

# **National Cancer Statistics Clearing House**

## **Protocol**

**(2009)**

**A collaborative partnership of the  
Australasian Association of Cancer Registries  
and the  
Australian Institute of Health and Welfare**

Australian Institute of Health and Welfare  
Canberra

**The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is *better information and statistics for better health and wellbeing.***

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# 1. Introduction

## What is the National Cancer Statistics Clearing House?

The National Cancer Statistics Clearing House (NCSCH) was established in 1986 as the national repository of cancer incidence and mortality statistics. Its general purpose is to monitor and report on Australia's cancer levels and trends and to help in planning and research that aim to reduce those levels.

The clearing house was set up in response to the large national toll of cancer and a growing public view that cancer was becoming increasingly common. Administered by the Australian Institute of Health and Welfare (AIHW), the clearing house is a collaboration with Australia's cancer registries through the Australasian Association of Cancer Registries (AACR) (see Appendix A for AACR terms of reference).

Cancer is a notifiable disease in Australia and each state and territory has a registry that assembles local information about new cases of cancers and about cancer deaths. The members of the AACR have agreed on a list of variables that they all provide to the AIHW and the data are supplied to the registries from a range of sources such as hospitals, pathology laboratories, radiotherapy centres and the relevant registry of births, deaths and marriages. The cancer registries' primary responsibilities are local: they supply information for use by their state or territory for planning of services, estimation of survival rates and treatment evaluation. Their data are also available for use in epidemiological studies. For the purposes of the national clearing house the registries forward their data annually to the AIHW to form a national database, The Australian Cancer Database (ACD). Data from the clearing house are then used for the monitoring of cancer control nationally and they are reported in a number of AIHW publications, including the AIHW biennial flagship report *Australia's health*.

This protocol is an update of the clearing house's objectives and working structure and of the operating arrangements between the AIHW and the AACR.

### History

- 1972-1982: Development of state and territory population-based cancer registries.
- 1982: AACR established as collaboration between the national Cancer Registries and recognised/endorsed by the International Association of Cancer Registries (IACR).
- 1984: The concept of a national collection of cancer statistics endorsed by the National Health and Medical Research Council.
- 1985: The Australian Institute of Health (now the AIHW) in collaboration with the AACR was appointed to establish the NCSCH.
- 1987: The first AACR and the Australian Institute of Health national report from the NCSCH was *Cancer in Australia 1982* (Giles G, Armstrong B, Smith L 1987).
- 1993 onwards: National Health Information Agreement (NHIA) between the Commonwealth and state and territory health departments, the AIHW and the Australian Bureau of Statistics (ABS), signed for 5-year periods, committing health departments to providing cancer incidence and mortality data.

## 2. Objectives and operating structure

This section outlines the clearing house's objectives, its operating structure and the main steps in how the clearing house and the AACR and registries work together.

### What are the objectives of the clearing house?

The clearing house's objectives comprise analysing and reporting on the data it holds, supporting research based on those data, and activities to develop and improve cancer statistics generally. This can be summarised as follows:

#### Data collection, analysis and reporting

- collecting cancer data from state and territory registries to form the national database, the Australian Cancer Database (ACD)
- data 'cleaning', such as investigating and eliminating duplicate records where necessary, to improve the data quality of both the ACD and the registries
- using the ACD to generate and report on cancer statistics at the national level
- estimating cancer survival by comparing named cancer cases in the ACD to named cases of death in a separate database, the National Death Index (NDI)

#### Supporting research

- supporting and assisting the use of the ACD by external researchers
- supporting Australian participation in international collaborative projects

#### Data development

- promoting nationwide standardisation in the collection of cancer data and in cancer classification

### What is the operating structure of the clearing house?

#### Location and day-to-day management of the clearing house

The clearing house is housed at the AIHW in Canberra. It is managed by the head of the Institute's Cancer and Screening Unit along with a designated project manager, and is supported by several staff.

#### Overall direction and technical advice

The AIHW is ultimately responsible for the clearing house's work program but in its planning it is advised by the AACR Executive Committee. Advice includes the clearing house's general directions, development of publication topics and technical matters. The AIHW is represented ex officio on the committee by the head of the Cancer and Screening Unit.

