Australian Government

Australian Institute of
Health and Welfare

Australian Cancer Database

Current status and a vision for the future

CANCER SERIES NO. 89

Australian Government
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Authoritative information and statistics
to promote better health and wellbeing

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Australian Institute of Health and Welfare
Canberra
Cat. no. CAN 86

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This publication is part of the Australian Institute of Health and Welfare's cancer series. A complete list of the Institute's publications is available from the Institute's website <www.aihw.gov.au>.

ISSN 1039-3307
ISBN 978-1-74249-660-3

Suggested citation

Australian Institute of Health and Welfare 2014. Australian Cancer Database: current status and a vision for the future. Cancer series no. 89. Cat. no. CAN 86. Canberra: AIHW.

Australian Institute of Health and Welfare

Board Chair	Director
Dr Mukesh C Haikerwal AO	David Kalisch

Any enquiries about or comments on this publication should be directed to:
Digital and Media Communications Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Tel: (02) 6244 1000
Email: info@aihw.gov.au

Published by the Australian Institute of Health and Welfare

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Contents

Acknowledgments

Authoring

This paper was prepared by staff of the National Centre for Monitoring Cancer at the Australian Institute of Health and Welfare (AIHW). The main authors were Ms Mardi Ellis, Mr Justin Harvey, Dr Mark Short, Ms Melissa Goodwin, Ms Anne Bech, Ms Christine Sturrock and Ms Lisa McGlynn.

The authors acknowledge the expert guidance of the Cancer Monitoring Advisory Group (CMAG), chaired by Professor Jim Bishop, and the Australasian Association of Cancer Registries (AACR) in preparing this paper.

Consultation

Documentation of data flows and governance processes within jurisdictional cancer registries was undertaken in close consultation with members of the AACR.

Definition of the goal state was undertaken with advice provided by members of the CMAG.

Funding

This work was funded through the AIHW's National Centre for Monitoring Cancer.

Abbreviations

AACR	Australasian Association of Cancer Registries
ABS	Australian Bureau of Statistics
ACD	Australian Cancer Database
ACTCR	Australian Capital Territory Cancer Registry
AIHW	Australian Institute of Health and Welfare
CCV	Cancer Council Victoria
CINSW	Cancer Institute New South Wales
CMAG	Cancer Monitoring Advisory Group
CSU	Cancer and Screening Unit
IARC	International Agency for Research on Cancer
METeOR	Metadata Online Registry
NCMC	National Centre for Monitoring Cancer
NCSCH	National Cancer Statistics Clearing House
NEHIPC	National E-Health and Information Principal Committee
NHIPPC	National Health Information and Performance Principal Committee
NHISSC	National Health Information Standards and Statistical Committee
NSWCCR	New South Wales Central Cancer Registry
NTCR	Northern Territory Cancer Registry
QCR	Queensland Cancer Registry
RBDM	Registry Births, Deaths and Marriages
SACR	South Australian Cancer Registry
SEER	Surveillance, Epidemiology and End Results Program
TCR	Tasmanian Cancer Registry
VCR	Victorian Cancer Registry
WACR	Western Australian Cancer Registry

Summary

The Australian Cancer Database: a national statistical asset

High quality data are essential national assets for the effective monitoring of cancer incidence, prevalence, survival and mortality in Australia. These data are vital to governments, clinicians and health services in delivering quality, evidence-based cancer care and broader cancer control initiatives. It is, therefore, important to define the availability, consistency and quality of these data that best serves this purpose.

The Australian Cancer Database (ACD) is collated annually and administered by the Australian Institute of Health and Welfare (AIHW) in collaboration with Australia's cancer registries through the Australasian Association of Cancer Registries.

As the only national collection of cancer incidence data, the ACD forms the backbone of all national cancer statistics produced by the AIHW. It also serves as a valuable resource for national performance reporting, cancer research and data linkage.

Current state: overall very good, with room for improvement

The current state of the ACD was assessed against the 7 dimensions of the Australian Bureau of Statistics (ABS) Data Quality Framework 2009 (ABS 2009): Institutional Environment, Relevance, Timeliness, Accuracy, Coherence, Interpretability, and Accessibility. The ACD was also compared with 9 countries and found to be comparable in most areas, and to lead the world in some.

The goal state: a vision for the future

Ensuring the continued supply of national, responsive, policy-relevant cancer incidence, prevalence, survival and mortality data is of great importance.

The data contained within the ACD are: covered under legislation, publicly funded and for the public good. The use and reporting of these data must always be considered in the context and interest of the public good and broader public needs.

To this end, the AIHW has set the following 5 goals for the future state of the ACD, related to the 7 dimensions of data quality:

1. That the ongoing provision, collation, maintenance and dissemination of national cancer incidence and mortality data through the ACD is secured and that appropriate arrangements are in place to support this.
2. That the data included in the ACD, and the means of disseminating those data, be appropriate to address the policy, planning and research questions of stakeholders and consumers of Australian cancer incidence and mortality data.
3. That the ACD contain incidence and mortality data 12 months from year of diagnosis or death, for reporting at a national level within 18 months from year of diagnosis or death.
4. That the ACD data accurately represent cancer incidence and mortality in Australia and that data are consistent and comparable between jurisdictions, internationally and over time.
5. That the information needed to aid the interpretation of cancer incidence and mortality data is current, complete and regularly reviewed.

1 The Australian Cancer Database: a national statistical asset

The Australian Cancer Database (ACD) was originally developed in 1986 to:

- monitor and report on levels of cancer incidence and trends in Australia
- help in research and planning that aims to reduce cancer incidence and mortality, and
- improve outcomes for people diagnosed with cancer.

The ACD, formerly known as the National Cancer Statistics Clearing House (NCSCH) database, is collated and administered by the Australian Institute of Health and Welfare (AIHW) in collaboration with Australia's cancer registries through the Australasian Association of Cancer Registries (AACR).

The ACD is recognised as an Essential Statistical Asset (ESA) for Australia. The ESA initiative has identified statistics that are critical to decision making in Australia, together with the datasets that underpin that list of statistics (ABS 2013). The ACD is a high quality, authoritative data source that is used extensively by governments, clinicians, health services and policymakers, and is essential for health performance reporting, service planning and evaluation, and meeting various national health reporting obligations.

The demand for cancer-related data has increased since the ACD was established, and the introduction in 2009 of annual National Healthcare Agreement reporting indicators for cancer incidence and survival highlight the importance of this collection for national reporting purposes (SCRGSP 2009).

To ensure that the AIHW can continue to supply national, responsive, policy-relevant cancer incidence, prevalence, survival and mortality data, the AIHW, with the support and cooperation of the cancer registries, examined all governance arrangements and end-to-end data processes that affect the quality and currency of the ACD.

In order for the AIHW to continue to inform and support the development of evidence-based policy, program development and clinical service delivery to improve outcomes for patients who develop, or are at risk of developing cancer, it must provide relevant, timely and high quality information on cancer incidence, survival, prevalence and mortality. Additional information such as structured pathology, treatment and cancer staging data would further enhance the currently available information on cancer incidence, survival, prevalence and mortality.

The ACD is compiled annually by the AIHW from data supplied by state and territory cancer registries. The quality and currency of data in the ACD relies on data and governance processes external to the AIHW as well as those within the AIHW. As the only nationally available collection of cancer incidence data, the ACD forms the backbone of all national cancer statistics produced by the AIHW. It also serves as a valuable resource for cancer research through ad-hoc data requests, analyses and data linkage.

The National Centre for Monitoring Cancer (NCMC), established in 2009, aims to provide accessible, policy-relevant national information for evidence-based decisions across the cancer pathway. The prioritisation of work by the NCMC is guided by the Cancer Monitoring Advisory Group (CMAG) comprising a number of experts in cancer data, cancer policies and practices, and emerging cancer-related issues.

An identified priority of the NCMC is the continued development and enhancement of the ACD. This is in keeping with the objectives of the NCMC to increase data availability, enhance data quality and improve data use (AIHW 2012). The ACD Project forms a fundamental piece of work towards this goal.

The ACD is used extensively by the AIHW, and in 2014 national cancer data are available in the following products and outputs:

- National Health Performance Indicator 4—Incidence of selected cancers, by state and territory for 2011
- National Health Performance Indicator 24—Survival rate of people diagnosed with notifiable cancer
- *Cancer in Australia: an overview*, biennial publication (scheduled for release December 2014)
- Australian Cancer Incidence and Mortality (ACIM) books (AIHW 2014b)
- Breast, cervical and bowel cancer incidence to assist in monitoring the three population-based screening programs for these cancers
- Other cancer-related reports—for example, *Head and neck cancer in Australia* (AIHW 2014c) and *Radiation oncology areas of need: cancer incidence projections 2014–2024* (AIHW 2014d).

1.1 What is the current state of the ACD?

The term ‘current state’ refers to the ACD as it exists in 2014. The assessment of that current state is made against the Australian Bureau of Statistics Data Quality Framework (ABS 2009). This framework specifies 7 dimensions against which the quality (fitness for purpose) of a dataset can be assessed. These dimensions are: Institutional Environment, Relevance, Timeliness, Accuracy, Coherence, Interpretability, and Accessibility. The AIHW has adopted this framework for assessing and reporting the quality of all its statistical resources.

A summary of those concepts with respect to the ACD, both as a national dataset and a composite of 8 jurisdictional datasets, is presented below. A summary statement is made against each dimension for comparison and assessment of ‘best practice’.

Further detail on each dimension, and of jurisdictional and international cancer data, can be found in:

- Appendix A Australian Cancer Database 2010 Data Quality Statement
- Appendix B ACD data items
- Appendix C Data quality summary—Australian states and territories
- Appendix D Data quality summary—International comparison.

The context in which these dimensions interact is described in Chapter 3—‘Building the Australian Cancer Database’.

Institutional Environment

There is currently no specific legislation to mandate the collection of national cancer data, however the *Australian Institute of Health and Welfare Act 1987* (AIHW Act) and the *Privacy Act 1998* (Privacy Act), among others, allow for it, and the National Health Information

Agreement 2013 and National Healthcare Agreement 2012 require it for reporting purposes (Table 1.1). The *National Cancer Statistics Clearing House Protocol 2013* (NCSCH Protocol) (AIHW & AACR 2013) and the *National Centre for Monitoring Cancer Framework 2012* (AIHW 2012) provide a framework and governance structures for that collection.

Each jurisdiction has specific legislation for the notification and collection of cancer incidence data. Two jurisdictions (New South Wales and the Northern Territory) also mandate notification of cancer-related mortality.

Table 1.1: Overview of cancer incidence and mortality data quality, Institutional Environment, Australia

Institutional Environment	
Administrative hierarchy	Parliament Minister for Health Australian Institute of Health and Welfare • Board • Director (CEO) • Head, Health Group • Head, Cancer and Screening Unit • Manager, Australian Cancer Database
Mandate for data collection	Legislation • *National Health Act 1953* (13 March 2014) • *Australian Institute of Health and Welfare Act 1987* (1 July 1987) • *Privacy Act 1988* (12 March 2014) • *Cancer Australia Act 2006* (27 December 2011) Agreements • National Health Information Agreement 2013 (1 October 2014) • National Healthcare Agreement 2012 (25 July 2012) There is no specific legislation to mandate the collection of national cancer data, however the Acts allow for it, the Health Agreements require it for reporting and the NCSCH Protocol provides a framework and governance structures.
Funding arrangements and resources	Funding for collection of cancer data by each Australian state or territory is through the jurisdictional departments of health (or equivalent) and, in some jurisdictions, also through non-government organisations. Collation of jurisdictional cancer data into a nationally consistent single dataset is through annual appropriation from the Australian Government to the AIHW. The Cancer and Screening Unit at the AIHW comprises approximately 12 full-time staff with 7 staff involved in cancer monitoring (including building and maintaining the ACD).
Quality commitment	The Australian Cancer Database housed at the AIHW is a collaborative effort between the 8 state and territory cancer registries and the AIHW. Ultimate authority and responsibility for the degree of coverage and the quality of the data resides with the states and territories. Before the availability of cancer statistics is announced, the publication data files are reviewed and approved for official release by each state and territory cancer registry.
Statistical confidentiality	AIHW Act 1987; Privacy Act 1988; AIHW policy on reporting to manage confidentiality and reliability 2013 (unpublished).

Relevance

The Australian Cancer Database is the only source of national cancer data in Australia. Although it is impossible to ensure that every case of cancer is registered, coverage is considered sufficiently complete for producing accurate statistics. Available estimates include incidence, mortality, survival and prevalence.

It is important to note that in Australia 'cancer' is used to mean 'cancer, excluding basal cell carcinomas of the skin and squamous cell carcinomas of the skin'. These two cancers are not consistently legislated or collected across jurisdictions and as such are not in the scope of the ACD.

Table 1.2: Overview of cancer incidence and mortality data quality, Relevance dimension, Australia

Relevance	
Coverage	Cancer is a legally notifiable disease in all states and territories; therefore coverage is virtually complete. However, it is important to note that what constitutes cancer notification, and those professions and institutions mandated to notify, is a feature of individual jurisdictional legislation, not Commonwealth legislation. These aspects are described more fully for each state and territory in Appendix C. Further, there is inconsistent notification and collection of basal cell and squamous cell carcinomas across jurisdictions: therefore these two cancers are excluded from the ACD.
Target population	Cancer incidence and mortality data provided by the jurisdictional cancer registries.
Data items	See Appendix B (Table B1).
Classifications	ICD-O-3, ICD-10.
Available estimates	Incidence, mortality, survival and prevalence.

