

Australian Mesothelioma Registry (AMR) Data Access Policy

Version 6.0

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Abbreviations and Acronyms

ACT	Australian Capital Territory
ADRI	Asbestos Diseases Research Institute
AIHW	Australian Institute of Health and Welfare
AMR	Australian Mesothelioma Registry
ANZSCO	Australian and New Zealand Standard Classification of Occupations
CCO	Chief Cancer Officer, CINSW
CHO	Chief Health Officer
CINSW	Cancer Institute NSW
DDA	Dust Diseases Authority
HREC	Human Research Ethics Committee
HRF	Hunter Research Foundation
iCare	Insurance and Care NSW
JSM	Job Specific Module
MonCOEH	Monash Centre for Occupational and Environmental Health
NCIS	National Coroner's Information System
NDI	National Death Index
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
OccIDEAS	Occupational Integrated Database Exposure Assessment System
Qld	Queensland
SA	South Australia
SWA	Safe Work Australia
Tas	Tasmania
Vic	Victoria
WA	Western Australia

Definitions

Term	Definition
Data custodian	is the agency, body, or designated role holding overall accountability and responsibility for the dataset. For the AMR, the Data custodian is the Chief Cancer Officer, CINSW.
Disclosure	Release of unit record data outside the NSW Ministry of Health. This includes release to states/territories, universities, and all other organisations or individuals.
Health record	An ongoing record of health care of an individual.
Ethics Committee	A committee constituted in accordance with NHMRC Ethics Committee guidelines, which protects the subjects of research and ensures that ethical standards are maintained by reviewing and advising on the ethical acceptability of research proposals.
Personal information (as defined in Privacy Act 1988)	Information or an opinion about an identified individual, or an individual who is reasonably identifiable: (a) whether the information or opinion is true or not; and (b) whether the information or opinion is recorded in a material form or not.
Health Information (as defined in Privacy Act 1988)	(a) information or an opinion about: (i) the health or a disability (at any time) of an individual; or (ii) an individual's expressed wishes about the future provision of health services to him or her; or (iii) a health service provided, or to be provided, to an individual; that is also personal information; or (b) other personal information collected to provide, or in providing, a health service; or (c) other personal information about an individual collected in connection with the donation, or intended donation, by the individual of his or her body parts, organs or body substances; or (d) genetic information about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual.
Unit record data	For the purpose of this document 'unit record data' are the full electronic records of information of an individual.

1 Introduction

1.1 Overview

The Australian Mesothelioma Registry (AMR) recognises the benefits from, and encourages the availability of, data it holds for the public good. This Data Access Policy has been developed to support this recognition.

This document outlines the policy for access to data from the AMR. It also provides background information about the AMR and outlines the types of data available, the relevant governing legislation and groups, and the processes involved in obtaining access to AMR data.

1.2 Background

The AMR became operational in 2011 and collects data on all mesothelioma cases in Australia. The principal objectives of the AMR are to monitor the national incidence of mesothelioma and identify patterns and trends of occupational and environmental asbestos exposure.

The AMR aims to provide access to the available data for scientifically sound research that may contribute to the prevention of mesothelioma and/or improvements in the care of people with mesothelioma. The Registry respects the privacy of people whose personal and health information it holds. It complies with the Privacy Act 1988 (Commonwealth of Australia) when providing access to data.

1.3 Scope

This policy covers the data within the AMR system and the exposure assessment tool, OccIDEAS.

2 Australian Mesothelioma Registry

The AMR is a national stand-alone database that contains information on patients diagnosed with mesothelioma in Australia from 1 July 2010 onwards. Information collected in the AMR is used to:

- Better understand the exact relationship between asbestos exposure and mesothelioma.
- Better understand the nature of asbestos exposure that can result in mesothelioma.
- Identify the groups of workers exposed to potentially dangerous levels of asbestos and to prevent that exposure.
- Assist the development of policies to best deal with the asbestos still present in our environment (mainly our built environment).
- Provide information to assist researchers in undertaking investigations with the aim of preventing mesothelioma in the future.
- Identify other potential exposures that may cause mesothelioma.

2.1 Key organisations

The AMR is funded by Safe Work Australia in conjunction with Comcare. The development and operation of the AMR is managed by a consortium of organisations. Two consortium members are responsible for the development and operation of the AMR. These are:

- The Cancer Institute NSW, which operates a number of cancer registries including the NSW Cancer Registries (NSWCRs), is responsible for the management and operation of the AMR. The Chief Cancer Officer (CCO) or formal delegate is the Data Custodian.
- The Monash Centre for Occupational and Environmental Health (MonCOEH) is responsible for developing tools used for collecting and evaluating patients' occupational and environmental exposure to asbestos.

The other consortium members provide expert scientific and medical advice. These are:

- The Asbestos Diseases Research Institute (ADRI);
- The School of Public Health of the University of Sydney;
- The University of Western Australia and Western Australian Cancer Registry; and
- The Dust Diseases Authority (DDA), Insurance and Care NSW (icare).

The Registry is overseen by the AMR Management Committee which comprises members of the consortium organisations and representatives from Safe Work Australia (SWA) and Comcare. The Committee sets the direction for the AMR and monitors its performance.

2.2 Data Collection

The AMR collects mesothelioma data to monitor incidence, mortality and asbestos exposure in Australia. The data collected are stored in the AMR system and/or OccIDEAS, the asbestos exposure tool.

2.2.1 Data Items

Incidence and mortality

The AMR incidence and mortality data for mesothelioma cases are collected through mandatory notifications of cancer to state and territory registries. Notification of cancer to relevant state/territory cancer registries are required by legislation for each jurisdiction. The data items provided to the AMR include:

- **Demographic:** name, address, date of birth, sex, country of birth and Indigenous status.
- **Diagnosis:** data items relating to the clinical details about the mesothelioma cancer case (e.g. date of diagnosis, best basis, laterality, and site and morphology of cancer)
- **Death:** date of death and cause of death (these data are also obtained from the National Death Index [NDI]).