## **Meetings and collaboration**

The AACR Executive Committee meets three or four times per year, usually by teleconference, and the AIHW reports on progress at each meeting. The head of the clearing house also consults frequently and informally, as necessary, with the committee's chair or other committee members.

## **Conditions of data release**

Data ownership is maintained by cancer registries at all times. Conditions for release of data from the clearing house vary depending on the level at which data are requested. These variations range from minimal conditions for national incidence and mortality statistics which are released publically and available on the AIHW website, through to extensive ethics committee and registry approvals required for among other things data linkage to the ACD. These conditions are discussed in detail in section five of this document 'Access to information from the NCSCCH'. For example

## **How does the clearing house work?**

This section describes in more detail the processes involved to achieve the objectives of the clearing house.

### **Data collection, analysis and reporting**

The AACR and the AIHW have agreed to a set of data that will be sent annually to the clearing house by each registry as described in section three of this document 'Data provision by state and territory cancer registries'.

Every year (usually early in the second half) the clearing house asks registries to provide their latest full-year of cancer data. The data include cancer incidence details and whether or not a person has died. Data usually 'lag' by two or more years; that is, data sent in 2008 apply to 2006.

Once data are received from cancer registries they are loaded into the national database where they are checked for consistency and duplicate records. Any duplicate records or inconsistencies are discussed with the relevant registry and the database adjusted accordingly.

When the database is ready national cancer incidence and mortality statistics are calculated and national summary data are made available to the public via the AIHW website. Data available electronically on the AIHW website are updated annually and includes:

- Australian Cancer Incidence and Mortality (ACIM) books: incidence numbers and rates from 1982, mortality numbers and rates from 1968,
- cancer incidence data cubes: numbers and rates from 1982,
- most frequently occurring cancers,
- major cancers, age-standardized incidence rates,
- state and territory 5-year average annual incidence numbers and rates, by sex and cancer type.

Every two years the AIHW publishes the report '*Cancer in Australia: an overview*'. This biennial report includes statistics and information on:

- cancer incidence and mortality,
- projections of cancer incidence and mortality,
- cancer throughout the lifespan,
- cancer prevalence,
- cancer survival,
- national cancer screening programs,
- burden of cancer,
- hospitalisations for cancer,
- information on specific selected cancers.

Throughout the year the AIHW publishes reports on specific areas of interest. These reports are commissioned by a variety of government departments such as Cancer Australia and non-government organisations such as the National Breast and Ovarian Cancer Centre. Detailed summary data are also included in the monitoring reports for the national breast, cervical and bowel cancer screening programs. Recent publications include:

*Non-melanoma skin cancer: general practice consultations, hospitalisation and mortality*

*Cancer survival and prevalence in Australia: cancers diagnosed from 1982 to 2004*

## **Supporting research**

As well as cancer publications the clearing house is able to support research into cancer by responding to specific ad hoc data requests. Data requests generally fall into one of the following three categories:

- Data requests from researchers which are straight forward and easily met by directing researchers to statistics on the AIHW website or in publications.
- Data requests for complex data requiring manipulation or analysis of data well beyond that which is readily available. Complex analysis often requires extensive input from the AACR Executive Committee on for example applied methodology.
- Some requests for information require other datasets to be linked with either the ACD or with the NDI. The clearing house undertakes these requests only when ethics approval has been granted by each of the state and territory cancer registries and the AIHW Ethics Committee.

Providing national data for inclusion in international cancer research is also undertaken by the clearing house.

## **Data development**

The clearing house regularly liaises with cancer registries and participates in AACR Coding Committee meetings and correspondence to assist in the standardisation of national cancer classifications.

National data standards facilitate comparability of data between jurisdictional cancer registries. In addition, the use of approved data standards supports comparison with other national data collections. The AIHW is committed to the use of approved national data standards where possible and clearing house staff works with the registries to define and develop data items.

## **What services do AIHW and AACR provide to the clearing house?**

Under this protocol the AIHW and the AACR have each agreed to provide services to facilitate the collation of consistent, high quality national cancer incidence and mortality data.