Timeliness

Australian cancer incidence and mortality data are available at the national level within 3 years of diagnosis (Table 1.3). That means cancers diagnosed from 1 January 2010 to 31 December 2010 were included in the ACD in 2013. That dataset, known as the ACD 2010, was available for internal AIHW analysis and reporting from August 2013.

Availability of jurisdictional data ranges between 1 and 4 years after diagnosis or death. The Victorian Cancer Registry made their 2012 data available within 12 months (1 year) of the reporting period, while data in New South Wales and the Australian Capital Territory currently have a lag of 4 years from the reporting period (2010 data may be available in 2014).

Table 1.3: Overview of cancer incidence and mortality data quality, Timeliness dimension, Australia

Timeliness	
Currency	Incidence: 1982–2010 (2011 data will be available later in 2014). Mortality: 1968–2011 (2012 data will be available later in 2014).
Factors affecting timeliness	Currency of jurisdictional data, and provision of those data to the AIHW. Resource intensity of validation, deduplication, linkage and clerical review of the ACD. Resource intensity of developing reporting products and clearing those for public release.
Frequency	Annual.

Accuracy

The data in the ACD are considered to have sufficiently complete coverage to produce accurate statistics for the cancers included in the mandatory collection (that is, all primary malignant tumours with the exception of basal cell and squamous cell carcinomas) (Table 1.4). This is a product of legislation in each jurisdiction for the mandatory notification of cancer incidence (and in some cases, mortality). Quality assurance and adherence to international standards for classification and coding means the accuracy of the ACD is considered very high.

The jurisdictional registries are rated by the International Agency for Research on Cancer (IARC) as 'Group A' registries, the highest data quality classification. 'Group A' registries are defined as those meeting the following (minimum) criteria:

- more than 80% of cases are microscopically verified
- death certificate only (DCO) cases make up less than 10% of registrations
- death certificate data are collected (Forman 2013).

Table 1.4: Overview of cancer incidence and mortality data quality, Accuracy dimension, Australia

Accuracy	
Quality assurance	IARC classification for data quality rated as 'Group A', based on rating for the contributing jurisdictional registries. De-duplication. Indigenous status.
Non-response error	Data for 2 jurisdictions, NSW and ACT, have not been available for inclusion in the 2010 or 2011 ACD. These data are therefore estimated by assessing the historical trend to 2009 and projecting forward to the current reporting year (2011 data in 2014).
Revisions to data	The database is a compilation of 'living' registry records. Complete, historical data are provided each year and revisions to these data will be incorporated into the ACD. State and territory datasets may also be revised as a result of de-duplication or linkage as part of the process of building the ACD. See also, 'Coherence' section below.

Coherence

Despite differences in legislation, funding and operational activities among the 8 Australian jurisdictions, the level of consistency of cancer incidence and mortality data, and by extension the comparability and coherence of the ACD, is very high. This is a direct result of the valuable and collaborative work of the AACR.

The coherence of the ACD is considered comparable over time and between jurisdictions.

Table 1.5: Overview of cancer incidence and mortality data quality, Coherence dimension, Australia

Coherence	
Comparability over time	The ACD is considered comparable over time. Data items may be added to or removed from the ACD. The definition or meaning of data items does not change over time. Changes to ICD-O classifications may cause a break in series for trend analyses. These are documented.
Comparison with jurisdictions	Analyses of the ACD by jurisdiction may differ from those published by the jurisdictions if the numbers are derived from different snapshots of the jurisdictional database. Furthermore, the AIHW undertakes a deduplication which may result in some tumour records being removed because they are registered in two different jurisdictions. This causes a temporary slight difference in tumour counts between the ACD and the jurisdictions.

Interpretability

The presentation of data from the ACD is intended to be read and understood by an 'interested 17 year old'. To this end, the data are layered and presented in a variety of formats (text, tables, figure, infographic) and at varying levels of complexity (summary statistics through to detailed statistical methodology) (Table 1.6). Data quality, methodology and supporting technical notes are available with each published report, and on the AIHW website. The interpretability of the ACD is therefore considered high.

Table 1.6: Overview of cancer incidence and mortality data quality, Interpretability dimension, Australia

Interpretability	
Presentation of data	AIHW reporting products appeal to, and are targeted at, a broad audience. Published information is layered: from summary or snapshot material through to more detailed statistical analyses. Tables, figures and dashboard infographics are used to illustrate key data.
Availability of information regarding the data	A data quality statement for the ACD is available on the AIHWs national Metadata Online Registry (METeOR), and included in full in AIHW publications that include data from the ACD. Technical notes, footnotes and summary text are provided in all publication, or as additional material to those publications. Additional data are provided to support figures and in-text references to data, where appropriate.

Accessibility

The ACD is publicly funded and for the public good. The use and reporting of these data must therefore reflect public need. Data outputs from the ACD are available free of charge on the AIHW website, and in a broad range of formats: from comprehensive published reports and detailed data tables to summary web-content. Other data are available through the ad hoc data request portal, and are provided on a cost-recovery, fee-for-service basis (Table 1.7). The accessibility of data from the ACD is consequently considered high.

Table 1.7: Overview of cancer incidence and mortality data quality, Accessibility dimension, Australia

Accessibility	
Accessibility to the public	AIHW products are available free of charge on the AIHW website. Content may be web-based, or downloadable print-ready publications. A print-on-demand service is available for most report products (at cost). Ad hoc data requests for unpublished data are provided on a cost-recovery fee-for-service basis.
Data products available	*Cancer in Australia: an overview* reports are produced biennially by the AIHW and is a report of the most recent cancer incidence, mortality, survival, prevalence, hospitalisations and burden of disease information due to cancer, as well as providing information on the national cancer screening programs. The report was last published in December 2012 using 2009 incidence and 2010 mortality data with year-to-date estimates for 2012. *Cancer in Australia: an overview 2014* is scheduled for release in December 2014. This publication is supplemented with online data, the Australian Cancer Incidence and Mortality (ACIM) books. These Microsoft Excel worksheets are updated annually as new national cancer incidence and mortality data become available. Cancer data and related information can be accessed through several entry points on the AIHW website (www.aihw.gov.au).

1.2 How does the current ACD compare internationally?

The ACD compares favourably with cancer registries in other countries across the 7 dimensions of Institutional Environment, Relevance, Timeliness, Accuracy, Coherence, Interpretability and Accessibility.

Nine cancer registries in other countries selected for comparison with the ACD (and the state and territory cancer registries):

- Canada
- New Zealand
- Nordic countries (Denmark, Finland, Iceland, Norway and Sweden)
- United Kingdom
- United States of America.

The quality of cancer incidence and mortality data for these 9 selected countries and the ACD, against 4 dimensions, are summarised in Table 1.8, below. More detail for each country is provided in Appendix tables D3–D7.

Table 1.8: Summary of cancer incidence and mortality data quality, selected dimensions, Australia, and selected countries (Canada, New Zealand, Nordic countries [5 nations], United Kingdom, United States of America)

Registry	Institutional Environment (legislated reporting)		Timeliness		Relevance (coverage)(a)	Accuracy (quality)(b)
	Incidence	Mortality	Incidence	Mortality		
Australia	No (Yes in 8 jurisdictions)	No (Yes in 3 jurisdictions)	3 years(c) (Jurisdictional: 1–4 years)(d)		Complete	Group A
Canada	Yes	Yes	3 years (also year-to-date incidence)		Complete	Group A
New Zealand	Yes	Yes	3 years (also 2-year provisional and 1-year fast-tracked incidence)		Complete	Group A
Nordic countries						Group A
Denmark	Yes	No	2 years	2 years	Complete	Group A
Finland	Yes	Yes	2 years	2 years	Complete	Group A
Iceland	Yes	No	2 years	2 years	Complete	Group A
Norway	Yes	Yes	2 years	2 years	Complete	Group A
Sweden	Yes	Yes	2 years	5 years	Complete	Group A
United Kingdom	Yes: England, Wales No: Northern Ireland, Scotland	No	2 years	2 years	Complete	Group A
United States of America	Yes (in most states)	Yes	4 years	4 years	Complete	Group A

(a) Based on assessment of the mandated target population and the data collected.

(b) Assessed according to the IARC rankings (Forman 2013).

(c) The national dataset (ACD) includes 2 years of projected estimates for NSW and the ACT to bring them in line with all other jurisdictions.

(d) For information on jurisdictional timeliness, see Appendix tables C1–C8.

Sources: Tables 1.1–1.3; Appendix tables C1–C8, D1–D5.

Institutional Environment

Although most of the 9 countries examined (excluding Northern Ireland and Scotland in the United Kingdom), have national legislation to collect and report a national cancer dataset, responsibility for that collection is managed at a sub-national level.

Relevance

Coverage in all countries is considered complete. This is assisted in most countries by legislation and local (decentralised) data collection.

Timeliness

Reasons cited by each country for the timeliness of cancer incidence data (that is, time from cancer diagnosis or death, to reflection of that event in nationally available statistics) were similar to the Australian experience.

In most countries, including Australia, cancer registration is the purview of jurisdictions, and the process of registering a cancer is complex and takes considerable time, with data needing to be sourced from a variety of medical facilities—including hospitals, physicians offices, radiation facilities, freestanding surgical centres, and pathology laboratories.

Similarly, deaths data, including deaths due to cancer, are recorded on death certificates that are sent to state vital statistics offices, with varied processes in place to retrieve these data for the registries.

A variety of data sources such as these requires a variety of processes at national and sub-national (state, province) level to ensure the data are of sufficiently high quality to be collated into a consistent dataset.

Timeliness of final incidence data ranged from 2 years in the Nordic countries to 4 years in the United States of America. More timely preliminary, fast-tracked and year-to-date estimates were available for New Zealand and Canada.

Timeliness of final mortality data ranged from 2 years in most Nordic countries to 5 years in Sweden.

The timeliness of the ACD is just outside the leading examples internationally, with 3 years for both incidence and mortality data. The exception is Victoria, with a 1-year turnaround for both incidence and mortality data in 2012 (reported in August 2013). This appears to be the standout example internationally.

Accuracy

The accuracy and data quality of the 9 international registries compared are also rated at the same classification as Australian cancer data of Group A by the IARC (Forman 2013).

The level of accuracy in the Nordic countries is enhanced by the use of personal identification numbers to validate records through routine linkage between cancer, mortality and health service data.

2 The goal state: a vision for the future

Ensuring the continued supply of national, responsive, policy-relevant cancer incidence, prevalence, survival and mortality data is of great importance. The data contained within the ACD are: covered under legislation; publicly funded; and for the public good. The use and reporting of these data must always be considered in the context and interest of the public good and broader public needs.

To this end, the AIHW has set 5 goals for the future of the ACD, related to the 7 dimensions of data quality. The goals for Relevance and Accessibility, and Accuracy and Coherence, respectively, had meaningful overlaps and were therefore combined. The 5 goals are outlined below.

2.1 5 goals for the future

Institutional Environment

1. That the ongoing provision, collation, maintenance and dissemination of national cancer incidence and mortality data through the ACD is secured and that appropriate arrangements are in place to support this.

Relevance, Accessibility

2. That the data included in the ACD, and the means of disseminating those data, are appropriate to address the policy, planning and research questions of stakeholders and consumers of Australian cancer incidence and mortality data.

Timeliness

3. That the ACD contain incidence and mortality data 12 months from year of diagnosis or death, respectively, for reporting at a national level within 18 months from year of diagnosis or death.

Accuracy, Coherence

4. That the ACD data accurately represent cancer incidence and mortality in Australia and that data are consistent and comparable between jurisdictions, internationally and over time.

Interpretability

5. That the information needed to aid the interpretation of cancer incidence and mortality data is current, complete and regularly reviewed.

2.2 Defining the ‘goal state’

The term ‘goal state’ is used in this report to refer to the desired outcome for the future of the Australian Cancer Database, and reflects the levels of quality required for each of the 5 goals in order to provide best evidence to underpin policy decisions.

The process used in defining the goal state, as well as the processes that might be used in achieving it, are described in the sections that follow.

In order to define the level of quality for the ACD required by stakeholders, Cancer Monitoring Advisory Group (CMAG) members were guided through a discussion using a series of questions designed to elucidate clearly the differing needs of policy makers, service providers and researchers, and the role of cancer incidence data in satisfying these needs.

In general, CMAG agreed that, as cancer incidence and mortality data are generally stable over time:

- more timely but less complete data (with clear caveats) would answer many policy and service planning questions, as well as queries from the media and general public
- more complete and accurate data were more often (but not always) important factors for the research community.

This is a general statement, derived from broad consultation, and the requirements of individual users of the ACD may differ.

While a goal state could be idealistic and aim for, for example, 'real time' data with direct feeds from the point of diagnosis, the exercise above reflects what is achievable and realistic in the Australian context in terms of technology, resourcing and integration between health services and levels of government.

2.3 Achieving the goal state

The next steps towards achieving the goal state are described in chapters 3 and 4, and are to:

- identify points in the process of compiling the ACD where improvements may be made;
- review the cancer data environment for current and future opportunities in cancer reporting; and
- define and scope the steps required to achieve the goal state.

Taking these steps will maximise the timeliness, quality and utility of this national data asset, and should be considered essential, priority work.

3 Building the Australian Cancer Database

There are 4 broad steps in building the ACD:

1. jurisdictional data collection
2. provision of those data to the AIHW
3. collation of those data by the AIHW into the ACD
4. dissemination of national (and other) data from the ACD to third parties.

Behind these broad steps, however, lie a series of contributing complex interactions among stakeholders, legislation and governance relating to cancer data in Australia that is difficult to describe linearly and must be examined concurrently in order to appreciate their inter-relatedness.