Exposure

Asbestos exposure data are obtained from consenting patients and are collected via a postal questionnaire and telephone interview. Information obtained from the postal questionnaire is entered into an asbestos exposure assessment tool, OccIDEAS, which is used by MonCOEH to assign a job specific module (JSM) to each relevant occupational history. A JSM is a sequenced set of tailored questions used to elicit specific information for each type of job considered to have potential asbestos exposure. Since non-occupational asbestos exposure is likely to be relevant, a non-occupational (environmental) module is also assigned to all participating patients. This

module is similar to a conventional JSM except that it asks questions about non-occupational exposures across the patient's lifespan, such as home renovations.

The Hunter Research Foundation (HRF) conducts the telephone interviews with patients to ascertain the responses for each allocated JSM, which are recorded in OccIDEAS. This enables MonCOEH to undertake an assessment and assign an estimate of each patient's lifetime asbestos exposure.

Exposure data include the following:

- **Residential history:** residential addresses the patients have lived in for at least one year in their lifetime. These data are held in both OccIDEAS and the AMR system.
- **Schooling history:** all schools the patients have attended in their lifetime. These data are only held in the AMR system.
- **Occupational history:** all jobs a patient has held for at least 6 months in their lifetime. These data are held in both OccIDEAS and the AMR System. Each job is also coded within the AMR system using the Australian and New Zealand Standard Classification of Occupations (ANZSCO) from the Australian Bureau of Statistics.
- **Family history:** the patient's family history of mesothelioma and their associated relationship. These data are only held in the AMR system.
- **JSM, non-occupational module and responses:** responses to specific questions for each exposed job and questions on non-occupational exposure. These data are held in OccIDEAS.
- **Exposure estimates:** calculated estimates of a person's lifetime asbestos exposure as assessed by MonCOEH staff. These data are held by MonCOEH and the AMR.

Death linkage

The AMR also performs an annual death data linkage to the national death database in Australia – the NDI, which is held by the Australian Institute of Health and Welfare (AIHW). This provides more complete data on date of death and cause of death for AMR cases. The data are stored in the AMR system.

2.2.2 Custodianship

The CCO, CINSW is the custodian of the AMR data, including the incidence and mortality data provided by the states and territories, the additional information added to the AMR (e.g. job codes) and the asbestos exposure data. The Custodian approves for the disclosure of AMR data. The state and territory cancer registry custodians approve disclosure of incidence and mortality data in certain circumstances.

2.2.3 Governance

Access to AMR's data holdings is governed by the CCO, CINSW with advice from the AMR Management Committee. The Committee is notified of each data request and makes a recommendation to the data custodian regarding release of the data. The AMR's governance structure is detailed in [Appendix 1](#).

3 Ethics Committees

The AMR operates with ethical approval from ethics committees within all states and territories, including:

- NSW Population and Health Services Research Ethics Committee (NSW PHSREC):
<http://www.cancerinstitute.org.au/research-grants-and-funding/ethics/nsw-population-health-services-research-ethics-committee>
- Cancer Council Victoria, Human Research Ethics Committee (HREC): www.health.vic.gov.au/ethics/
- Queensland Health, Health and Medical Research HREC:
https://www.health.qld.gov.au/ohmr/html/regu/aces_conf_hth_info.asp
https://www.health.qld.gov.au/ohmr/html/regu/info_hrec_administr.asp
- Far North Queensland (FNQ) Human Research Ethics Committee:
https://www.health.qld.gov.au/ohmr/html/regu/hrec_contacts.asp
- Department of Health WA Human Research Ethics Committee (DOH HREC) :
www.health.wa.gov.au/healthdata/HREC/
- SA Department of Health HREC:
<http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/health+and+medical+research/research+ethics/sa+health+human+research+ethics+committees/sa+health+human+research+ethics+committee>
- Tasmania Health and Medical HREC: <http://www.utas.edu.au/research-admin/research-integrity-and-ethics-unit-rieu/human-ethics/human-research-ethics-review-process/health-and-medical-hrec>
- ACT Health HREC: www.health.act.gov.au/research/human-research-ethics-committee
- Central Australian HREC:
http://health.nt.gov.au/Agency/Advisory_Groups_and_Taskforces/Human_Research_Ethics_Committee/index.aspx
- NT Department of Health and Menzies HREC:
http://health.nt.gov.au/Agency/Advisory_Groups_and_Taskforces/Human_Research_Ethics_Committee/index.aspx
- Australian Institute of Health and Welfare Ethics Committee: www.aihw.gov.au/ethics/
- Monash University HREC: <http://www.monash.edu.au/researchoffice/ethics.php>

4 Types of Data

4.1 De-identified data

De-identified data are data where no specific individual can be identified. These data do not include identifiers such as names.

4.1.1 De-identified aggregate data

Requests for de-identified aggregated data are requests where the data may be stratified by non-identifiable data elements, including age (or age group), sex, cancer site, and diagnosis year(s). The level of aggregation would

be sufficiently high so as to prevent the indirect identification of any individual. To assist with this, the AMR may suppress any data cell containing fewer than five cases.

4.1.2 De-identified individual unit record

Requests for de-identified individual unit record information are requests where the dataset would not contain any identifying or potentially identifying details. That is, they would not include name, address, full date of birth, or any data items that either singly or collectively may identify an individual e.g. country of birth, postcode, Indigenous status and age.

4.2 Identifiable, re-identifiable or potentially identifiable data

Identified data are data where specific individuals can be identified. These data include identifiers. Re-identifiable data are data where identifiers have been removed (and replaced by a code), but it remains possible to re-identify a specific individual. Potentially identifiable data are data where identifiers have been removed, but data items are included that either singly or collectively may identify an individual e.g. country of birth, postcode, Indigenous status and age. The potential for this information to become identifying is higher when provided for states or territories with smaller populations.

4.2.1 Identifiable unit record information

Individually identifiable data are data where the identity of a specific individual can be reasonably ascertained.

Request for individually identifiable unit record information are requests where the dataset would include identifiers such as the individual's name, date of birth or address (including residential histories).

Individually identifiable unit record information may be made available for:

- Return to notifier (specific state or territory cancer registry) whereby individual unit record data may be returned to the original notifying state and territory registry;
- The individual concerned, whereby an individual may request access to data about themselves;
- A third party, such as a family member, accessing information about an individual;
- A data linkage study; or
- A study of asbestos exposure including full residential histories or details of certain (small) companies.