### **The AIHW provides the following services:**

- Collate state and territory cancer incidence and mortality data into the ACD;
- Identify possible duplicate records and notify state and territory registries;
- Link cancer records with the NDI on request and with appropriate approvals;
- Publish hard copy and electronic national cancer statistics in collaboration with the AACR;
- Acknowledge the partnership of the AACR and its members in national cancer statistical reports, and also acknowledge the operators of the state and territory cancer registries;
- Maintain on the AIHW web-site an AACR portal publicising the AACR;
- Facilitate national epidemiological studies including using record linkage with the ACD, ensuring appropriate approval of the state and territory cancer registries and the AIHW Ethics Committee;
- Provide secretariat services to the AACR Executive Committee and to the annual general meeting (AGM) of the AACR;
- Work with the AACR to promote standardisation of data collection and comparability of data, and inclusion of definitions in the National Health Data Dictionary;
- Liaise with the AACR on data development issues such as improved Indigenous identification in cancer statistics collections, on behalf of appropriate Australian Health Information committees;
- Liaise with the AACR on ad hoc issues as they arise in regard to national cancer statistics.

### **The AACR members provide the following services:**

- Provide annual cancer incidence records to the clearing house in accordance with the dataset and time lines agreed jointly by the AACR and AIHW;
- Provide expert management advice through the AACR Executive Committee on the work program of the clearing house, including coding issues, data definitions, data analysis and reporting, new projects and reporting time lines;
- Provide input into AIHW national cancer publications and any other reports or analysis involving state and territory cancer data;
- Provide feedback on the results of AIHW provision of possible duplicate records and matches with the NDI;
- Consider requests to approve national epidemiological research studies requesting linkage with the ACD;
- Work with the AIHW in national cancer statistics data development, including notification of coding variations;
- Work with the AIHW in national cancer statistics data analysis and reporting;
- Host the AACR annual general meeting.

# 3. Data provision by state and territory cancer registries

## Who owns the data in the clearing house?

The clearing house assembles state and territory cancer registry case information into a national database, the ACD. Agreements between the AIHW and the state and territory cancer registries specify conditions under which data are provided to the clearing house and the items to be included. The AIHW acts as a custodian of state and territory data for the purposes of producing national cancer statistics. At all times, the state and territory cancer registries retain ownership of their jurisdiction's data. The analysis and publication of state and territory data and the facilitation of research at the jurisdictional level remains the prerogative of the state and territory cancer registries. In addition to the agreed set of items that the state and territory cancer registries supply to the clearing house, the state and territory cancer registries hold other information including multiple source records and additional data items.

## What data are provided to the clearing house?

Data provided to the clearing house comprise reports of initial diagnoses, deaths from malignant tumours and deaths of cancer cases due to other causes occurring in Australian residents. Collection of this information at the national level commenced with those patients first diagnosed with cancer in 1982. Occasionally earlier data may be sourced and used for retrospective analyses with the cooperation of registries.

At the 2002 AACR AGM it was agreed that the following list of variables (Table 1) would be provided to the AIHW by each state and territory cancer registry in order to form the ACD data set. This data set does not prevent registries providing additional data to the clearing house if they wish to do so. For example, data on ductal carcinoma in situ are not part of the data set but are regularly requested for national reporting in the annual statistical report monitoring the BreastScreen Australia Program.

## How are data provided?

Each state or territory data set provided to the clearing house contains a file or files encompassing all cancer cases (alive and dead) notified to the registry since 1982 to the most recent completed year, for example 1982–2006. Data files are transferred from registries to the AIHW in a format which meets the security standard of both the registry and the AIHW.

**Table 1: Australian Cancer Database agreed minimum data set**

Person-level attributes	Tumour-level attributes
State/territory person id number	State/territory tumour id number
Surname	Date of diagnosis
First given name	Date of diagnosis flag
Second given name	Age at diagnosis
Third given name	ICD-O-3 <sup>(a)</sup> topography code
Sex	ICD-O-3 <sup>(a)</sup> morphology code
Date of birth	ICD-10 <sup>(b)</sup> disease code
Date of birth flag	Most valid basis of diagnosis
Indigenous status	SLA at diagnosis
Country of birth	Postcode at diagnosis
Date of death	Melanoma thickness in mm
Age at death	
Cause of death	

(a) International Classification of Diseases for Oncology, 3<sup>rd</sup> version.