This exercise is not intended to be a detailed account of the process in each jurisdiction, nor to rank one jurisdiction against another. Rather, the intention is to provide context and a practical focal point for the goal state by identifying points of influence in the process. These points of influence can highlight:

- stages in the process that present a challenge to the quality of the ACD
- opportunities to overcome those challenges in order to achieve the goal state against each relevant data quality dimension.

Points of influence are developed further in Chapter 4, 'Discussion—securing the Australian Cancer Database, a vision for the future'.

A diagram summarising the governing instruments and stakeholders at each point in the pathway from jurisdictional data collection to dissemination of national cancer data is provided in Figure 3.1. A more detailed description of each point in the pathway, and the relevant points of influence, is provided in sections 3.1 to 3.4.

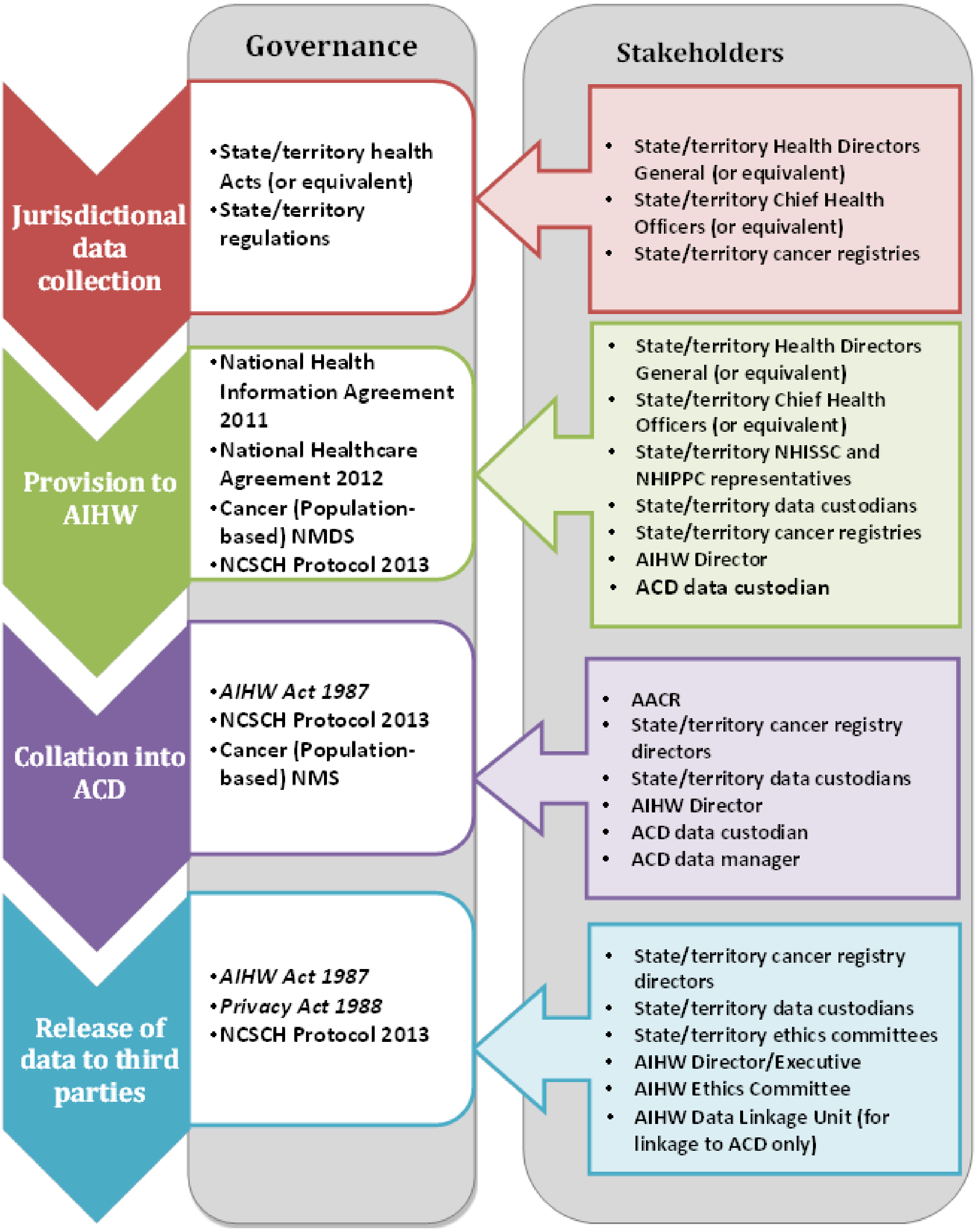

Figure 3.1: Overview of stakeholder and governance relating to collation of the Australian Cancer Database

3.1 Jurisdictional data collection

The process of data collection by the jurisdictions most strongly influences three quality dimensions of the ACD: Institutional Environment, Relevance and Accuracy. Specific points of influence to achieve the goal state are listed in Box 3.1, with more detail provided under each relevant dimension, below.

Box 3.1: Points of influence—jurisdictional cancer data collection

Institutional Environment, Relevance

- Variation in jurisdictional legislation governing the target population, mandated cancers, mandated notifiers and mandated reporting of cancer-related deaths.
- Variation in jurisdictional legislation governing the ability of cancer registries to share information (cross-border) and access electoral roll information.
- Variation in jurisdictional data arrangements between cancer registries and Registrars of Births, Deaths and Marriages (RBDM) for the provision of mortality data.
- Jurisdictional registry resourcing issues: funding, training and retention of coding staff.

Accuracy

- Jurisdictional variations in coding of cancer-related deaths and treatment of death-certificate-only cases.
- Lack of recognised national standards for, and independent auditing of, coding practices.

Institutional Environment, Relevance

In Australia, the collection of cancer data is not governed by national legislation—instead, each of the states and territories legislate for the reporting of all cancer diagnoses and cancer-related deaths. While legislation in each jurisdiction mandates the notification of cancer diagnoses, the legislation regulating notification, governance structures, and funding arrangements of the registries vary between jurisdictions.

Mandatory notification of cancer incidence by hospitals and pathology services (or pathologists) is common to all jurisdictions. Notification of cancer-related deaths is mandated in New South Wales and the Northern Territory only. Notification by radiotherapy centres, cancer screening registers, residential aged care facilities, ophthalmologists, general practitioners, forensic medicine services and medical oncology is mandated in some, but not all, jurisdictions.

Most cancer registries fall within the governance structure of their jurisdictional health department and report to the relevant Minister for Health. The exception to this is the Victorian Cancer Registry, which operates under the Cancer Council of Victoria (a statutory authority).

While Queensland, Northern Territory, Tasmania and the Australian Capital Territory outsource operational responsibility for their registers, legal ownership and responsibility remain with the relevant health department.

The cancer registries in each jurisdiction are funded by their health departments. Three registries—Victoria, Queensland and Tasmania—also receive funding, or in-kind resourcing, from other bodies.

Accuracy

In Australia, cancer registries are 'case-based' data collections, and registration and coding of each cancer diagnosis can be a complex and protracted task.

Each pathology report, cancer notification or other piece of information provided to the registry is considered in the context of other information about the same person, and used to progressively create and edit one or more tumour records for that person.

While cancer notification is mandatory in all Australian states and territories, there are a number of differences across the jurisdictions in how cancer registrations are notified and processed. Broadly, these differences relate to variations in the Institutional Environment for each jurisdiction, namely the size, scope and capacity of the registry, mandatory notifiers and the process of notification, and access to cancer-related mortality information.

3.2 Providing jurisdictional data to AIHW

The provision of jurisdictional data to the AIHW most strongly influences three quality dimensions for the ACD: Institutional Environment, Timeliness, and Coherence. Specific points of influence to achieve the goal state are listed in Box 3.2, with more detail provided under each relevant dimension, below.

Box 3.2: Points of influence—providing jurisdictional data to AIHW

Institutional Environment

- Absence of a formal agreement mandating the supply of jurisdictional cancer data to the ACD.
- Absence of formal recognition and authority of the NCSCH Protocol, underpinning the provision of cancer data to the AIHW.

Timeliness

- There is no set date for data supply to the ACD, and in practice this varies between years and jurisdictions.

Coherence

- There is no mandated set of data items for supply to the ACD.

Institutional Environment

There are two legislative instruments that describe the collection and use of health (cancer) information in the national interest. These are the:

- *National Health Information Agreement 2013*
- *National Healthcare Agreement 2012*.

The provision of cancer data to a national register or collection is mentioned in legislation for some jurisdictions, but is not explicit for all. The ACD is not currently mandated under any legislation or formal agreement among Australian health ministers.

The AIHW was established by the *Australian Institute of Health and Welfare Act 1987* (AIHW Act) as a statutory authority, governed by a management Board that is appointed by and accountable to Parliament. The health-related functions of the AIHW, specified in section 5 of the Act, are broadly to collect, produce and publish health-related information and statistics, alone or in conjunction with other bodies. In addition, the AIHW may develop statistical standards and methods, conduct and promote research, and enable researchers to have access (subject to section 29, mentioned below) to the information and statistics held by the AIHW.

The AIHW operates under a confidentiality regime prescribed in section 29 of the AIHW Act that protects information about individuals both living and deceased and associations of persons, such as bodies politic and bodies corporate.

The provisions of the *Privacy Act 1988* and the Australian Privacy Principles outlined in that Act establish the framework for the collection, storage, use and release of personal information at the AIHW (and other government and non-government organisations) from a privacy perspective. In contrast to the AIHW Act, the Privacy Act protects only information about living individuals.

These two pieces of legislation underpin the collection, storage and use of data contained within the ACD.

The governance arrangements for the transfer of jurisdictional data to the AIHW are set out in the National Cancer Statistics Clearing House Protocol (NCSCH Protocol) (AIHW & AACR 2013). The NCSCH was established in 1986, at the AIHW, as the national repository of cancer incidence and mortality statistics. It operates as a collaborative partnership between the jurisdictional cancer registries and the AIHW through the Australasian Association of Cancer Registries (AACR), and houses the ACD. The protocol was most recently endorsed by the AIHW Ethics Committee in 2013 and is the only formal agreement between the AIHW and the AACR for provision of cancer data. While this underpins the agreement between the AIHW and cancer registries to provide data to a national register, it is not legally binding.

With respect to the provision of jurisdictional cancer data to the AIHW, the NCSCH Protocol specifies that:

> *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.*

Funding for the supply of jurisdictional cancer data to the AIHW is at the discretion of the states and territories, and differs between the registries.

Timeliness

Cancer data are requested of the jurisdictions by the AIHW each year, according to the NCSCH Protocol. Data are provided to the AIHW once the state and territory registries are satisfied that the data are of a suitable standard for both publication and combining with data from other registries. Consequently, timelines are decided by negotiation between the registries and the ACD data manager, and may vary between jurisdictions and years. In the previous four years (2011 to 2014) the date on which the final jurisdiction submitted their dataset to the NCSCH, were:

- 13 Sep 2011 (2008 ACD)
- 18 Jun 2012 (2009 ACD)
- 1 Aug 2013 (2010 ACD)

- 27 Jun 2014 (2011 ACD).

Coherence

Requests for cancer data are made to cancer registries in accordance with the data formats described in the *Australian Cancer Database agreed minimum data set* (see Appenxix B).

In accordance with AIHW policy on the transmission and receipt of data, all unit record cancer data are supplied via the AIHW Validata™ system. Validata™ is a secure online data receipt and validation product. The data are stored at AIHW in accordance with the strict privacy and security provisions, prescribed in the AIHW Act and the Privacy Act.

The agreed minimum data set and the use of the AIHW Validata™ tool facilitate the supply of comparable jurisdictional data to AIHW for collation into the ACD.

3.3 Collating the national dataset

The process of collating the national dataset, by the AIHW, most strongly influences 3 quality dimensions for the ACD: Institutional Environment, Accuracy, and Coherence. Specific points of influence to achieve the goal state are listed in Box 3.3, with more detail provided under each relevant dimension, below.

Box 3.3: Points of influence—collating the national dataset

Institutional Environment

- Absence of a formal agreement for the collation of a national cancer dataset (ACD).
- Collation of jurisdictional data into the ACD is currently funded through discretionary budget allocation of AIHW's appropriation funding.

Accuracy, Coherence

- No defined criteria for the quality of cancer data supplied to the NCSCH for inclusion in the ACD.

Institutional Environment

The AIHW Act stipulates the role of the AIHW in producing national health-related information and statistics. Under section 5 of this Act, the AIHW is established to co-ordinate, collect and produce health-related statistics, as well as to provide assistance (including financial assistance) for the collection and production of health-related information and statistics by others.

The NCSCH Protocol underpins collation of jurisdictional cancer data into the ACD, and described the services provided by the AIHW and the AACR to the clearing house. The NCSCH Protocol specifies that:

> *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.*

Collation of jurisdictional data into the ACD and subsequent production of the biennial report *Cancer in Australia: an overview* is currently funded through AIHW discretionary budget allocation of its annual appropriation funding.

Accuracy, Coherence

The jurisdictional data are collated into the ACD in 5 broad steps:

1. Data loading, cleaning and validation (using Validata™)
2. Derivation of ACD-specific data items from those provided by the jurisdictions
3. De-duplication, and notification of duplicates to the relevant registry
4. Linkage to the NDI to ascertain death notifications, for survival and prevalence analysis
5. Final approval of jurisdictional data for inclusion in the ACD.

There are no defined criteria for the quality of data provided by the jurisdictions for inclusion in the ACD. Each of the steps above contributes to the improved accuracy and coherence of the national dataset, and the final step, approval of jurisdictional data for inclusion in the ACD, in particular recognises that the data provided by the jurisdictions have been adjusted by the AIHW in steps 1–3. The jurisdictions retain custodianship of these modified data.