In the case of identified unit record data being returned to the notifying state or territory cancer registry, the information must not contain additional personal information from another source (e.g. the NDI). Individually identifiable unit record information will only be made available in accordance with privacy and right to information legislation, where relevant. All requests for identifiable incidence and mortality data would be sent to the state and territory cancer registries for approval.

5 Types of Reports

5.1 Published reports

The AMR publishes yearly statistical reports showing numbers and rates of mesothelioma and deaths from mesothelioma in Australia. These reports present de-identified aggregated data and are widely available to the public. The level of aggregation is sufficiently high so as to prevent the indirect identification of any individual. To assist with this, the AMR suppress cells containing fewer than five cases where a breakdown by state/territory or another smaller, potentially identifiable group is presented. For the 2015 report, small cells of less than five cases have been presented, as this would allow an accurate count of mesothelioma diagnoses and deaths in Australia, so as to inform public health and government policy relating to asbestos and mesothelioma. These reports are included in the *Mesothelioma in Australia 2011, 2012, 2013, 2014 and 2015* reports, available at: <https://www.mesothelioma-australia.com/publications-and-data/publications>

5.2 Operational reporting

The AMR system allows for operational reports to monitor progress regarding timeframes for receiving notifications and for patient recruitment, invoicing for notifications and interviews, and status reports. These are accessible only by AMR staff and can be prepared for a specified date range.

6 Types of Data Requests

6.1 Ad hoc aggregate data requests

The AMR may provide de-identified aggregated data (i.e. cross-tabulations) to particular stakeholders, researchers and requestors. These include the public, media, clinicians, health services, health service planners, researchers and educators.

6.2 Research and other bulk data requests

The AMR, apart from collecting data and producing periodical reports, aims to provide data to requestors undertaking investigations for the purpose of preventing mesothelioma in the future. Researchers need to submit an appropriate study protocol.

Individually identified, re-identifiable or potentially identifiable unit record data

Applications for release of unit record data comprising health information (individually identifiable, re-identifiable or potentially identifiable) should be first discussed with the AMR Manager, then a written request submitted using the AMR Unit Record Request Data Form B ([Appendix 4](#)).

Approval to release the data will then be sought from the appropriate custodians, depending on the request. Chief Health Officer (CHO) approval would also be sought from states and territories, where required.

De-identified unit record data

If the unit record data to be released does not comprise personal information (i.e. are de-identified), the AMR must ensure that the data are released in such a way that minimises the chance of individuals being recognised or in some other way identified. Some options for doing this are:

- Minimising the range of fields to be released
- Avoiding the disclosure of dates. For example, disclose age rather than date of birth.
- Grouping categories. For example, age could be grouped into 5-year age groups or geographic areas grouped into larger areas.
- Care must be taken when considering the disclosure of information concerning relatively small communities, where the chance of individuals being recognised may be greater than in large communities.

Approval for disclosure of unit record data

Approval to disclose the data must be sought from the person/s whom the authority to disclose unit record data is vested. Release of data will comply with guidelines of the Privacy Act 1988 (Commonwealth of Australia).

Incidence and mortality data are collected from state and territory cancer registries and do not require patient consent. Approval from states and territories is required to disclose this information to requestors, in line with ethics and other processes agreed with the individual jurisdictions. Information from the NDI are included in the AMR with approval from the AIHW Ethics Committee. Asbestos exposure information is collected with patient consent and the CCO, CINSW is responsible for approving release of these data.

6.3 Other data requests

Other types of requests include those for data about individuals, return of data to notifiers (state/territory cancer registries) and data under a Subpoena. Further details are outlined in the AMR's Operations Manual. All data requests are considered on a case-by-case basis and should be discussed with the AMR Manager in the first instance.

7 Data Access

7.1 Purpose for data access

Access to AMR unit record data will be provided for the following purposes:

- To facilitate mesothelioma related research; and
- To contribute to improvement in research and analysis methodologies, data collection processes, and quality assessment or assurance programmes.

7.2 Prioritisation of access to data

Access to data will generally be provided on a "first come-first served basis". However, the following factors may be taken into consideration when prioritising access:

- Data availability,
- Technical feasibility or complexity of project,
- Resource availability, or
- Urgency of request if required for a specific date (e.g. conference).

7.3 Application process

Flowcharts of the data access process for ad-hoc aggregate and unit record data requests are presented in [Appendix 3](#).

Once the request has been discussed with the AMR Manager, the requestor will be directed to submit their request to: amr@cancerinstitute.org.au

To access unpublished data from the AMR, there are two request forms available:

- AMR Aggregated Data Form (Form A) ([Appendix 4](#)); and
- AMR Unit Record Request Data Form (Form B) ([Appendix 4](#)).

Research requests also require inclusion of a brief protocol. The forms to apply for data access are available from the AMR Manager.

Special circumstances

Access to JSM data, non-occupational exposure modules and exposure assessments should be discussed with MonCOEH. Release of these data items is subject to approval by the data custodian, following consultation with, and a recommendation by, the AMR Management Committee.

Where data from the NDI are requested (date and cause of death), an amendment needs to be submitted to the AIHW Ethics Committee to obtain approval for the individual/s to access these data. The AMR Manager coordinates this process. It includes the requestor signing and submitting an s.29 Confidentiality Undertaking. More information can be found at: <https://www.aihw.gov.au/ethics/>

For cause of death information, an application to the National Coroner's Information System (NCIS) may also be required.

7.4 Approval requirements

The Data will be released to researchers or other bona fide data users when:

- all the relevant Data Custodians have approved the use of the data under their supervision; and
- the project has been approved by all relevant human research ethics committees.

Access to data about an individual

AMR data for an individual may be provided to the individual or to a third party, provided that the requestor:

- provides sufficient identification; and
- has a right to access the data.

This type of request would only apply to exposure data as requests for individual incidence and mortality data would be directed to the relevant cancer registry. These requests would be processed in line with CINSW's requirements for release of data to individuals.

Research and other bulk data requests

A summary of the approvals required by the type of data to be accessed is summarised in Table 1. Table 2 outlines the requirements of the individual states and territories. Table 3 summarises the approvals required where asbestos exposure data are requested.