(b) International Statistical Classification of Diseases and Related Health Problems, 10<sup>th</sup> revision.

## When are data provided?

State and territory registries provide data annually once they are satisfied that the data are of a suitable standard for both publication and combining with data from other registries. Timelines for data provision are agreed between registries and the clearing house. These timelines may vary between jurisdictions and from year to year so data provision dates require annual liaison between staff in the state and territory registries and the ACD manager.

## What quality control measures are in place?

The compilation of state and territory data into the ACD increases the need for standardising data collection and coding practices. The use of standard Australian Bureau of Statistics (ABS), International Classification of Diseases (ICD) and International Agency for Research on Cancer (IARC) codes and rules throughout each of the registries is agreed on. In order to maintain consistency in the ACD, variations in coding procedures at each registry are notified to the ACD manager so that adjustments may be made to the coding documentation of the ACD and, if relevant, appropriate steps taken by clearing house staff to improve consistency of the ACD data. Registries supply the clearing house with copies of all coding documentation and modifications.

As well as standardising coding the clearing house conducts a variety of checks to identify potential errors in the data supplied to the ACD. The AACR Executive Committee is consulted on checking procedures and any definitional problems. Appropriate amendments or deletions of data resulting from the quality control checks can only be undertaken by specifically authorised personnel following notification of the state or territory registry of origin.

## **4. NCSCCH procedures**

### **How is privacy maintained?**

#### **Physical and computer security systems**

The state and territory registries supply the clearing house with data on the basis that they will be maintained securely. The AIHW has building security systems and a dual level physical security system for its computer facility whereby access is restricted to authorised personnel only. This system is further strengthened by limiting access to the data to personnel with authorised system accounts and passwords. The AIHW internet connection and computer system have been audited and certified by the Defence Signals Directorate. Backup files relating to clearing house data are held in offsite secure areas with restricted accesses that have had their security certified by the Australian Security Intelligence Organisation (ASIO).

#### **Legislative protection for the Australian Cancer Database**

All personnel with access to the ACD are employees of the AIHW and, as such, are regulated by the confidentiality provisions of the AIHW Act (1987) and liable to the penal provisions of the Crimes Act (Commonwealth) for breaches of confidentiality. The AIHW has a statutory Ethics Committee which is required to adhere to the Privacy Act 1988, which incorporates Information Privacy Principles (IPPs), and the National Health and Medical Research Council (NHMRC) data acquisition and release guidelines. Research studies using the ACD which have been approved by the AIHW Ethics Committee must also be approved by each of the state and territory cancer registries, and any other relevant ethics committees.

### **What happens when a cancer case is notified to more than one registry?**

#### **Inter-registry case notification**

The clearing house has been given approval by the AIHW Ethics Committee for inter-registry patient linking of data as an ongoing activity since cancer patients who interact with the health system in more than one state/territory might have their cancer data recorded on more than one cancer registry. Thus the ACD is checked for duplicate records after all the jurisdictions have supplied their annual data to the clearing house. Inter-registry matches of cases will be notified to registries for further investigation, at least on an annual basis. Registries involved in this process advise the ACD manager of the result of these investigations so that amendments to the ACD may be made. Registries may at any time be provided with information containing patient and unit record identifiers that were originally supplied by their organisation.

## **Why is record linkage important?**

### **Record linkage with ACD**

An objective of the clearing house is to facilitate the conduct of national epidemiological studies. Undertaking these types of studies may require linkage of research cohorts with the ACD.

When a researcher indicates to the AIHW that an application for linkage with the ACD will be lodged with the AIHW Ethics Committee, the researcher is advised that AIHW Ethics Committee approval must be supported by state and territory cancer registry approval and that the researcher needs to lodge a separate application with each cancer registry. Record linkage is not undertaken by the clearing house until it is approved by the AIHW Ethics Committee and by each of the respective cancer registries ethics committees. If a state or territory cancer registry does not give approval for a particular linkage project, then that jurisdiction's data is excluded and a subset of the ACD linked to the researcher's data set.