3.4 Disseminating national cancer data

The process of disseminating information from the national dataset most strongly influences 3 quality dimensions for the ACD—Institutional Environment, Relevance, and Accessibility—and to a lesser extent two others (Timeliness and Coherence). Specific points of influence to achieve the goal state are listed in Box 3.4, with more detail provided for Institutional Environment, Relevance and Accessibility, below.

Box 3.4: Points of influence—disseminating national cancer data

Institutional Environment

- Variation in jurisdictional confidentialisation protocols
- Variation in jurisdictional clearance processes and approvals for data release
- The high cost of producing detailed cancer-specific reporting products in terms of the resourcing and time required.

Relevance, Accessibility

- Common data requests for data available in the public domain, extrapolation of published material, or unpublished material suggests current products are not accessible or not meeting all the data needs of users
- Responding to new and emerging needs in relation to national cancer data.

Timeliness, Coherence

- Jurisdictional variation in data release policies and timing.

Institutional Environment

The AIHW Act and the Privacy Act outline provisions concerning third party access to data held by the AIHW. Dissemination of data from the ACD must:

- comply with section 29 of the AIHW Act, that prohibits the AIHW releasing any information which can identify an individual to anyone outside the AIHW except for research purposes which have been approved by the AIHW Ethics Committee, or with the express written permission of the data providers

- adhere to the Australian Privacy Principles outlined in the Privacy Act, or have been waived by the AIHW Ethics Committee under strict guidelines.

Within the requirements of the AIHW Act and Privacy Act, dissemination of data from the ACD is governed by the NCSCH Protocol (AIHW & AACR 2013) and the AIHW Policy on reporting to manage confidentiality and reliability (unpublished) (see Guidelines 1–7 from the Policy in Table 3.1). The NCSCH Protocol defines the levels at which data may be made available, and the conditions governing the release of those data, as summarised in Appendix Table E1. These differ by jurisdiction.

Requests for data that involve de-identified unit record files, linked datasets, or contact with individuals, are forwarded to the AIHW Ethics Committee, and relevant state and territory ethics committees for unilateral action or approval.

Clearance processes for the release of data from the ACD include those internal to the AIHW and those from the registries. The AIHW internal clearance processes include:

- Data checking processes, including adherence to the 7 guidelines for managing confidentiality and reliability (see Table 3.1)
- Data custodian (Head, Cancer and Screening Unit) approval
- Head, Health Group approval
- Director (CEO) approval.

Table 3.1: Seven guidelines for managing confidentiality and reliability, AIHW

Guidelines	Details
To manage attribute disclosure	
Guideline 1	If the data AIHW is releasing has already been released publicly at the granularity AIHW intends to release, further confidentialisation is not required.
Guideline 2	Cells in tables where the value of the cell is the same as a row/column/wafer total (that is, all other cells in the row, column or wafer are zero) must be confidentialised unless the attribute that would be disclosed is deemed to be non-sensitive in the context of the data being published. This is because cells where the value of the cell is the same as a row/column/wafer total generally lead to disclosure of an additional attribute.
Guideline 3	Data on organisations must be confidentialised if one organisation contributes more than 85% of the total, or two organisations more than 90%, unless the attribute that would be disclosed is deemed to be non-sensitive in the context of the data being published or the data provider(s) have given consent to release.
Guideline 4	Guidelines 2 and 3 need to be applied so as to ensure that attribute confidentiality is maintained within tables and across tables within the same release. That is, when assessing whether a cell needs to be confidentialised consideration needs to be given to whether there are other cells in that table, or other tables in the release, which may require consequential confidentialisation.
To manage reliability	
Guideline 5	Rates, averages and other statistics based on denominators of less than 100 are usually not reliable and should generally not be reported. There may be exceptions to this guideline where it is deemed that data are, in fact, reliable *and* where users seek such data be published and data custodians agree.
To manage specific requirements of data providers or clients	
Guideline 6	If data suppliers or clients require additional suppression rules be applied to an AIHW release in order to manage confidentiality or reliability, then – following discussion at which the strength of the requirement is ascertained – these should be applied. Where such additional rules are applied they should be described in the release, and it should be noted that this approach is required by the data supplier.
Guideline 7	If a client wishes to be provided with data output (e.g. tables) at a more detailed level than any of the above guidelines would allow, then they may apply to be provided output against which some or all of the above guidelines are not applied. Provision of this more detailed output would be subject to the client signing a confidentiality undertaking and agreeing that any publication of information (including in on line data cubes) based on output released to them will comply with this policy.

Source: AIHW Policy on Reporting to Manage Confidentiality and Reliability 2013 (unpublished).

Relevance, Accessibility

Data may be disseminated from the ACD directly into the public domain from the AIHW or through individuals or other organisations. The AIHW makes all publications available through its website, in the form of published (or print-ready) reports, online data tables or other web-based materials.

Researchers and other individuals may request unpublished data through an ad hoc data requests portal on the AIHW website. Approval for the release of these data falls under the governance and ethics arrangements described in 'Institutional Environment', above. During 2013 there were 229 requests for unpublished ACD data on a wide range of cancer-related topics.

Examples of recent AIHW products using data from the ACD are provided below.

Published (print-ready) reports

- *Cancer in Australia: an overview 2012*, the biennial flagship publication of the ACD (next edition due in December 2014) (AIHW & AACR 2012)
- *Australia's health 2014* (AIHW 2014a)

- *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview* (AIHW & Cancer Australia 2013).

Web-based snapshots

- *Bowel cancer,* <http://www.aihw.gov.au/cancer/bowel/>.

Online data tables

- *Australian Cancer Incidence and Mortality (ACIM) books,* <http://www.aihw.gov.au/acim-books/>.

4 Discussion—securing the Australian Cancer Database, a vision for the future

This chapter focuses on how the points of influence raised in Chapter 3 might be acted on to achieve the goal state. These opportunities are presented as points for further consideration and discussion among ACD stakeholders and contributors. The discussion points are aligned with the five goals outlined in Chapter 2.

4.1 Discussion points for consideration

Institutional Environment

The collection of national cancer incidence data in Australia is currently not mandated, however the collection of cancer incidence data is legislated in each jurisdiction.

The goal state for the Institutional Environment dimension of the ACD is:

> *That the ongoing provision, collation, maintenance and dissemination of national cancer incidence and mortality data through the ACD is secured and appropriate arrangements are in place to support this.*

This goal may be achieved by acting on opportunities in relation to variation in jurisdictional legislation governing data collection and supply, and potentially the development of a formal agreement between states, territories and the Commonwealth for the supply of data to a national data set. The AIHW propose that the following discussion points be considered, as next steps to achieving the goal state.

- In relation to variation in jurisdictional legislation governing the target population, mandated cancers, mandated notifiers and mandated reporting of cancer-related deaths—consider exploring opportunities to make:
  - the same neoplasms notifiable in each state and territory
  - all in situ neoplasms notifiable in each state and territory
  - benign and uncertain-behaviour neoplasms of the central nervous system notifiable in each state and territory
  - all cancer registries able to contact the same types of organisations and health professionals (such as GPs, nursing homes) to follow up on incomplete data.
- In relation to variation in jurisdictional legislation governing the ability of cancer registries to share information (cross-border) and access electoral roll information, consider exploring opportunities to enable:
  - all registries to have access to at least their own jurisdiction's electoral roll, but preferably the national electoral roll. This would help to resolve which registry 'owns' each case, which would ensure registries only register cases belonging to their state or territory.
  - each registry of births, deaths and marriages to notify all potential cancer deaths, not only to their own jurisdiction's cancer registry but also to the cancer registry for the

  deceased's address of usual residence. Alternatively, that all cancer registries are allowed to share death certificates with each other, irrespective of the state or territory in which the death was registered. This would help registries to obtain adequate cause-of-death information for people who die interstate.

- In relation to variation in jurisdictional data arrangements between cancer registries and Registrars of Births, Deaths and Marriages (RBDM) for the provision of mortality data, consider exploring opportunities for:
  - each jurisdiction's registry of births, deaths and marriages to notify all potential cancer deaths to the cancer registry. This would ensure the ongoing supply of this information to cancer registries.
  - the AIHW to provide cancer registries with the cause-of-death information obtained via National Death Index linkages when that death was a coroner's case. This would enable cancer registries to assign cause-of-death for interstate deaths referred to a coroner (which is not always possible currently, and leads to incomplete data).
- In relation to issues of jurisdictional registry resourcing (funding, training and retention of coding staff), consider:
  - any efficiencies that may be achieved through improved systems, standardising some processes and sharing learnings across registries where appropriate.
- In relation to the absence of a formal agreement mandating the supply of jurisdictional cancer data to a national dataset (ACD), consider the benefits and risks of a more formal agreement between the states and territories and the Commonwealth for the supply of cancer incidence data to form a national collection, noting that the benefits of a mandated data supply would need to be weighed carefully against the current 'goodwill' arrangement that has successfully supplied national data to date. A more formal arrangement may include:
  - endorsement of the ACD collection as a National Minimum Data Set (NMDS) to support the national collection of cancer incidence data within agreed timeframes
  - broadening the adoption of the ACDs Data Set Specifications and developing an agreed schedule for the provision of data to the ACD.
- In relation to the absence of formal recognition and authority of the NCSCH Protocol underpinning the provision of cancer data to the AIHW, consider formal recognition of the AACR as part of a national cancer data strategy. Sponsorship of the AACR by AIHW (under section 5 of the AIHW Act) could:
  - formalise the current arrangements
  - provide the AACR with a clearer pathway to have issues considered by national committees such as the National Health Information Standards and Statistical Committee (NHISSC) and the National Health Information and Performance Principal Committee (NHIPPC).
- In relation to the absence of secured funding for the collation and maintenance of the ACD, consider developing a sustainability plan for the continued maintenance of a national collection, and the supply of data by jurisdictions to this collection. This may help to:
  - secure the future of the ACD
  - help address issues within jurisdictions of competing priorities and resourcing.

Relevance, Accessibility

The Australian Cancer Database is the only source of national cancer data in Australia. Although it is impossible to ensure that every case of cancer is registered, coverage is considered sufficiently complete for producing accurate statistics.

Data outputs from the ACD are available free of charge on the AIHW website in a broad range of formats, and other data are available through the ad hoc data request portal. The accessibility of data from the ACD is considered high.

The goal state for the Relevance and Accessibility dimensions of the ACD is:

> *That the data included in the ACD, and the means of disseminating those data, be appropriate to address the policy, planning and research questions of stakeholders and consumers of Australian cancer incidence and mortality data.*

This may be achieved by addressing opportunities in relation to unmet stakeholder and consumer need for detailed data, and accessibility issues. The AIHW proposes that the following discussion points be considered, as next steps to achieving the goal state.

- In relation to ensuring that current and emerging needs in relation to national cancer data continue to be met, consider:
    - ensuring all states are able to supply the required geographies for all records
    - that if a person dies of a non-notifiable primary cancer, that is, a basal cell or squamous cell carcinoma of the skin, the registry registers that cancer and hence records the death
    - the implications for the ACD as cancers are increasingly re-classified from a genomic perspective, which could become as clinically relevant as histology is currently
    - routinely linking cancer incidence and mortality data with other major datasets—such as hospital admission data, MBS data and PBS data—which would be a major step forward for more comprehensive national cancer data in Australia
    - the value of building and maintaining other cancer datasets, such as a dataset that includes the costs of cancer service provision, as estimates become available in jurisdictional data settings as part of health reform reporting.
- In relation to common requests for data to be made available in the public domain, or for extrapolation of published material, or for special requests for unpublished material (suggesting current products are not accessible or not meeting all the data needs of users), consider:
    - assessing the usefulness of the recent change of focus in *Cancer in Australia: an overview* to year-to-date estimates to provide a more current picture of cancer incidence, with a view to continuing this practice in future releases, and in other products, such as the ACIM books
    - separating the release of annual cancer incidence data from the biennial production of *Cancer in Australia: an overview* to allow updated data to be published more frequently
    - releasing individual chapters of *Cancer in Australia: an overview* as data become available (which occurs at various times during the year for different data) to form an updatable compendium to provide more timely access to cancer-related data

  - producing shorter, more frequent reports to produce more timely cancer data and to focus on specific issues
  - seeking further opportunities to collaborate with organisations that also have an interest in cancer data such as Cancer Australia and the Australian Bureau of Statistics
  - providing additional data that can be interrogated by users with options for aggregation by cancer type, sex and age
  - providing downloadable PowerPoint slides of tables and figures for user presentations.
- Continue to support current work being led by Cancer Australia towards consistent collection of staging data in all jurisdictions to provide national staging data, and look for opportunities to contribute to this process with the aim of including these data in the ACD.
- Continue to support current work being undertaken to introduce consistent structured pathology reporting in Australia, such as considering:
  - the implications for pathology laboratories, cancer registries and the ACD as changes occur
  - including any key performance indicator data obtained through structured pathology reporting of cancer to benchmark and monitor quality of service.
- Consider the most appropriate data to include in the ACD and whether it could be used more extensively by clinicians, hospital administrators and health administrators.
- Consider opportunities for the ACD as direct data feeds become more commonplace (such as for pathology, imaging, and radiotherapy information systems), and as Electronic Medical Records (EMR) become a reality. This could be relevant for clinical and mortality outcome reporting, for example, around rare cancers.

Timeliness

Australian cancer incidence and mortality data in the ACD are available at the national level within 3 years of diagnosis or death, respectively, with jurisdictional data ranging between 1 year and 4 years after diagnosis or death.

The goal state for the Timeliness dimension of the ACD is:

> *That the ACD contain incidence and mortality data 12 months from year of diagnosis or death, for reporting at a national level within 18 months from year of diagnosis or death.*

This may be achieved by addressing opportunities in relation to receipt of jurisdictional data, and approvals to release jurisdictional data. The AIHW propose that the following discussion points be considered, as next steps to achieving the goal state.