Table 1: Approvals required for AMR state/territory incidence and mortality data by type of data

Data type	State/territory data custodian ^c	State/territory HREC ^d	AMR Management Committee
De-identified aggregated data ^a <i>National data</i>	See Table 2	No	No, FYI only
De-identified aggregated data ^a <i>State/territory data</i>	See Table 2	No	No, FYI only
De-identified individual unit record data (without identification of state/territory)	See Table 2	No, requestor's institutional HREC only	No, recommendation only
De-identified individual unit record data (with identification of state/territory)	Yes	Requestor's institutional HREC plus ACT HREC low-risk application	No, recommendation only
Identified individual unit record data (e.g. for linkage) ^b	Yes	Yes	No, recommendation only

a. Cells of less than 5 in aggregated data would be suppressed.

b. The linkage would be performed by an outside party (e.g. CHeReL, AIHW, etc.) . The researcher would only receive de-identified data.

c. See Table 2 for further detail.

d. HREC=Human Research Ethics Committee.

Where approval is required from state/territory cancer registry custodians, the 'State/territory cancer registry custodian sign-off form' in Appendix 5 will be used to obtain sign-off. The individual state/territory will advise if CHO approval also needs to be sought. If the state/territory only needs to be informed of the request, the template in Appendix 6 will be completed and circulated.

Table 2: State and territory data custodian approvals required for AMR state/territory incidence and mortality data by type of data

Data type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
De-identified aggregated data <i>National data</i>	No	No	No	No	No	No	Yes	No
De-identified aggregated data <i>State/territory data</i>	Yes	No, FYI only	Yes	No, FYI only	No, FYI only	Yes	Yes	Yes
De-identified individual unit record data (without identification of state/territory)	No, FYI only	No, FYI only	No, FYI only	No, FYI only	Yes	Yes	Yes	Yes
De-identified individual unit record data (with identification of state/territory)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Identified individual unit record data (e.g. for linkage)	Yes	Yes	Yes	Yes	Yes	Yes	Yes ^a	Yes

a. Legal advice and Ministerial approval required.

Where AMR Data custodian approval is required (for example, for a request not identified by state/territory or for exposure data), the form in [Appendix 7](#), 'AMR data custodian sign-off form', should be completed. This form will be used where an ethics committee requires data custodian sign-off for inclusion in a submission, and a copy will also be kept for AMR records. Once the data are approved for release, the requestor will be required to sign a 'Conditions of release' form ([Appendix 8](#)). Other conditions on the release of the data may be imposed depending on the nature of the individual project and the requirements of the specific data custodians.

Table 3: Approval required for AMR asbestos exposure data by type of data

Data type	CINSW data custodian	Ethics approval	AMR Management Committee
De-identified aggregated data	Yes	No	No, recommendation only
De-identified individual unit record data	Yes	Yes	No, recommendation only
Identified individual unit record data e.g. for linkage	Yes	Yes	No, recommendation only

The role of the AMR Management Committee

The AMR Management Committee support reasonable access to the AMR data as a public resource. The role of the Committee is to consider whether or not the data requested would be used in an appropriate manner; that is that it would be used in a way which would assist in preventing mesothelioma in the future and is consistent with the requirements outlined in this Policy. It is not the role of the AMR Management Committee to provide a peer review process for research projects.

The Committee will be notified of all requests. For unit record data requests, for either the incidence and mortality data or the exposure data, the Committee will be asked to make a recommendation to the data custodian regarding release of data.

Conflicts of interest

Members of the Management Committee should apply for access to the data in the AMR in the same way as other requestors. Conflicts of interest should be declared during the submission process. Where a member of the Management Committee is part of a research team requesting access to AMR data, that member will be excluded from discussions regarding release of that data.

The Management Committee members do not have exclusive rights to the data or to publishing from the AMR prior to external researchers. The AMR Authorship Policy provides more information about publication of papers using AMR data.

8 Data Release

8.1 Terms and conditions of release of data

AMR data are released:

- in accordance with relevant legislation, regulations and guidelines;
- with approval of the relevant data custodians; and
- where applicable, for ethically approved human research projects of scientific merit.

Conditions for release will be modified according to the type of data being accessed. In general, data will be released on the condition that:

- unless otherwise explicitly allowed, no attempt will be made to use the data to identify an individual, including linkage of the data to another dataset;
- published data are sourced to the AMR and the AMR will be acknowledged in any presentation of the data, as well as MonCOEH if exposure data are used; and
- a copy of any publications or presentations containing AMR data be provided to the AMR Management Committee for information.

9 Charges

The data request service operates on a cost recovery basis. While obligation-free quotes can be provided for customised data, charges apply for the time taken to research the request, the size and complexity of the request, data extraction, analysis and presentation tasks involved. The cost also depends on the number of years and number of individuals in the data extract, when relevant to the amount of time needed to process the request. Larger and more complex requests will usually cost more than smaller, less complex requests. Each request will be assessed based on the available resources. The CINSW Charging Statement is available at: <http://www.cancerinstitute.org.au/media/165394/charging-statement.pdf>

10 Data Security

All identified or potentially identifiable/re-identifiable individual record data that are disclosed must be stored by the recipient in a secure environment at all times. Acceptable secure storage includes storage on physically secure file servers that are configured in such a way that password protection is universally enforced, or in files that are encrypted by “strong” encryption software, provided that the passwords used for encryption are also kept secure. The encryption offered by file compression utilities or by word processors, spreadsheets and other software that is not specifically designed to offer high-level encryption are inadequate and can be easily broken. Data should be strongly encrypted and password protected before being transferred electronically using a Secure File Transfer Protocol or email, or being saved onto a transport medium and mailed to the recipient.

One of the Conditions of release of the data states that unit record data needs to be deleted on completion of the study. This is usually in line with the relevant ethical approval and NHMRC requirements to keep research data for a specified period.

11 Support and Advice

For initial queries about the availability and quality of AMR data, the AMR Manager should be contacted:

amr@cancerinstitute.org.au

12 Review

The AMR Data Access Policy and associated charging information will be reviewed regularly by the AMR Management Committee.