The matching of data from the ACD with a researcher's data set is undertaken using both automated and manual processes. A probabilistic record linkage package using SAS statistical software and developed at AIHW is used for the automated analysis. Manual checking of matches is performed by clearing house staff. Perfect and near-perfect matches are sent directly to the researcher. Matches which are less than near-perfect but considered by clearing house staff to be likely are returned to the relevant cancer registry for their decision.

All research staff accessing records provided as a result of matching with the ACD must sign an undertaking of confidentiality under the AIHW Act with criminal penalties for a breach of the Act.

### **Record linkage with the NDI**

Another objective of the clearing house is to match information from the ACD with that of the NDI in order to determine the date and cause of death of cancer patients who have died. This matching process allows for survival analysis to be undertaken.

The clearing house will undertake the matching of the ACD with the NDI on request and with appropriate approvals. Where relevant, information from the matches will be added to the ACD and provided to the relevant state and territory cancer registries.

# 5. Access to information from the NCSCH

## How are data released from the clearing house?

Release of data from the clearing house varies according to the level at which they are requested. This section outlines the availability of data depending on the level of the request.

### 1. National cancer statistics

The clearing house generates extensive annual national cancer statistics which are released publicly on the AIHW website ([www.aihw.gov.au](http://www.aihw.gov.au)) as a published report or as data tabulations of each calendar year's incidence and mortality, aiming for a maximum lag of no more than two and a half years after the close of that year. The annual statistics contain at least the following tabulations:

- Annual numbers of new cancers and deaths by age, sex and anatomical site;
- Annual crude, age-sex specific, standardised and cumulative incidence and death rates by anatomical site.

National cancer monitoring and surveillance publications may also be produced on an ad hoc basis for government departments, non-government cancer organisations and for researchers or other interested parties. These publications may examine specific cancer issues to inform public discussion; for example, survival analysis, analyses by country of birth and socioeconomic status, overseas trends, cohort projections and intervention modelling. One example of such a report is *Breast cancer survival by size and nodal status* which was produced for the National Breast and Ovarian Cancer Centre. These national reports can be accessed either in hard copy or electronically from the AIHW website.

Statistical publications produced by the clearing house are released through the AIHW in partnership with the AACR and with acknowledgment of AACR members and badged accordingly. In addition, sponsor and funding organisations are also acknowledged appropriately.

### 2. More detailed analysis of publicly available national cancer statistics

Researchers may request a more detailed analysis of previously published data; for example, sub-types of a cancer type. The clearing house provides such data analyses at the national level with advice from the AACR Executive Committee when appropriate.

### 3. National cancer statistics not in the public domain

Researchers and cancer-related organisations may request additional analyses of unpublished national data held by the clearing house. Proposed analyses are discussed by the AACR Executive Committee which reserves the right to refer proposals to the state and territory cancer registries for approval as appropriate.

Successful applications are usually subject to a fee based on cost recovery. Broad analyses of national de-identified data by the clearing house do not usually require additional approvals or ethics committee clearance. Much of this sort of statistical analysis is performed within the context of a planned program of work to produce periodic reports in collaboration with

major cancer interest groups such as Cancer Australia where any necessary approvals have been obtained in advance during a consultation process.

#### **4. Cancer statistics below the national level**

The clearing house does not generally release unpublished cancer incidence data at state or territory level or smaller without the approval of the state and territory cancer registries (and their ethics committees if the data are potentially identifiable). Requests for national statistical analysis that wish to include breakdowns by state and territory, or other regional category, are referred to the AACR Executive Committee which will consider such applications for approval and advise AACR members accordingly. Appendix A provides a table where the level at which AIHW has approval to release cancer incidence and mortality data by state or territory is outlined.

#### **5. National cancer statistics which requires approval from the AIHW and state and territory ethics committees**

Requests which fall into this category are forwarded to the AIHW and state and territory cancer registry ethics committees for unilateral action and/or approval. This applies, for example, to any request for:

- access to original source records,
- de-identified unit record files for epidemiological analysis,
- linking a study's population records with the ACD to measure cancer incidence,
- linking records for a cohort of cancer cases with the NDI,
- inviting registered cancer patients to participate in research, or
- confirming cancer diagnoses in family pedigrees.

### **What are the processes for data requests that require approval?**

#### **Application to cancer registries**

Any request involving the types of data access described in sections 4 and 5 will require the following documentation to be provided to all cancer registries in advance of the proposed project commencement date (see approval process flowchart, Appendix C).