- In relation to there being no set date for data supply to the ACD and the variation in timing between years and jurisdictions, consider:
  - the goal of cancer registries in every state and territory being able to provide their data to the AIHW as fast as Victoria currently can. Victoria published its 2012 incidence report in October 2013.
  - exploring the idea of providing access to jurisdictional-level and pooled jurisdictional data as soon as they are made available to the AIHW, rather than not

releasing any data until all 8 jurisdictions have submitted their data. Given that incidence rates do not vary greatly between jurisdictions (with some notable exceptions), some users may prefer to use the most up-to-date sub-national incidence rates rather than older national rates.

  - exploring the benefits and risks of alternative models of delivering jurisdictional cancer data to the AIHW, such as providing preliminary data which would be revised as more complete data become available, or 'fast-tracking' priority cancers, as is done in New Zealand. These approaches would need to be assessed against the impact on jurisdictions, additional costs of multiple releases by AIHW, possible detrimental effects on other coding practices if undertaken using existing resources and bias in ongoing reporting. One recent example of fast-tracking Australian cancer incidence data was in the context of National Cervical Screening Program (NCSP) Safety Monitoring. Incidence data from some states were fast-tracked to provide more current data on the incidence of cervical cancers. These data were an important part of the monitoring activities undertaken to ensure the safety of Australian women after a change to the NCSP was implemented. For further information see the *Report on monitoring activities of the National Cervical Screening Program Safety Monitoring Committee* (AIHW 2013).
  - improving consistency of data between pathology laboratories and cancer registries to aid the efficient transfer of these data.

- In relation to the jurisdictional variation in data release policies and timing, consider ways to address the current variation in data release policies and timing across all jurisdictions. This could streamline data release processes and decrease delays in providing data to third parties. Examples include:
  - agreeing a schedule of approvals between the AIHW and the AACR for the release of data in reports such as Cancer in Australia: an overview
  - seeking pre-approval or standing approvals for release of data commonly requested, such as high-level standard state and territory data tables.

Accuracy, Coherence

The accuracy of the ACD is rated at the highest level internationally due to legislation in each jurisdiction for the mandatory notification of cancer incidence (and in some cases, mortality) and to quality assurance and adherence to international standards for classification and coding.

Despite differences in the legislation, funding and operational activities among the 8 Australian jurisdictions, in practice the level of consistency of cancer incidence and mortality data, and by extension the comparability and coherence of the ACD, is very high, largely as a result of the collaborative work of the AACR. The coherence of the ACD is considered comparable over time and between jurisdictions.

The goal state for the (combined) Accuracy and Coherence dimensions of the ACD is:

> *That the ACD data accurately represent cancer incidence and mortality in Australia and that data are consistent and comparable between jurisdictions, internationally and over time.*

This may be achieved by addressing opportunities in relation to inconsistencies in case verification practices between jurisdictions, lack of defined items or data quality for supply to AIHW and variation between jurisdictional and national reporting for the same period.

The AIHW proposes that the following discussion points be considered, as next steps to achieving the goal state.

- In relation to jurisdictional variations in coding of cancer-related deaths and treatment of death-certificate-only cases, consider:
  - validating registry-supplied mortality data in the ACD against those in the National Mortality Database, and evaluating the use of registry-supplied mortality data in future cancer reporting by the AIHW
  - exploring the potential expansion of the definition of cancer deaths to include other causes, such as where cancer or cancer-related treatments and therapies are an associated cause-of-death
  - developing a complete and standardised set of cause-of-death fields (for example: cause-of-death as coded by cancer registries; cause-of-death as coded by the ABS; state or territory in which the death was registered; year in which the death was registered; and, if a cancer death, the topography code, histology code and behaviour code)
  - assessing the variation in cancer mortality data as coded by the jurisdictional cancer registries, and exploring the benefits and risks of its use in national cancer statistics
  - harmonisation among jurisdictional cancer registries of follow-up time and processes for death-certificate-only cases, as this ultimately determines when the dataset is considered complete, which can lead to delays in supply to AIHW.
- In relation to there being no mandated set of data items for supply to the ACD, consider investigating avenues and implications for developing nationally consistent arrangements for data collection and supply at the jurisdictional level. This could help resolve some potential issues with quality, consistency and incomplete information, as well as under-utilised data sources. For example:
  - consistent access to deaths information through the Registrars of Births Deaths and Marriages would likely improve timeliness
  - confirm that all cancer registries use standardised mortality coding guidelines to ensure data consistency and quality
  - data supply from other sources that are currently excluded by jurisdictional legislation (for example radiation oncology) may enhance data collection.
- In relation to the lack of defined criteria for the quality of cancer data supplied to the NCSCH for inclusion in the ACD, consider:
  - developing criteria for data quality in order for jurisdictional data to be included in the ACD. For example, case ascertainment must be above a set amount. Criteria would set a minimum standard of data that are essential for national reporting, and could potentially be implemented using the AIHW Validata™ system
  - adopting/adapting a set of criteria such as those used by the United States Cancer Statistics available as an example at <http://www.cdc.gov/cancer/npcr/uscs/technical_notes/criteria.htm>.
- To more readily enable various analyses by person (for example, multiple primary cancers diagnosed for the same person), consider assigning a national person identification number for people on the ACD. Preserving this identification number from

one version of the ACD to the next may require participation from the registries in resupplying this ID in subsequent data supplies.

Interpretability

The interpretability of the ACD is considered high—data quality, methodology and supporting technical notes are made available with each published report, and on the AIHW website.

The goal state for the Interpretability dimension of the ACD is:

> *That the information needed to aid the interpretation of cancer incidence and mortality data is current, complete and regularly reviewed.*

This may be achieved by addressing the discussion points that follow.

- Examine the information in this paper on key stakeholders, legislation and governance to identify elements relating to the Institutional Environment that should be updated annually, or more often if required. This could, for example, be done as part of the annual cancer data supply request from the AIHW to the registries, or as part of the annual AACR meeting cycle.
- Build on existing work to develop and disseminate data interpretation and technical notes for policy makers and data users to understand the strengths and limitations of the ACD.

4.2 Conclusion: working toward the goal state

The ACD currently provides high quality national data, and continues to be an essential national asset for the effective monitoring of cancer incidence, prevalence, survival and mortality in Australia. The data provided through the ACD are vital to governments, clinicians, health services and policymakers in delivering quality, evidence-based cancer care and broader cancer control initiatives.

Collaborative arrangements between the Commonwealth and all states and territories deliver national cancer data. Key stakeholders are committed to continuing to improve the governance, collection and dissemination of national cancer incidence data.

The AIHW is well-placed to both contribute to, and broker the involvement of other key stakeholders in improving the quality and timeliness of cancer data. The AIHW may also be in a position to lead some of this work using its expertise and experience in championing issues on behalf of the states and territories.

Some of this activity may be implemented under the framework of the National Centre for Monitoring Cancer, and some work that may contribute to the goal state is already in progress. This work, developed in collaboration with the CMAG and AACR as part of the NCMC work program, and in parallel with this project, includes:

- presenting incidence and mortality projections for 2014, 2015 and 2016 in the forthcoming *Cancer in Australia: an overview 2014*. This work extends the well-received use of year-to-date estimates in *Cancer in Australia: an overview 2012*, in recognition of the need for more timely cancer data (Timeliness: first discussion point).

- developing a high-level summary of key information related to the collection, collation, analysis, reporting and interpretation of cancer data in Australia (Interpretability: second discussion point).

Appendix A: Australian Cancer Database 2010 Data Quality Statement

Important note

To avoid excessive repetition in this data quality statement, the word 'cancer' is used to mean 'cancer, excluding basal cell carcinomas of the skin and squamous cell carcinomas of the skin'. In most states and territories these two skin cancers are not notifiable diseases, and in any case are not collected, and as such are not in the scope of the Australian Cancer Database (ACD).

The data quality statement is also available online, <http://meteor.aihw.gov.au/content/index.phtml/itemId/565218>.

Summary of key points

All states and territories have legislation that makes cancer a notifiable disease. Various institutions such as hospitals, pathology laboratories and registries of births, deaths and marriages must report cancer cases and deaths to their jurisdictional cancer registry.

Each registry supplies incidence data annually to the AIHW under an agreement between the registries and the AIHW. These data are compiled into the ACD, the only repository of national cancer incidence data.

2010 incidence data for NSW and ACT were not available for inclusion in the 2010 version of the ACD. Therefore 2010 incidence data for NSW and ACT were estimated by the AIHW. Although the estimation procedure has been shown to be reasonably accurate for estimating overall cancer incidence, its accuracy with respect to individual cancers will vary. As NSW and ACT make up about a third of Australia's population, the national incidence data for 2010 is likely to be somewhat inaccurate for some individual cancers; which cancers these are is not predictable. Until the actual 2010 cancer data are available from these jurisdictions caution should be exercised when comparing the 2010 NSW, ACT and Australian data with data from previous years.

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 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 data sets based on data from each jurisdiction, to analyse these data sets and disseminate information and statistics. The *Australian Institute of Health and Welfare Act 1987*, in conjunction with compliance to the *Privacy Act 1988* (Commonwealth), 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 <http://www.aihw.gov.au/home/>. All states and territories have legislation that makes cancer a notifiable disease. Various institutions such as hospitals, pathology laboratories and registries of births, deaths and marriages must report cancer cases and deaths to their jurisdictional cancer registry. Each registry supplies incidence data annually to the AIHW under an agreement between the registries and the AIHW. These data are checked, standardised and compiled into the ACD, the only repository of national cancer incidence data. The jurisdictions retain ownership of the data and must approve any jurisdiction-level output before it is released. Jurisdictional approval is also required for national-level output if it is sufficiently fine-grained. The agreement and processes for operating the ACD are detailed in the National Cancer Statistics Clearing House Protocol which can be accessed from <http://www.aihw.gov.au/national-cancer-statistics-clearing-house/>. The AIHW has been maintaining the ACD since 1986.
Timeliness	This data quality statement refers to the 2010 version of the ACD, which contains data on all cancer cases diagnosed between 1982 and 2010. However, the number of cases in 2010 for NSW and the ACT was estimated (see 'Accuracy' section below). Each jurisdictional cancer registry supplies data annually to the AIHW. Because each jurisdiction operates on its own data compilation and reporting cycle, the ACD cannot be fully compiled until the final jurisdiction supplies its data. It generally takes a year or more for the state and territory cancer registries to fully process and release their latest full-year of cancer data to the AIHW. Once the AIHW receives all the data sets from cancer registries, time is needed to check for data consistency and to de-duplicate the data before the new version of the ACD is available for reporting purposes.
Accessibility	The AIHW website provides cancer incidence and mortality data that can be downloaded without charge. The main online product is the set of Australian Cancer Incidence and Mortality (ACIM) books, available at <http://www.aihw.gov.au/acim-books/>. Numerous published reports, including the biennial *Cancer in Australia: an overview*, are available on the AIHW website where they can also be downloaded without charge. Users can request data not available online or in reports by lodging a customised data request at <https://datarequest.aihw.gov.au/_layouts/AdHocDataRequest/LodgeRequest.aspx/>. and can ask questions via the Cancer and Screening Unit of the AIHW on (02) 6244 1000 or via email to cancer@aihw.gov.au. Data requests are charged for on a cost-recovery basis. General enquiries about

	AIHW publications can be made to the Digital and Media Communications Unit on (02) 6244 1032 or via email to info@aihw.gov.au. Researchers following a cohort of people enrolled in a longitudinal study of health outcomes can request the AIHW to undertake data linkage of their cohort to the ACD. Such requests must be approved by the AIHW Ethics Committee as well as the ethics committees governing access to the state and territory cancer registries.
Interpretability	Information on the content and scope of the ACD is available on the AIHW website at <http://www.aihw.gov.au/australian-cancer-database/>. While numbers of new cancers are easy to interpret, other statistics, e.g. age-standardised rates, are more complex and their concepts may be confusing to some users. In most cancer publications there is an appendix on statistical methods as well as technical notes.
Relevance	The ACD is highly relevant for monitoring trends in cancer incidence. The data are used for many purposes, such as by policy makers to evaluate health intervention programs and as background data for health labour force planning and health expenditure; by pharmaceutical companies to assess the size of the market for new drugs; by researchers to explore the epidemiology of cancer; by insurance companies to evaluate the risk of people being diagnosed with cancer. The ACD contains information on all reported cancer cases and deaths in Australia for the period 1982–2010. Data can be provided at state and territory level though this requires approval from the state and territory cancer registries. The 3rd edition of the International Classification of Diseases for Oncology (ICD-O-3) is used to classify cancer cases. Data can also be classified according to the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). The ACD contains the name and date of birth of each person diagnosed with cancer. This allows researchers who have enrolled people in a study to link their cohort to the ACD to determine which of their study subjects have been diagnosed with cancer, what kind of cancer, and when. (Such data linkage can only be undertaken after receiving approvals from various ethics committees.) This kind of research gives insight into cancer risk factors. Data linkage is also undertaken when a researcher has been contracted to investigate a potential cancer cluster in a workplace or small area.
Accuracy	The book *Cancer incidence in five continents* is updated about every 5 years in a collaborative effort between the International Agency for Research on Cancer (IARC) and the worldwide network of cancer registries. The data from each of Australia's cancer registries are classified by IARC as 'A', which is the highest data quality grade in their scale. Details of IARC's tests and Australia's cancer registries' results in them can be found in the above-mentioned book and the registries' annual incidence reports. Each year, when all the registries' new data have been compiled into the new ACD, a data linkage process called the national deduplication is undertaken. This process detects instances where the same person and cancer have been registered in two or more jurisdictions. This could happen, for example, when a person attends hospitals in different jurisdictions. All such instances that are found are provisionally resolved at the AIHW by removing one record while the relevant jurisdictions are notified of the situation so that they can determine in which jurisdiction the person was a usual resident at the time of diagnosis. Their resolution will flow through to the ACD in the following year's data supply. In