Appendix 1: AMR Governance

Data owners

The Commonwealth of Australia as represented by Safe Work Australia

Data custodians

Chief Cancer Officer, Cancer Institute NSW

State/territory Cancer Registries

Advice on data release

AMR Management Committee

Comprising representatives from:

Safe Work Australia
Comcare
Cancer Institute NSW
Monash Centre for Occupational and Environmental Health
Asbestos Diseases Research Institute
WA Mesothelioma Registry
Dust Diseases Board
University of Sydney
State/territory cancer registry

Guest attendees as required

Ethics and other approvals

NSW Population and Health Services Research Ethics Committee

Other state/territory ethics committees

AIHW Ethics Committee

Monash University Human Research Ethics Committee

Chief Health Officer, Public Health Act (depending on state/territory)

Appendix 2: AMR Dataset

Incidence and mortality data

	Data items	Available for release (Y/N)
ID	AMR ID	N
	Cancer registry ID	N
DEMOGRAPHIC DATA	Surname	N
	Given names	N
	Alias names	N
	Sex	Y
	Country of Birth	Y
	Indigenous Status	Y
	Year of Birth	Y
	Month of Birth	Y
	Day of Birth	Y
	Street address at diagnosis	N
	Suburb at diagnosis	N
	State/territory at diagnosis	Y
	Postcode at diagnosis	Y
	CANCER DIAGNOSIS DATA	Year of Diagnosis
Month of Diagnosis		Y
Age at Diagnosis		Y
ICD-O-3 Topography Code		Y
ICD-O-3 Morphology Code (5 digit)		Y
Best Basis of Diagnosis		Y
Laterality		Y
CANCER DEATH DATA	Year of Death	Y
	Month of Death	Y
	Day of Death	Y
	Cause of death type	Y
	Cause of death code	Y

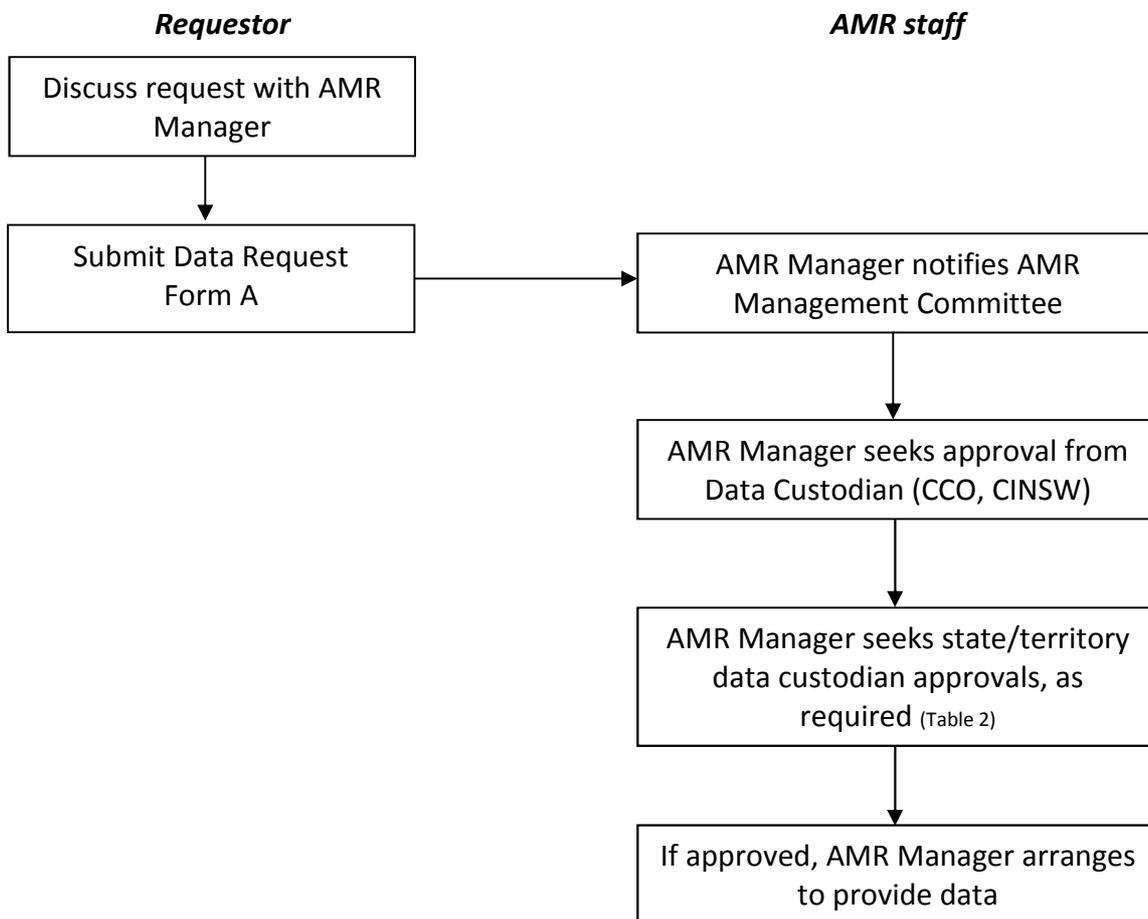
Asbestos exposure data

	Data items	Available for release (Y/N)
ID	AMR ID	N
OccIDEAS/AMR SYSTEM POSTAL QUESTIONNAIRE DATA (from patient)	Residential histories: residence number	Y
	Residential histories: country	Y
	Residential histories: address	Y
	Residential histories: suburb/town	Y
	Residential histories: state	Y
	Residential histories: postcode	Y
	Residential histories: from date	Y
	Residential histories: to date	Y
	School histories: school number	Y
	School histories: institution name	Y
	School histories: campus/site	Y
	School histories: suburb/town	Y
	School histories: type of institution	Y
	School histories: from year	Y
	School histories: to year	Y
	School histories: attendance mode	Y
	Occupational histories: job number	Y
	Occupational histories: from date	Y
	Occupational histories: to date	Y
	Occupational histories: company name	Y
	Occupational histories: company address	Y
	Occupational histories: company suburb/town	Y
	Occupational histories: company state	Y
	Occupational histories: company postcode	Y
	Occupational histories: company country	Y
	Occupational histories: job title/description	Y
	Occupational histories: main product/activity	Y
	Occupational histories: hours per week	Y
Family history: yes/no	Y	
Family history: relationship	Y	
AMR SYSTEM DATA	Australian and New Zealand Standard Classification of Occupations (ANZSCO) classification code	Y
OccIDEAS INTERVIEW DATA (from patient)	Non-occupational interview module	Y*
	Job Specific Module (JSM) interviews	Y*
MonCOEH SYSTEM DATA	Asbestos exposure assessment	Y*