A written application which includes:

- a question or hypothesis,
- a description of a study design appropriate to the question,
- a feasible research plan,
- calculations of statistical power required to address the question,
- an analysis plan,
- details of staff who will have access to the data,
- an information dissemination plan,
- a data disposal plan,

- demonstrated concern of ethical and confidentiality issues consistent with the *National Statement on Ethical Conduct in Human Research (2007)*, in particular the chapter on databanks, and
- demonstrated researcher expertise or access to appropriate supervision required to conduct the research.

AIHW and the state and territory cancer registry data custodians will review the application and approve if appropriate.

### **Applications to ethics committees**

All requests requiring linkage of a study population with the ACD require the approval of the AIHW Ethics Committee and that of the directors of all state and territory cancer registries and their ethics committees. Securing all approvals can take from several months to a year and should be factored into project planning.

In turn, the AIHW Ethics Committee and the state and territory ethics committees will require the researcher to have institutional ethics committee approval from the researcher's university, hospital or other research facility, and an independent peer review of the project.

Where there is consent by the study subjects for linkage with ACD, the AIHW Ethics Committee and the directors of all state and territory cancer registries and their ethics committees may approve release of identified information to the researcher concerning which subjects were diagnosed with cancer, the date of diagnosis and the site and morphology of the cancer.

Where there is no consent by the research subjects for linkage with the ACD, the AIHW Ethics Committee and the directors of all state and territory cancer registries and their ethics committees may approve release of de-identified, unidentifiable information to the researcher on cancer incidence in the study population.

In some instances where consent has not been obtained but the public interest arguments are compelling, the relevant ethics committees may approve identified linkages under Section 95A of the Privacy Act 1988.

### **Permission for data release**

Apart from routine tabulations, all information transactions between researchers and the clearing house shall have formal documentation including the following:

- a detailed description of the data to be supplied,
- an agreement on levels of data privacy and security, including named individuals who will have access to the data,
- an agreement not to attempt to identify any individuals (if applicable),
- an agreement not to share the data with third parties,
- the required form of acknowledgement of the NCSCH,
- an agreement on the fee to be paid to the NCSCH,
- security provisions for storage and access to the data provided,
- an agreed schedule and scope for the dissemination of results and
- an agreed schedule for data disposal.

## Appendix A: Level at which AIHW has approval for cancer incidence and mortality data release by State/Territory

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Geographic levels								
• National	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
• Whole of state	Yes	Yes	Yes	Yes	Yes	Yes	Negotiation	Yes
• SLA or LGA	Restricted	Restricted	Restricted	Restricted	Restricted	Negotiation	Negotiation	Ethics
• CCD or Mesh Block	Negotiation	Negotiation	Negotiation	Negotiation	Ethics	Negotiation	Negotiation	Ethics
Age group levels								
• 5 Year Age Group	Restricted	Yes	State only	State only	State only	State only	Negotiation	Restricted
• Screening target group	Restricted	Yes	State only	State only	State only	State only	Negotiation	Restricted
Survival data	State only	State only	State only	State only	State only	State only	Negotiation	Negotiation
Unit record data	Negotiation	Negotiation	Negotiation	Negotiation	Negotiation	Negotiation	Negotiation	Negotiation
Contacting cases	No	No	No	Negotiation	Negotiation	No	No	No

### Notes:

**Restricted** – data may be restricted to major cancers – areas and/or years may need to be pooled

**Negotiation** – must be discussed with individual registry, may or may not require ethical approval

**State only** – available at whole state level only

**Ethics** – jurisdictional & AIHW ethical approval required

# Appendix B: Australasian Association of Cancer Registries terms of reference

## Membership

The Australasian Association of Cancer Registries (AACR) is an association of the state and territory population-based cancer registries of Australia, the New Zealand cancer registry and National Cancer Statistics Clearing House (NCSCCH), housed at the Australian Institute of Health and Welfare (AIHW). Membership of AACR is open to population-based registries, eligible to be voting members of the International Association of Cancer Registries (IACR). AACR members are represented on the IACR Executive through the Oceania representative, who may or may not be associated with an AACR member registry.