	recent years the national deduplication has resulted in the removal of about 3,500 records from the ACD, which is about 0.17% of all records supplied by the jurisdictions. While all state and territory cancer registries collect information on Indigenous status, in four jurisdictions the level of identification of Indigenous Australians is considered to be insufficient to enable meaningful analysis. Data for four jurisdictions are considered suitable for analysis: New South Wales, Queensland, Western Australia and the Northern Territory. 2010 incidence data for NSW and ACT were not available for inclusion in the 2010 version of the ACD. The development of the new NSW Cancer Registries system has resulted in a delay in processing incidence data for 2010 onwards. Details of the expected time-line for processing of 2010 cancer incidence data for NSW and ACT are available at: <http://www.cancerinstitute.org.au/data-and-statistics/accessing-our-data/availability-of-nsw-central-cancer-registry-data#incidence-when-2009>. Therefore 2010 incidence data for NSW and ACT were estimated by the AIHW. Although the estimation procedure has been shown to be reasonably accurate for estimating overall cancer incidence, its accuracy with respect to individual cancers will vary. As NSW and ACT make up about a third of Australia's population, the national incidence data for 2010 is likely to be somewhat inaccurate for some individual cancers; which cancers these are is not predictable. Until the actual 2010 cancer data are available from these jurisdictions caution should be exercised when comparing the 2010 NSW, ACT and Australian data with data from previous years. 2009 incidence data for NSW and ACT include estimates of so-called 'provisional death certificate only' (provisional DCO) cases. An extended delay in the provision of 2009 mortality data from the Council of Australian Registrars has meant that NSW and ACT have not been able to register cases of cancer that are recorded on a death certificate but which have not been notified to the cancer registry by any other means up to that point in time. Armed with the details on the death certificate the registry can make inquiries to hospitals and other notifiers to try to locate any missing cancer notifications for the deceased person. If any other notifications are found then the case is reclassified from a provisional DCO case to a non-DCO case. If none are found the case is reclassified as a DCO case. The number of provisional DCO cases in 2009 for each cancer, sex and age group has been estimated by the AIHW based on the numbers observed for 2004–2008. Overall about 1.7% of NSW cases and 1.9% of ACT cases in 2009 are estimated provisional DCO cases.
Coherence	Cancer diagnosis data are classified according to the International Classification of Diseases for Oncology (ICD-O). Sometimes updated codes are issued to align with new understandings of cancer types, and about every ten years an entirely new edition of ICD-O is issued. Updates and new editions can cause trend breaks in time series for particular cancers, but only at quite a fine level of detail. These trend-break issues are known to the registries and AIHW and relevant advice is provided to any client who requests data at a fine-enough level of detail for this to be a potential issue. The data supplied annually by each cancer registry to the AIHW come from a snapshot of their database at a specific point in time. Cancer registry databases change every day, and not just because new records are added. Existing records are changed if new, more precise information about the diagnosis or person

	becomes available. Also, any typographical errors that are discovered by routine data checking procedures are corrected. Finally, existing records can be deleted if it is discovered that the initial diagnosis of cancer was incorrect (for example, the tumour was in fact benign) or the person is found to be not a resident of that state or territory. As a result of all these factors, for years prior to 2010 the number of cancer cases reported by AIHW based on the 2010 ACD may differ from the corresponding number reported based on the 2009 or earlier versions of the ACD. Similarly, the number of cases in a given jurisdiction when based on the 2010 ACD may differ from the corresponding number published by that jurisdiction in its own reports if the numbers are derived from different snapshots of the jurisdictional database.

Appendix B: ACD agreed data items

Table B1: Australian Cancer Database: agreed data set for supply in NCSCH Protocol

Person-level attributes	Tumour-level attributes
Items agreed for supply under the NCSCH Protocol	
State/territory person ID number	State/territory tumour ID number
Surname	Date of diagnosis
First given name	Date of diagnosis accuracy indicator
Second given name	Age at diagnosis(b)
Third given name	ICD-O-3 topography code
Sex	ICD-O-3 histology code
Date of birth	ICD-O-3 behaviour code
Date of birth accuracy indicator	ICD-10 disease code
Indigenous status	Most valid basis of diagnosis
Country of birth	SLA at diagnosis
Date of death	Postcode at diagnosis
Age at death(a)	Breslow thickness (cutaneous melanomas) (in mm)
Cause-of-death(c)	
Items supplied in addition to the agreed set	
COD ICD-O-3 topography code	State/territory of tumour registration
COD ICD-O-3 histology code	Tumour size (breast cancer only)
COD ICD-O-3 behaviour code	State/territory registry comment
COD ICD-10 disease code	

COD	cause-of-death.
ICD-O-3	International Classification of Diseases for Oncology, 3rd version.
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th revision.

(a) Derived from *Date of birth* and *Date of death* items.

(b) Derived from *Dates of birth* and *Date of diagnosis* items.

(c) Derived from *COD ICD-O-3 topography code*, *COD ICD-O-3 histology code*, *COD ICD-O-3 behaviour code* and *COD ICD-O-3 disease code* items, supplied in addition to the agreed set.

Source: AIHW & AACR 2013.

Appendix C: Data quality summary—Australian states and territories

The information presented in Tables C1–C8 relate broadly to the seven dimensions of data quality referenced throughout the report. Information for the coherence and interpretability dimensions were not available from all jurisdictions at the time of publication and these dimensions have been excluded from the tables below. For information on these dimensions relevant to the ACD, see 'Appendix A: Australian Cancer Database 2010 Data Quality Statement'.

Table C1: Overview of cancer incidence and mortality data quality, as at June 2014, New South Wales

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Parliament Minister for Health and Minister for Medical Research Cancer Institute NSW • Board • Chief Cancer Officer/Chief Executive Officer • Director, Cancer Services and Information Division • Manager, Cancer Information and Analysis • Manager, Data and Information Governance Manager, Registries and Data Collections.
Mandate for data collection	*Public Health Act 2010* (23 May 2014) *Cancer Institute (NSW) Act 2003* (1 July 2013) Public Health Regulation 2012 (1 January 2014 to date) NSW Health Policy Directive PD2009_012 (12 March 2009 (publication date)) The relevant objects of the *Public Health Act 2010* are: • To prescribe cancer as a notifiable disease and scheduled medical condition • To prescribe the circumstances under which notifiable diseases and scheduled medical conditions must be notified to the Director-General To prescribe the forms for notifying cancer to the Director-General.
Responsible body	Cancer Institute NSW manages the Central Cancer Registry (CCR) on behalf of Ministry of Health Chief Cancer Officer is the data custodian. Chief Health Officer provides approval to disclose data in CCR.
Reporting authority	Director-General, Ministry of Health.
Funding arrangements	Funded by NSW Health.
Quality commitment	Cancer Institute NSW Data Governance Policy and Procedure.

(continued)

Table C1 (continued): Overview of cancer incidence and mortality data quality, as at June 2014, New South Wales

Quality dimension	Comment
Relevance	
Coverage	Cancer is a legally notifiable disease in New South Wales. Coverage is almost complete.
Target population	Any person who has cancer and is or was at a hospital, has a test result that is positive for cancer or has died with cancer.
Mandatory notifiers	Pathology laboratories Registry of Births Deaths and Marriages Hospitals, including: • Radiotherapy and medical oncology departments • Admitted patient departments • Multi-purpose services • Forensic medicine • Residential aged-care facilities • Day procedure centres.
Death certificate	Mandated.
Other (not mandated)	
Timeliness	
Currency	Incidence:1972–2009 Mortality: 1972–2008.
Factors affecting timeliness (in relation to the ACD)	Provision of coded causes of death data by ABS Processing of ABS data Availability of experienced coding staff Fast-tracking of certain cancers for research projects removes experienced coders from current incident year coding Poor case notification from hospitals and path labs requiring coders to chase up missed information Not insignificant number of paper-based notifications which are slower to process Other CINSW projects of higher priority Development of new NSW Cancer Registries system (NSWCRs).
Frequency	Annual reporting, ongoing collection Frequency and method of reporting varies by notifier.
Accuracy	
Coding rules for date of diagnosis	As per IARC
Quality assurance	Field and cross-field validation checks Standard IARC checks Measurement of coding accuracy No double-coding.
Contact outside notifiers	Doctors named on pathology forms Interstate cancer registries Electoral roll.
Coding of mortality data	Death notifications provided fortnightly. Coded cause-of-death provided annually by ABS and reviewed and amended by CCR once consolidated with other information held on CCR.

(continued)

Table C1(continued): Overview of cancer incidence and mortality data quality, as at June 2014, New South Wales

Quality dimension	Comment
Accessibility	
Available reporting	*Cancer in New South Wales: incidence report 2009*, published February 2014, presents the most current cancer incidence data. *Cancer in New South Wales: incidence and mortality 2008*, published August 2010, presents the most current cancer mortality data for NSW. These reports are supplemented by online statistics modules.
Further information	<http://www.cancerinstitute.org.au/data-and-statistics/cancer-statistics>.

Table C2: Overview of cancer incidence and mortality data quality, as at June 2014, Victoria

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Parliament Cancer Council Victoria (a statutory authority) • Council • Executive Committee (Board) • Chief Executive Officer • Head, Research Pillar Director, Victorian Cancer Registry.
Mandate for data collection	*Cancer Act 1958* (1 January 2011) Cancer (Reporting) Regulations 2012 (1 July 2013) The objectives of these Regulations are: (a) to prescribe health service establishments required to report cancer to the Anti-Cancer Council of Victoria under the Cancer Act 1958 (b) to prescribe the timing of and the forms for the reporting of cancer to the Anti-Cancer Council of Victoria by persons required to report cancer under the Cancer Act 1958.
Responsible body	Governor in Council (of Cancer Council Victoria).
Reporting authority	Anti-Cancer Council of Victoria.
Funding arrangements	Cancer Council Victoria Victorian Department of Health.
Relevance	
Coverage	Cancer is a legally notifiable disease in Victoria. Coverage is virtually complete.
Target population	Any person who it is known is suffering from or commences to suffer from cancer, identified by a specified reporting group.
Mandatory notifiers	Hospitals Public health services State funded and supported residential care services Day procedure centres Cervical (and other) registers Any place that performs a cancer test.
Death certificate	Not mandated.
Other (not mandated)	

(continued)

Table C2(continued): Overview of cancer incidence and mortality data quality, as at June 2014, Victoria

Quality dimension	Comment
Timeliness	
Currency	Incidence:1982–2012 Mortality: 1982–2012.
Factors affecting timeliness (in relation to the ACD)	Availability of experienced coding staff Fast-tracking of certain cancers removes experienced coders from current incident year coding Poor case notification from hospitals and path labs requiring coders to chase up missed information Not insignificant number of paper-based notifications which are slower to process.
Frequency	Annual reporting, ongoing collection Frequency and method of reporting varies by notifier This is the first time incidence and mortality statistics have been available for a calendar year within 12 months of its completion.
Accuracy	
Coding rules for date of diagnosis	Earliest date of microscopic diagnosis IARC rules for multiple primaries.
Quality assurance	Insufficient resources to double code Exception reports and edit reports generated for checking.
Contact outside notifiers	No contact permitted outside those notifiers described in the Act.
Coding of mortality data	Written annual administrative agreement between Cancer Council Victoria and RBDM is renewed annually Data provided electronically monthly Deliberate lag by Victorian Cancer Registry (VCR) to ensure incident cases are recorded first Cause-of-death coded by VCR. Once consolidated with other information held by VCR it is deemed to be part of the cancer record, and can be passed to the AIHW with appropriate ethics approvals.
Accessibility	
Available reporting	*Cancer in Victoria: statistics and trends 2012*, published in October 2013, presents the most current overview of cancer data in Victoria. This report is a continuation of the series formerly known as Canstat and includes incidence and mortality projections to 2013.
Further information	<http://www.cancervic.org.au/about-our-research/registry-statistics>.

Table C3: Overview of cancer incidence and mortality data quality, as at June 2014, Queensland

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Operational responsibility lies with Cancer Council Queensland: • Chief Executive Officer • Director, Queensland Cancer Registry (QCR) • Registrar Legal ownership and responsibility lies with Queensland Health: • Director General • Medical Director, Cancer Services, Princess Alexandra Hospital • Queensland Cancer Control Analysis Team.
Mandate for data collection	*Public Health Act 2005* (21 May 2014) Public Health Regulation 2005 (31 March 2014) The purposes for establishing the Register, under the Act, are as follows: • to collect data to help in: • monitoring and analysing the outcomes and patterns of cancer; • monitoring cancer mortality; and • increasing public awareness of cancer; • to help in the planning of services and strategies for the prevention and management of cancer.
Responsible body	Queensland Health Director General.
Reporting authority	Queensland Health Director General.
Funding arrangements	Queensland Health Cancer Council Queensland.
Relevance	
Coverage	Cancer is a legally notifiable disease in Queensland. Coverage is virtually complete.
Target population	Any person who is identified as suffering from cancer or receives treatment for cancer by a specified reporting group.
Mandatory notifiers	Pathology laboratories Hospitals Residential aged-care facilities.
Death certificate	Not mandated.
Other (not mandated)	
Timeliness	
Currency	Incidence:1982–2011 Mortality: 1982–2011.
Factors affecting timeliness (in relation to the ACD)	Length of time coding and data entry of RBDM deaths ABS coded cause-of-death data has not been provided to QCR since 2007, which may adversely affect completeness and accuracy Validation Missing notifications National Death Index linkage Approvals through Queensland Health QCR computing facilities are hosted by Queensland Health network.
Frequency	Annual reporting, ongoing collection Frequency and method of reporting varies by notifier.