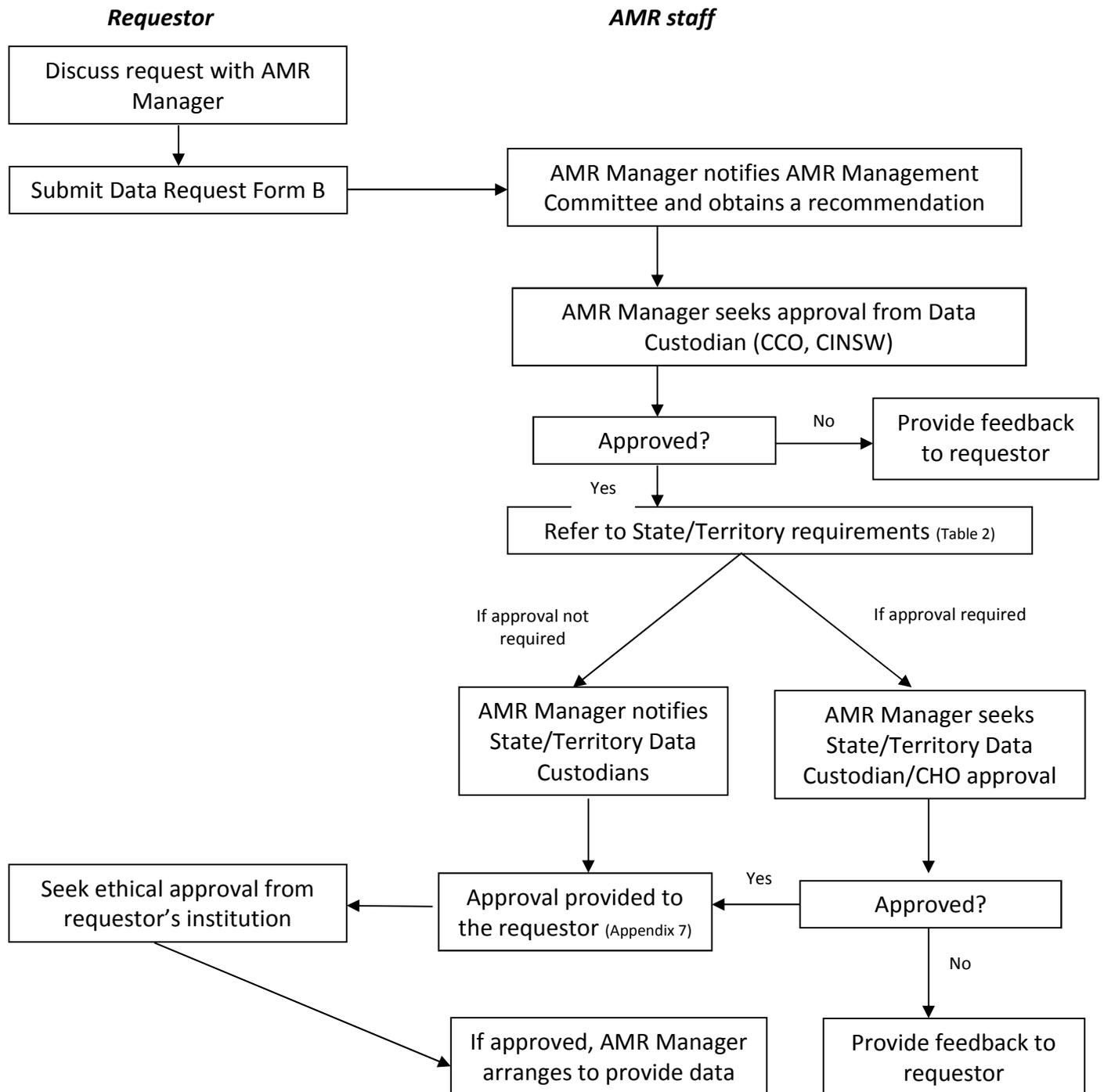
*Subject to discussion with MonCOEH and approval by the data custodian.

Appendix 3: Flowchart of data request process

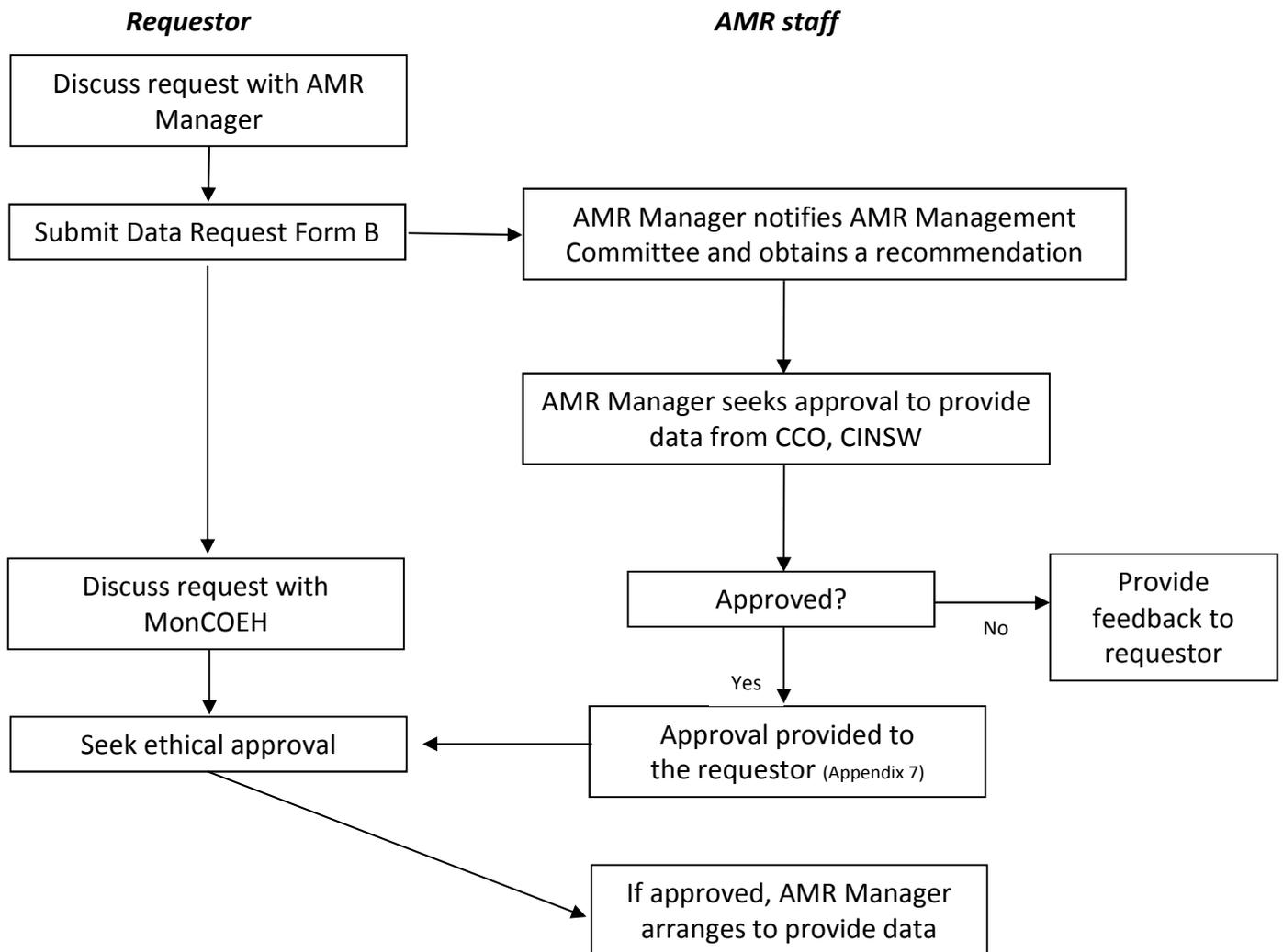
Aggregated data: State/territory incidence and mortality



