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The Institute also plays a role in developing and maintaining national metadata standards. This work contributes to improving the quality and consistency of national health and welfare statistics. The Institute works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

One of the main functions of the AIHW is to work with the states and territories to improve the quality of administrative data and, where possible, to compile national datasets based on data from each jurisdiction, to analyse these datasets and disseminate information and statistics.

The [Australian Institute of Health and Welfare Act 1987](#), in conjunction with compliance to the [Privacy Act 1988 \(Cth\)](#) ensures that the data collections managed by the AIHW are kept securely and under the strictest conditions with respect to privacy and confidentiality.

For further information see the AIHW website [www.aihw.gov.au](http://www.aihw.gov.au)

**Timeliness:**

The Registrars of Births, Deaths and Marriages in each State and Territory provide to the AIHW on a monthly basis, the details of deaths registered in a given month, as soon as that month ends, usually within the first two weeks of the following month.

In most cases, deaths that were registered in a given month did happen in that month, however some deaths are registered many years after death occurs, for example in cases when the remains are found.

Cause of death information is derived from the National Mortality Database, which records the underlying and other causes of death as ICD10 codes derived by the Australian Bureau of Statistics from the death certificates. This information is generally not available for the most recent two years of data.

The latest and the most current NDI data are available to link to the researchers' cohort.

**Accessibility:**

Researchers can access the National Death Index if their study generally meets the following set of conditions;

- the study focuses on health issues;
- the study has been approved by the researcher's host institution ethics committee and the AIHW Ethics Committee. Typically this review concentrates on the issues of public interest and use of confidential information;
- the study is scientifically valid (as judged by a peer review process);
- the study results will be placed in the public domain (e.g. published papers or books, conference presentations, feedback to patients);
- the study will not break confidentiality provisions;
- the study investigators comply with the AIHW legislation under which the data are released; and
- the data will be secured in an environment that guarantees confidentiality of individual's data.

Given that the study can meet these conditions, it can be best progressed by researchers discussing feasibility and likely costs with one of the contact officers in the AIHW. To formally apply for NDI use, researchers can obtain from the Institute's web page [www.aihw.gov.au/national-death-index/](http://www.aihw.gov.au/national-death-index/), an NDI data provision package. This package gives instructions as to what data formats are required, a description of the NDI, the legislation covering the use of NDI data and the AIHW Ethics Committee application forms.

These forms contain questions relating to the objectives of the project, the security of the confidential information, the intended release of the study results and the public benefit that might be gained from conducting the study. The Ethics Committee will consider these factors in determining whether to grant approval to the project. The Committee meets four times a year. Once a study is given an Ethics Committee certificate the project can proceed.

**Interpretability:**

The NDI database held by the AIHW comprises such variables for each deceased person as: name, alternative names (including maiden names), date of birth (or estimated year of birth), age at death, sex, date of death, marital status, indigenous status, State/Territory of registration, registration number. In some records the additional information of address and the text related to cause of death is available.

Cause of death information in a coded form is derived by linking the National Death Index registration numbers for deaths with the National Mortality Data Base. This latter data base records underlying cause of death in ICD10 codes as derived by Australian Bureau of Statistics from the death certificates. This information is generally not available for the most recent two years of data.

A description of the NDI is included in the application package that researchers use when applying to link their data to the NDI. The researchers are made aware of the probabilistic nature of the data linkage method and are instructed to treat the linkage results as indication or index of death, rather than as an absolute fact.

**Relevance:**

The National Death Index contains records of all deaths that occurred in Australia since 1980 and up to the most recent month past.

Researchers are made aware of the limitation of the probabilistic data linkage method and that they need to provide sufficient details of their subjects for the technique to be effective.

**Accuracy:**

Deaths occurring in Australia are registered and maintained by the Registrars of Births, Deaths and Marriages in each State and Territory. These registration details are then provided to the AIHW and are assumed to be as correct as possible. The AIHW has no ability to confirm the correctness and completeness of these data.

It is expected that some death registration details may contain errors and some information that is critical might be missing. The AIHW uses a probabilistic data linking technique to link researchers' data to the NDI. Consequently, the linkage result is an indication or index of death, rather than an absolute fact of death. These issues are communicated to the researchers.

Incorrect linkages can result because of errors or incorrect details in personal information supplied when deaths are registered. Examples of such errors are: the changed surname when women marry is not provided; given names are transposed, incorrectly spelt, or partly replaced by nicknames; the date of birth is wrong, the birth day of an elderly relative might be known, but not the year of birth.

Linkages are tailored to the needs of the researcher, in terms of the matching tightness. For example some studies require that the matching be very precise and the researchers will only accept matches that are identical in terms of name, date of birth/death and sex, whereas others will allow for variations in names and dates at least. These scenarios are catered for by using probabilistic record linkage software. The AIHW undertakes the linkage and in some cases clerical reviews of marginal matches. Reports of the final matches are then provided to the researchers. The linkage result is an indication or index of death, rather than an absolute fact of death.

**Coherence:**

Only a small number of variables such as: names, sex, date of birth, date of death and components of address, are utilised from the NDI for the linking purpose. Although the file formats in which data are provided by the Registrars changes from time to time, the contents of data remains constant. To ensure consistency, a substantial cleaning and standardisation of data takes place before loading to the database. For example, names are converted to upper case, dates are standardised to 'yyyymmdd' format and gender is set to '1' for males and '2' for females.

The one serious exception from the consistency over time is coded cause of death. This field was derived by Australian Bureau of Statistics from the death certificates and is obtained from the National Mortality Data Base, by linking it to the NDI. The causes of death are coded using the International Classification of Diseases (ICD) which originated in the 1800s and undergoes revisions from time to time. The current version is ICD-10. It is critical to know the version of the ICD that relates to given data. This information and the description of data items are provided to the researchers with the linking results.