(continued)

Table C3(continued): Overview of cancer incidence and mortality data quality, as at June 2014, Queensland

Quality dimension	Comment
Accuracy	
Coding rules for date of diagnosis	SEER, for date of incidence.
Quality assurance	Weekly and random audits Annual validation program Comparison of research cohorts to Registry data.
Contact outside notifiers	Other states.
Coding of mortality data	MoU with RBDM to provide electronic weekly data to Queensland Health, who in turn provide relevant data to QCR RBDM Cause-of-death coded by QCR in one batch near the end of the annual cycle. Hospitals deaths coded during normal processing. COD becomes part of cancer unit record.
Accessibility	
Available reporting	*Cancer in Queensland: incidence, mortality, survival and prevalence 1982 to 2011*, published November 2013, presents cancer incidence and mortality to 2011. These reports are supplemented by online analysis tools QSCOL and OASys.
Further information	<http://www.cancerqld.org.au/page/research_statistics/queensland_cancer_registry/>.

Table C4: Overview of cancer incidence and mortality data quality, as at June 2014, Western Australia

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Parliament Minister for Health Department of Health • Director General for Health • Executive Director, Performance Activity & Quality Division • Director, Data Integrity Branch • Assistant Director, Data Collection & Analysis—Statutory and Non-Admitted • Principal Medical Officer/Manager, WA Cancer Registry (WACR).
Mandate for data collection	*Health Act 1911* (6 December 2013) Health (WA Cancer Register) Regulations 2011 (10 June 2011) The register is to be kept for the following purposes • to monitor the number of cases of cancer in Western Australia • to plan, monitor and evaluate services for the control of cancer and the care of cancer patients in Western Australia • to compile and publish general or statistical information relating to cancer • to carry out research into the causes, prevention, screening and treatment of cancer.
Responsible body	Department of Health, Executive Director (Public Health) Delegated to Principal Medical Officer/ Manager, WA Cancer Registry.
Reporting authority	Department of Health, Executive Director (Public Health).
Funding arrangements	WA Department of Health.

(continued)

Table C4(continued): Overview of cancer incidence and mortality data quality, as at June 2014, Western Australia

Quality dimension	Comment
Relevance	
Coverage	Cancer is a legally notifiable disease in Western Australia. Coverage is virtually complete.
Target population	Any person identified by any specified reporting group to have been diagnosed with, treated for or died from cancer.
Mandatory notifiers	Medical specialists including pathologists, haematologists and clinical biochemists Radiation oncologists Ophthalmologists Hospitals.
Death certificate	Not mandated.
Other (not mandated)	
Timeliness	
Currency	Incidence:1982–2012 Mortality: 1968–2012 Note: preliminary data for 2013 are being provided when requested with commentary about likely completeness issues. The Registry aims to have incidence and mortality data in a publishable state by 12 months after the close of a calendar year.
Factors affecting timeliness (in relation to the ACD)	Data preferred to be of acceptable quality for jurisdictional reporting before providing to external users.
Frequency	Annual reporting, ongoing collection. Frequency and method of reporting varies by notifier.
Accuracy	
Coding rules for date of diagnosis	IARC.
Quality assurance	All notifications assessed and recorded Verification by second coder Issues followed up.
Contact outside notifiers	Electoral roll.
Coding of mortality data	Provided regularly through data linkage MoU with WA Data Linkage Unit. Cause-of-death coded by WACR.
Accessibility	
Available reporting	*Cancer incidence and mortality in Western Australia, 2012*, published in April 2014, presents cancer incidence and mortality data to 2012. Reports on issues such as geographic variation in cancer rates, data quality, extent of disease for breast cancer and melanoma, and cancer in Indigenous Australians are published periodically.
Further information	<http://www.health.wa.gov.au/wacr/home/>.

Table C5: Overview of cancer incidence and mortality data quality, as at June 2014, South Australia

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Parliament Minister for Health and Ageing Department for Health and Ageing • Chief Executive • Deputy Chief Executive, Health System Performance • Director, Data and Reporting Services Director, Epidemiology.
Mandate for data collection	*SA Health Care Act 2008* (16 September 2012) Health Care Regulations 2008 (13 February 2014) The object of the Regulations in relation to cancer notification and reporting is not specified.
Responsible body	Director, Epidemiology (under *SA Health Care Act 2008*).
Reporting authority	Minister for Health (within 3 months of notification).
Funding arrangements	SA Department for Health and Ageing.
Relevance	
Coverage	Cancer is a legally notifiable disease in South Australia. Coverage is virtually complete.
Target population	Any person identified by any specified reporting group to have been diagnosed with, treated for or died from cancer.
Mandatory notifiers	Hospitals Health services Radiotherapy centres Pathology laboratories.
Death certificate	Not mandated.
Other (not mandated)	
Timeliness	
Currency	Incidence:1977–2011 Mortality: 1977–2011.
Factors affecting timeliness (in relation to the ACD)	RBDM linkage National Death Index linkage Note: Migration to new database in 2011–12, including coding in ICD-O-3. This will improve registration time by 25%–30% and will also improve coverage.
Frequency	Annual reporting, ongoing collection. Frequency and method of reporting varies by notifier.

(continued)

Table C5(continued): Overview of cancer incidence and mortality data quality, as at June 2014, South Australia

Quality dimension	Comment
Accuracy	
Coding rules for date of diagnosis	IARC for incidence. SEER for multiple primaries.
Quality assurance	Continual edit checks. Quality Assurance Plan.
Contact outside notifiers	Medical practitioners Hospitals Nursing homes.
Coding of mortality data	Provided monthly through ongoing MoU with RBDM on a fee-for-service basis. Cause-of-death coded by SA Cancer Registry.
Accessibility	
Available reporting	*Cancer in South Australia 2009—with projections to 2012*, published in May 2013, includes cancer incidence and mortality data to 2009, with projected data to 2012.
Further information	<http://www.health.sa.gov.au/pehs/branches/branch-cancer-registry.htm>.

Table C6: Overview of cancer incidence and mortality data quality, as at June 2014, Tasmania

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Minister of Health Director of Public Health, Department of Health and Human Services (DHHS) (or delegate) Director Tasmanian Cancer Registry (TCR), Menzies Research Institute Tasmania (under service agreement between MRIT and DHHS).
Mandate for data collection	Tasmania Public Health Act 1997 (1 October 2011) There are no specific regulations or objects.
Responsible body	Director of Public Health
Reporting authority	Director of Public Health.
Funding arrangements	Department of Health and Human Services, Tasmania, with significant in-kind contributions from Menzies Research Institute Tasmania (MRIT).
Relevance	
Coverage	The Tasmanian Cancer Registry was established in 1977, and cancer notification was mandated by legislation in Tasmania in 1992. Coverage is virtually complete from 1980. A non-melanoma skin cancer (NMSC) registry was established in Tasmania in 2001. The registry is complete for notifications of NMSC from 1978 to 2005. The registry is updated when funding is made available.
Target population	Any person identified by a reporting group as suffering from cancer.
Mandatory notifiers	Hospitals Health services Radiotherapy centres Pathology laboratories.
Death certificate	Not mandated.
Other (not mandated)	

(continued)

Table C6(continued): Overview of cancer incidence and mortality data quality, as at June 2014, Tasmania

Quality dimension	Comment
Timeliness	
Currency	Incidence:1980–2011 Mortality: 1980–2011.
Factors affecting timeliness (in relation to the ACD)	Funding and capacity to recruit skilled staff Availability of skilled coders Note: TCR evaluating opportunities to move to full electronic notification of cancer cases.
Frequency	Annual reporting, ongoing collection Frequency and method of reporting varies by notifier.
Accuracy	
Coding rules for date of diagnosis	Date of incidence is earliest date of diagnosis Generally SEER for multiple primaries, but may follow other guidelines for specific sites.
Quality assurance	Mortality to Incidence ratio Histological and morphological verification analyses UPS analysis DCO investigations Automated reporting with alert systems Sampling Regular procedural reviews Notifier follow up.
Contact outside notifiers	Electoral roll Through agreement with DHHS, access to Digital Medical Record of admitted patients of Royal Hobart Hospital. GPs and other medical professionals.
Coding of mortality data	Electronic file provided monthly through an MoU between TCR and RBDM, for supply and permitted uses of the data specific to the operation of the TCR. Processed annually, apart from fast-tracked cancers. Currently under review: evaluating monthly processing of death notifications. COD recorded by TCR as specified by RBDM.
Accessibility	
Available reporting	*Cancer in Tasmania: Incidence and Mortality 2010*, and *Cancer in Tasmania 2010—a snapshot*, published in October 2013, present cancer incidence and mortality data for 2010.
Further information	<http://www.menzies.utas.edu.au/article.php?Doo=ContentView&id=920>.

Table C7: Overview of cancer incidence and mortality data quality, as at June 2014, Australian Capital Territory

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Parliament Minister for Health ACT Health Directorate • Director General • Chief Health Officer/Deputy Director General and Executive Director, Population Health Division • Director, Health Improvement Branch • Senior Manager, Epidemiology Section, which includes the role of Director, ACT Cancer Registry.
Mandate for data collection	ACT Public Health Act 1997 (25 November 2013) Public Health Regulation 2000 (25 November 2013) The object of the regulations with respect cancer notification and report is not specified.
Responsible body	Chief Health Officer/Deputy Director General.
Reporting authority	Chief Health Officer/ Deputy Director General.
Funding arrangements	ACT Health Directorate as part of funding for the Epidemiology Section. Coding functions are performed under contract by the NSW Central Cancer Registry (NSW CCR). The NSW CCR undertakes data management and coding on behalf of the ACT Cancer Registry, reflecting both the considerable resources required to collect, code and process cancer registry data, and cross-border use of medical services between the ACT and NSW.
Relevance	
Coverage	Cancer incidence and mortality have been collected since 1972, however notification has only been mandatory since 1994, when the ACT Cancer Registry was formalised under the Public Health Act. Coverage is virtually complete from 1982.
Target population	Any person ordinarily resident in the ACT who is diagnosed with, or treated for cancer by any of the specified reporting groups.
Mandatory notifiers	Hospitals Nursing homes Medical practitioners Pathologist.
Death certificate	Not mandated.
Other (not mandated)	Cancer care centres Palliative care (through Calvary Public Hospital).

(continued)

Table C7(continued): Overview of cancer incidence and mortality data quality, as at June 2014, Australian Capital Territory

Quality dimension	Comment
Timeliness	
Currency	Incidence:1982–2009 Mortality: 1982–2008.
Factors affecting timeliness (in relation to the ACD)	Coding of data is performed under contract by NSWCCR. Issues affecting NSW coding will also affect ACT. Namely: • provision of coded cause-of-death data by ABS • processing of ABS data • availability of experienced coding staff • fast-tracking of certain cancers for research projects removes experienced coders from current incident year coding • poor case notification from hospitals and path labs requiring coders to chase up missed information • not insignificant number of paper-based notifications which are slower to process • other Cancer Institute NSW projects of higher priority • development of new NSW Cancer Registries system (NSWCRs).
Frequency	Annual reporting, ongoing collection Frequency and method of reporting varies by notifier.
Accuracy	
Coding rules for date of diagnosis	IARC (as per NSW).
Quality assurance	As per NSW: • field and cross-field validation checks • standard IARC checks • measurement of coding accuracy • no double-coding.
Contact outside notifiers	Doctors named on pathology forms Interstate cancer registries Electoral roll • Electoral roll permitted under Public Health Regulation 2000 (ACT). • Provided to NSWCCR for checking personal details under *Electoral Act 1992* and Electoral Regulations 1993.
Coding of mortality data	The ACT Registrar of Births, Deaths and Marriages provides mortality data for the monitoring of cancer-related deaths Formal agreement with ACT Registrar General's Office for regular provision of deaths data NSWCCR obtains fact of death separately from ACT Registrar General's Office, and ACT cause-of-death data from ABS Cause-of-death as provided by ABS.
Accessibility	
Available reporting	*Cancer in the ACT Incidence and Mortality 2011*, published in November 2011, presents incidence and mortality data to 2008. For some analyses, five years of data (2004–2008) are combined to address issues of small cell sizes.
Further information	<http://health.act.gov.au/health-services/population-health/health-improvement/epidemiology-branch/epidemiology-publications-health-series/cancer-in-the-act-incidence-and-mortality-2011>.