Unit record data: State/territory incidence and mortality



Unit record data: exposure information



Appendix 4: AMR Data request forms

Aggregated Data Request Form (Form A)

DATA REQUEST FORM: Australian Mesothelioma Registry (AMR) Aggregated Data

Please COMPLETE and email this form to: amr@cancerinstitute.org.au

SECTION 1:		
First Name:	Surname:	
Organisation:		
Address:		
Suburb:	State:	Post Code:
Phone:	Email:	

SECTION 2: Please state briefly (one or two dot points) the question you want to answer using Australian Mesothelioma Registry data.

SECTION 3: Selection criteria (only complete applicable items)		
National data or state/territory	<input type="text"/>	
Sex	<input type="checkbox"/> Male	<input type="checkbox"/> Female <input type="checkbox"/> All Persons
Year(s) of Diagnosis	<input type="text" value="YYYY"/> to <input type="text" value="YYYY"/>	
Year(s) of Death	<input type="text" value="YYYY"/> to <input type="text" value="YYYY"/>	
Age	<input type="text" value="YY"/> to <input type="text" value="YY"/>	by <input type="checkbox"/> 5 Year Age Group
		or <input type="checkbox"/> Other Age Group <input type="text"/>
Other criteria or display items (e.g. country of birth, location of tumour)	<input type="text"/>	
Statistics required:		
	Incidence	Mortality
Counts (number of cases)	<input type="text"/>	<input type="text"/>
Age Standardised Rates (Direct)	<input type="text"/>	<input type="text"/>
Age Standardised Rates (Indirect)	<input type="text"/>	<input type="text"/>
Age Specific Rates	<input type="text"/>	<input type="text"/>

IMPORTANT NOTES:

- Please note any cell containing counts less than five will be reported as “not published” to maintain confidentiality.
- We may group certain categories in the selection criteria where counts are too small.

Unit Data Request Form (Form B)

DATA REQUEST FORM: AMR Unit Record Data Request

Please COMPLETE and email this form to: amr@cancerinstitute.org.au

SECTION 1:

First Name: _____ Surname: _____
 Organisation: _____
 Address: _____
 Suburb: _____ State: _____ Post Code: _____
 Phone: _____ Email: _____

SECTION 2: Please state briefly (one or two dot points) the question you want to answer using Australian Mesothelioma Registry data or attach abstract/research protocol.

(Attach protocol for research requests)

SECTION 3: AMR unit record data required: notification data

Please complete the table below providing justification for each data item requested.

	ID	Variable	Tick if required	Justification
DEMOGRAPHIC DATA	1	AMR ID		
	2	Cancer registry ID		
	3	Sex		
	4	Country of Birth		
	5	Indigenous Status		
	6	Year of Birth		
	7	Month of Birth		
	8	Day of Birth		
	9	State at diagnosis		
	10	Postcode at diagnosis		
CANCER DIAGNOSIS	11	Year of Diagnosis		
	12	Month of Diagnosis		
	13	Age at Diagnosis		
	14	ICD-O-3 Topography Code		
	15	ICD-O-3 Morphology Code (5 digit)		
	16	Best Basis of Diagnosis		
	17	Laterality		
CANCER DEATH	18	Year of Death		
	19	Month of Death		
	20	Day of Death		
	21	Cause of death type		
	22	Cause of death code		

OTHER COMMENTS/REQUIREMENTS:

Please include years/dates of data required, and any other exclusions.

SECTION 4: AMR unit record data required: asbestos exposure data

Please complete the table below providing justification for each data item requested.

ID	Variable	Tick if required	Justification
1	AMR ID		
2	Residential histories: residence number		
3	Residential histories: country		
4	Residential histories: address		
5	Residential histories: suburb/town		
6	Residential histories: state		
7	Residential histories: postcode		
8	Residential histories: from date		
9	Residential histories: to date		
10	School histories: school number		
11	School histories: institution name		
12	School histories: campus/site		
13	School histories: suburb/town		
14	School histories: type of institution		
15	School histories: from year		
16	School histories: to year		
17	School histories: attendance mode		
18	Occupational histories: job number		
19	Occupational histories: from date		
20	Occupational histories: to date		
21	Occupational histories: company name		
22	Occupational histories: company address		
23	Occupational histories: company suburb/town		
24	Occupational histories: company state		
25	Occupational histories: company postcode		
26	Occupational histories: company country		
27	Occupational histories: job title/description		
28	Occupational histories: main product/activity		
29	Occupational histories: hours per week		
30	Family history: yes/no		
31	Family history: relationship		
32	Australian and New Zealand Standard Classification of Occupations (ANZSCO) classification code		

OTHER COMMENTS/REQUIREMENTS:

Please include years/dates of data required, and any other exclusions.