The members are:

- The New South Wales Central Cancer Registry
- The Victorian Cancer Registry
- The Queensland Cancer Registry
- The Western Australian Cancer Registry
- The South Australian Cancer Registry
- The Tasmanian Cancer Registry
- The Australian Capital Territory Cancer Registry
- The Northern Territory Cancer Registry
- The New Zealand Cancer Registry, and
- The National Cancer Statistics Clearing House.

Other cancer registries that are restricted to specific cancers or subgroups defined by age or region are not voting members of the AACR but may, by invitation from the AACR Executive Committee, become associate members and send observers to the AACR meetings.

## Objectives

The objectives of the AACR are to:

- Achieve national agreement on cancer-specific data definitions and coding and to encourage compliance with such agreements. As far as possible, data definitions and coding should be consistent with existing IACR protocols and conventions.
- Facilitate the production of Australian national and state and territory statistical publications on cancer that are comparable with each other and with international statistical publications, such as those from New Zealand.
- Improve the operational efficiency, and data completeness and quality, of the state and territory and New Zealand cancer registries through collaborative sharing of information.
- Contribute to national cancer control development in Australia and New Zealand through the regular and timely publication of local and national cancer statistics and the provision of data for cancer control research and health promotion.

- Contribute national data to international publications of the IACR.
- Contribute to international cancer coding and statistical analysis developments via members' involvement with IACR.
- Facilitate national epidemiological research projects on cancer (given appropriate local and AIHW ethics committee approvals).

## **Governance**

The AACR shall meet at least once annually at its Annual General Meeting (AGM). The AACR annual general meeting is usually held in conjunction with the annual conference of either the Clinical Oncology Society of Australia (COSA), to which it is formally affiliated, or the Australian Epidemiological Association (AEA). The AGM is the principal decision making forum of the AACR. In conjunction with the COSA and/or AEA, the AACR organises a cancer registry and cancer epidemiology day of presentations and post-presentation audience discussions as part of the annual conference.

The AACR shall elect an Executive Committee annually at the AGM. Elections shall be organised by the AIHW representative and their staff and nominations should be canvassed at least 5 working days in advance of the AGM. In cases of ties, the AIHW representative shall have the casting vote.

The AACR Executive Committee shall comprise 2 registry directors, 3 other state and territory representatives (2 registrars and 1 coder) and 1 AIHW representative (ex officio). Membership should be drawn from at least 3 jurisdictions.

One of the registry directors shall be elected as chair of the AACR Executive Committee.

One person may not hold the office of chair of the AACR Executive Committee for more than 3 years continuously and may not hold continuous office on the AACR Executive Committee for more than 5 years. After 5 years continuous office, persons must abstain from nominating for election for a period of 2 years.

Secretariat support and centralised documentation for the AACR meetings and agreements is provided by the AIHW, as part of its responsibilities managing the NCSCH. The NCSCH in collaboration with the AACR publishes hard copy and electronic national cancer incidence and mortality statistics and, from time to time, jointly produce national reports on cancer topics such as survival.

## **Activities**

The AACR Executive Committee meets 3 or 4 times per year, usually by teleconference. The Executive Committee provides advice to the AIHW on operations of the NCSCH, considers recommendations of the AACR committees, and deals with other AACR business matters throughout the year. It also undertakes email consultation during the year, distributes minutes of the Executive Committee to all member registries, and has annual reporting at the AGM.

The **AACR Coding and Reporting Committee** meets 2 or 3 times per year by teleconference and then in person before the AGM. It discusses issues in coding and reporting of incidence data and makes recommendations to the Executive Committee. All registries may be represented on the coding and reporting committee.

The **AACR Statistical Advisory Committee** is a small group of persons with special expertise in cancer statistics and epidemiology that provides advice to the AIHW and to the AACR Executive Committee on cancer statistics methodology. These are nominated by the member cancer registries at the AACR AGM.

The **AACR Aboriginal and Torres Strait Islanders Data Committee** is a small group of persons with special expertise in ATSI data that provides advice to the AIHW and to the AACR Executive Committee on ATSI data issues. These are nominated by the member cancer registries at the AACR AGM.

# Appendix C: Approval flow for ACD data