Appendix 5: State/territory cancer registry custodian sign-off form

State/territory cancer registry custodian approval to release AMR Data

Please SIGN this form and email to: amr@cancerinstitute.org.au

REQUESTOR
Name:
Organisation:

REASON: The question requestor would like to answer using Australian Mesothelioma Registry data. (Protocol attached for research requests)
--

REQUESTED DATA:				
Aggregate (see attached table/s)		Unit record (see below)		
<input type="checkbox"/>		<input type="checkbox"/>		
National or state/territory		<input type="text"/>		
Sex		<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> All Persons
Year(s) of Diagnosis		<input type="text" value="YYYY"/> to <input type="text" value="YYYY"/>		
Year(s) of Death		<input type="text" value="YYYY"/> to <input type="text" value="YYYY"/>		
Age		<input type="text" value="YY"/> to <input type="text" value="YY"/>		
Other criteria		<input type="text"/>		
ID	Variable	Tick if required	Justification	
DEMOGRAPHIC DATA	1	AMR ID		
	2	Cancer registry ID		
	3	Sex		
	4	Country of Birth		
	5	Indigenous Status		
	6	Year of Birth		
	7	Month of Birth		
	8	Day of Birth		
	9	State at diagnosis		
	10	Postcode at diagnosis		
CANCER DIAGNOSIS	11	Year of Diagnosis		
	12	Month of Diagnosis		
	13	Age at Diagnosis		
	14	ICD-O-3 Topography Code		
	15	ICD-O-3 Morphology Code (5 digit)		
	16	Best Basis of Diagnosis		
	17	Laterality		
CANCER DEATH	18	Year of Death		
	19	Month of Death		
	20	Day of Death		
	21	Cause of death type		
	22	Cause of death code		

APPROVAL

I approve release of the specified AMR data to the requestor.

Signed:

Date:

Name:

Conditions/comments:

Appendix 6: State/territory cancer registry custodian 'FYI'

State/territory cancer registry custodian FYI: release AMR Data

REQUESTOR
Name:
Organisation:

REASON: The question requestor would like to answer using Australian Mesothelioma Registry data. (Protocol attached for research requests)
--

REQUESTED DATA:	
Aggregate (see attached table/s)	Unit record (see below)
<input type="checkbox"/>	<input type="checkbox"/>
National or state/ territory	<input type="checkbox"/>
Sex	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> All Persons
Year(s) of Diagnosis	YYYY to YYYY
Year(s) of Death	YYYY to YYYY
Age	YY to YY
Other criteria	<input type="checkbox"/>

	ID	Variable	Tick if required	Justification
DEMOGRAPHIC DATA	1	AMR ID		
	2	Cancer registry ID		
	3	Sex		
	4	Country of Birth		
	5	Indigenous Status		
	6	Year of Birth		
	7	Month of Birth		
	8	Day of Birth		
	9	State at diagnosis		
	10	Postcode at diagnosis		
CANCER DIAGNOSIS	11	Year of Diagnosis		
	12	Month of Diagnosis		
	13	Age at Diagnosis		
	14	ICD-O-3 Topography Code		
	15	ICD-O-3 Morphology Code (5 digit)		
	16	Best Basis of Diagnosis		
	17	Laterality		
CANCER DEATH	18	Year of Death		
	19	Month of Death		
	20	Day of Death		
	21	Cause of death type		
	22	Cause of death code		

Appendix 7: AMR data custodian sign-off form

AMR data custodian approval to release AMR Data

REQUESTOR
Name:
Organisation:

REASON:

REQUESTED DATA:	
Aggregate (see attached table/s)	Unit record (see below)
<input type="checkbox"/>	<input type="checkbox"/>
National or state/territory	<input type="checkbox"/>
Sex	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> All Persons
Year(s) of Diagnosis	<input type="text" value="YYYY"/> to <input type="text" value="YYYY"/>
Year(s) of Death	<input type="text" value="YYYY"/> to <input type="text" value="YYYY"/>
Age	<input type="text" value="YY"/> to <input type="text" value="YY"/>
Other criteria	<input type="text"/>
Data items required:	

APPROVAL	
This request has been discussed with the AMR Manager and reviewed by the AMR Management Committee. The Data Custodian supports the release of AMR data for the above purpose.	
Signed:	Date:
Name:	
Conditions/comments:	

Appendix 8: Conditions of release of AMR data

1. the data are to be used only for the project entitled “[NAME OF PROJECT]”;
2. [WHERE APPROVAL IS SUBJECT TO THE APPROVAL OF A HUMAN RESEARCH ETHICS COMMITTEE] the project is carried out in accordance with the approved ethics application and all subsequent amendments;
3. the project is carried out in accordance with all relevant Information Privacy legislation;
4. the data are to be kept in a secure physical and electronic environment that is accessible only by persons directly involved in the above project;
5. a confidentiality undertaking for the AMR and State/Territory (as required) will be completed prior to the information being released;
6. the AMR is to be acknowledged in any publication or report that arises from the use of the data, including Safe Work Australia, Comcare and Cancer Institute NSW;
7. the data will not be matched with information on individuals from another source [WHERE APPROVAL IS SUBJECT TO THE APPROVAL OF A HUMAN RESEARCH ETHICS COMMITTEE] other than the datasets specified in the approved ethics application;
8. a copy of any publication or report is to be provided to the AMR Management Committee prior to public release;
9. [WHERE APPROVAL IS SUBJECT TO THE APPROVAL OF A HUMAN RESEARCH ETHICS COMMITTEE] the data are to be destroyed after [NUMBER] years;
10. no information will be released with which it may be possible to identify an individual person;
11. individuals identified in the data are not to be personally identified in any publication or report; and
12. [WHERE DATA ARE BEING PROVIDED IN THE FUTURE AS THEY BECOME AVAILABLE] this authority continues until and unless it has been revoked in writing.

[ADDITIONAL CONDITIONS MAY BE INCLUDED AS REQUIRED]

.....
Signature

.....
Date