Table C8: Overview of cancer incidence and mortality data quality, as at June 2014, Northern Territory

Quality dimension	Comment
Institutional Environment	
Administrative hierarchy	Parliament Minister of Health Department of Health • Chief Executive • Head, Strategy and Reform Division • Director, Health Gains and Planning Branch, (which includes the role of Director, NT Cancer Registry) • Senior Epidemiologist, Health Gains and Planning Branch (which includes the role of Registrar, NT Cancer Registry).
Mandate for data collection	Cancer (Registration) Act (1 July 2011) Cancer (Registration) Regulations (1 September 2010) The object of the regulations in relation to cancer notification and reporting is not specified.
Responsible body	Chief Health Officer.
Reporting authority	Registrar of NT Cancer Registry.
Funding arrangements	NT Department of Health In 1997, the Northern Territory Cancer Registry contracted the South Australian Cancer Registry (SACR) to perform data coding and processing as well as database maintenance functions. This arrangement concluded in 2013. From 2014, these functions are outsourced to the South Australian Health and Medical Research Institute (SAHMRI).
Relevance	
Coverage	Cancer is a legally notifiable disease in the Northern Territory. Coverage is virtually complete. There is some uncertainty about coverage of pathology notifications. The NT Cancer Registry rely on other registries, linkages to the National Death Index and the national de-duplication to find out about NT residents registered interstate.
Target population	Any person who has tissue collected, or is diagnosed, treated or dies with cancer in the Territory.
Mandatory notifiers	Specimen collectors (including those outside NT) Hospitals Registrar of Births Death and Marriages.
Death certificate	Mandated.
Other (not mandated)	

(continued)

Table C8(continued): Overview of cancer incidence and mortality data quality, as at June 2014, Northern Territory

Quality dimension	Comment
Timeliness	
Currency	Incidence:1991–2011 Mortality: 1991–2011.
Factors affecting timeliness (in relation to the ACD)	Coding of data was performed under contract by SACR from 1997–2013 and by SAHMRI from 2014. Issues affecting SACR or SAHMRI coding timeliness will also affect NT Cancer Registry. While coding was/is performed at SACR/SAHMRI, data entry and other administrative tasks take place in NT. Conversion of database to Registry Plus (as used by SACR).
Frequency	Annual reporting, ongoing collection Frequency and method of reporting varies by notifier.
Accuracy	
Coding rules for date of diagnosis	As per SACR from 1997–2013, and SAHMRI from 2014.
Quality assurance	As per SACR from 1997–2013, and SAHMRI from 2014. NT checks with hospitals and RBDM to make sure they have received all notifications.
Contact outside notifiers	Contact of general practitioners (as per the Act).
Coding of mortality data	Provision of data by RBDM specified in legislation Cause-of-death coded by SACR from 1997–2013, and SAHMRI from 2014.
Accessibility	
Available reporting	*Cancer incidence and mortality, Northern Territory 1991–2005*, published in May 2008, is the most recent publication from the Northern Territory Cancer Registry, and presents cancer incidence data to 2005 and mortality data to 2003.
Further information	<http://digitallibrary.health.nt.gov.au/dspace/bitstream/10137/165/1/Cancer%20Incidence%20%26%20Mortality%20Report2008.pdf>.

Appendix D: Data quality summary—International

Table D1: Overview of cancer incidence and mortality data quality as at June 2014, Canada

Canada (Canadian Cancer Registry)	
Institutional Environment	National data is collected from all provincial and territorial cancer registries through the federally funded National Cancer Incidence Reporting System. The Canadian Cancer Registry is a collaborative effort between the 13 Canadian provincial and territorial cancer registries and the Health Statistics Division of Statistics Canada, where the data are housed. Provincial cancer registries report cancer incidence (clinical and demographic) data to Statistics Canada on an annual basis. These data are added to the Canadian Cancer Registry. Demographic and cause-of-death information are reported to the Canadian Vital Statistics Death Database (CVS:D). The coverage, quality and timeliness of the data are the responsibility of the provinces and territories. All data files are reviewed and approved for official release by each provincial and territorial cancer registry, before publication by the CCR.
Relevance	Cancer notification is mandatory in each Canadian province and territory. As a result, cancer incidence and mortality coverage is essentially complete.
Timeliness	Incidence 1970–2010 (with projections to 2014) Mortality 1970–2009 (with projections to 2014).
Accuracy	Classified as a Group A registry, based on approximately 85% microscopic verification and 2% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	The *Canadian Cancer Statistics* report is an annual publication series that began in 1987, and is a joint report by the Canadian Cancer Society and Statistics Canada. The most recent edition is *Canadian Cancer Statistics 2012*, published in May 2014. The publication presents both actual and estimated incidence and mortality data.
Further information	<http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3207&lang=en&db=imdb&adm=8&dis=2>.

Table D2: Overview of cancer incidence and mortality data quality as at June 2014, New Zealand

New Zealand	
Institutional Environment	The New Zealand Cancer Registry sits within the New Zealand Ministry of Health. All processes that contribute to cancer data collection are funded through the ministry—this includes the data coming into the Registry and the coding of the data. Analytical Services, who are responsible for extracting data, and Statistics and Reporting who provide the Cancer publications, also sit within the Ministry of Health. From 2011, the New Zealand Cancer Registry was expanded to capture TNM staging data, with a plan to implement structured pathology reporting in line with the protocols being developed by the Royal College of Pathologists of Australasia.
Relevance	Cancer notification is mandatory in New Zealand. The New Zealand Cancer Registry was established in 1948 as a hospital-based register, and in 1994 mandatory notification by pathology laboratories was introduced. Coverage is essentially complete from that year.
Timeliness	Incidence: 1948–2010 • 2011 provisional summary data (published August 2013) for selected sites (cervical, colorectal, female breast, leukaemia, melanoma, prostate, lung, Hodgkin lymphoma, non-Hodgkin lymphoma) • 2012 provisional data (published August 2013) for selected sites (cervical, colorectal, female breast, leukaemia, melanoma, prostate, lung, Hodgkin lymphoma, non-Hodgkin lymphoma). Mortality: 1948–2010 The NZ Cancer Registry cites the following reason for the time elapsed between diagnosis or death and publication of incidence and mortality data*: ‘The process of collecting, coding and collating national information on cancer registrations and deaths is complex. Data in the Cancer Registry come from laboratory reports, hospital information and mortality information. Data in the Mortality Collection come from certificates of cause-of-death from doctors or coroners, post-mortem reports from private pathologists and hospitals, and death registration forms. Neither set of information can be finalised until completed from all sources. The timing of publication of these data is affected by manual processing of death data and the need to wait until almost all coroners’ findings for any particular year have been received. In addition, there are several steps required to ensure the final information is of good quality.’*
Accuracy	Classified as a Group A registry, based on approximately 85% microscopic verification and 4% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	The *Cancer—new registrations and deaths* report is an annual publication by the National Collections and Reporting Group. This publication contains detailed information on numbers and rates of cancers according to year of registration, and the most recent available edition is *Cancer—New Registrations and Deaths 2010* (published August 2013). More timely provisional cancer data for selected (priority) cancer sites are made available annually in the *Cancer: selected sites* reporting series. The most recent release is *Cancer: selected sites 2010, 2011, 2012*, presenting provisional incidence data in 2011 and 2012 (published August 2013). Historical summary (trend) data are also published annually, in the *Cancer: historical summary* reporting series. The most recent edition of that report is *Cancer: historical summary 1948–2010* (published August 2013).
Further information	<http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/new-zealand-cancer-registry-nzcr>. The NZ Cancer Registry Review (2010): <http://cancercontrolnz.govt.nz/sites/default/files/Review%20of%20the%20NZ%20Cancer%20Registry.pdf>. Cancer Registry Act 1993: <http://www.legislation.govt.nz/act/public/1993/0102/latest/DLM318888.html?search=ts_act_cancer+registry_resel&p=1&sr=1>.

Table D3: Overview of cancer incidence and mortality data quality as at June 2014, Denmark, Finland, Iceland, Norway and Sweden (Association of the Nordic Cancer Registries)

Association of the Nordic Cancer Registries	
Institutional Environment	The NORDCAN database and program is jointly funded by the member countries of the Association of the Nordic Cancer Registries (ANCR).
Relevance	Notification is compulsory in all of the Nordic countries, and almost complete coverage of incident cases is achieved by all of the Registries.
Timeliness	The Association of the Nordic Cancer Registries (ANCR) is an association of cancer registries from the 5 Nordic countries—Denmark, Finland, Iceland, Norway and Sweden—and the Faroe Islands. The available comparable data for the 5 Nordic countries contained in the NORDCAN database, are: • Incidence: 1960–2011 • Mortality: 1953–2009 Note that preliminary data are available for the Faroe Islands, but that these are not yet included as part of the Nordic countries summary. More recent data than those published through NORDCAN are available for some Nordic countries. See individual country sections (including the Faroe Islands) below for more information.
Accuracy	Available for individual countries, shown below.
Accessibility	Comparable data on 50 major cancers for the Nordic countries are available from NORDCAN.
Further information	<http://www.ancr.nu/data.asp> <http://www-dep.iarc.fr/NORDCAN/English/frame.asp>.
Denmark (Danish Cancer Registry)	
Institutional Environment	The Danish Cancer Registry is government-funded. From 2004 to 2008 the Registry was modernised to an electronic notification system. Records of cancer incidence from Greenland have been included in the Registry since 1953.
Relevance	Cancer notification has been mandatory in Denmark since 1987, with almost complete coverage of all cancers since the establishment of the Danish Cancer Registry in 1943. All residents of Denmark are assigned a personal identification number. This number acts as a linkage key and assists with the accuracy and completeness of the Danish Cancer Registry.
Timeliness	Incidence: 1943–2012 (includes Greenland from 1953) Mortality: 1970–2012.
Accuracy	Classified as a Group A registry, based on approximately 90% microscopic verification and 1% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	*Facts and analysis: the cancer registry*, is an annual report of cancer incidence and mortality. The most recent edition is *Facts and analysis: the cancer registry 2012*, published in December 2013. The report is not available in English.
Further information	<http://www.ssi.dk/Sundhedsdataogit/Registre/Cancerregisteret.aspx> (not available in English).

(continued)

Table D3 (continued): Overview of cancer incidence and mortality data quality as at June 2014, Denmark, Finland, Iceland, Norway and Sweden (Association of the Nordic Cancer Registries)

Faroe Islands (The Faroe Islands Cancer Registry)	
Institutional Environment	Not determined
Relevance	The Faroese Cancer Registry was established on 1 January 1994, and includes complete and retrospective incidence from 1960 and mortality from 1983. The Registry contains the same data elements as the Danish Registry, on which it was based.
Timeliness	Incidence: 1960–2010 Mortality: 1983–2010.
Accuracy	Not available.
Accessibility	Preliminary data are reported in NORDCAN. These data are not yet included as part of the ‘Nordic countries’ summary. A 2009 report on cancer in the Faroe Islands provided incidence, mortality, prevalence and survival data to 2005 (not available in English).
Further information	<http://www.lsh.fo> (not available in English).
Finland (Finnish Cancer Registry)	
Institutional Environment	The Finnish Cancer Registry is funded by The Cancer Society of Finland, with partial funding by The National Institute for Health and Welfare (THL).
Relevance	Cancer notification has been mandatory in Finland since 1961, with almost complete coverage of all cancers since the establishment of the Finnish Cancer Registry in 1952. Since 1967, all residents of Finland have been assigned personal identification numbers. This number acts as a linkage key and assists with the accuracy and completeness of the Finnish Cancer Registry. As an example, Statistics Finland provides information on all deaths where cancer is listed as a cause-of-death, through an annual automatic record linkage with the Finnish Cancer Registry.
Timeliness	Incidence:1953–2012 Mortality: 1953–2012.
Accuracy	Classified as a Group A registry, based on approximately 90% microscopic verification and 2% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	The *Cancer in Finland* report is published biennially, with biannual web-based data updates. The most recent report is *Cancer in Finland 2008/2009*. The most recent web-based data are for 2012 incidence and 2012 mortality, as at 24 April 2014.
Further information	<http://www.cancerregistry.fi/>.
Iceland (Icelandic Cancer Registry)	
Institutional Environment	The Icelandic Cancer Registry is predominantly funded through the Icelandic Cancer Society. The Registry has been partially funded through the Department of Health since 2007, when cancer notification became mandatory.
Relevance	Cancer notification has been mandatory in Iceland since 2007, with almost complete coverage since the register was established in 1955. All residents of Iceland are assigned a personal identification number. This number acts as a linkage key and assists with the accuracy and completeness of the Icelandic Cancer Registry.
Timeliness	Incidence: 1955–2012 Mortality: 1951–2009.
Accuracy	Classified as a Group A registry, based on around 95% microscopic verification and 1% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	Cancer incidence, prevalence and survival data are published annually by the Icelandic Cancer Society, and annual web-based data updates are available through the Icelandic Cancer Registry. The *Cancer in Iceland* report is published every four years.
Further information	<http://www.krabbameinsskra.is/indexen.jsp?id=summary>.

(continued)

Table D3 (continued): Overview of cancer incidence and mortality data quality as at June 2014, Denmark, Finland, Iceland, Norway and Sweden (Association of the Nordic Cancer Registries)

Norway (Cancer Registry of Norway)	
Institutional Environment	The Cancer Registry of Norway is a Government-funded independent research institute. The Cancer Registry of Norway houses clinical cancer registries, a cancer incidence registry, national breast, cervical and bowel screening programs, and cancer-related research interests.
Relevance	Cancer notification has been mandatory in Norway since 1952, with almost complete coverage of cancer incidence from that year.
Timeliness	Incidence: 1953–2012 Mortality: 1953–2012.
Accuracy	Classified as a Group A registry, based on approximately 90% microscopic verification and 1% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	The *Cancer in Norway* report is published annually by the Cancer Registry of Norway. The most recent report is *Cancer in Norway 2012* (published in May 2014).
Further information	<http://www.kreftregisteret.no/en/>.
Sweden (Swedish Cancer Registry)	
Institutional Environment	The Swedish Cancer Registry is funded by the Swedish Government, through the National Board of Health and Welfare.
Relevance	Cancer notification is mandatory in Sweden, with almost complete coverage of cancer incidence since the establishment of the Swedish Cancer Registry in 1958. The Swedish Cancer Registry does not accept death-certificate-only notifications, and this contributes to an estimated 4% under-reporting.
Timeliness	Incidence: 1958–2012 Mortality: 1952–2012.
Accuracy	Classified as a Group A registry, based on around 95% microscopic verification and 1% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	The *Cancer incidence in Sweden* report has been published annually since 1958. The most recent report is *Cancer incidence in Sweden 2012*.
Further information	<http://www.socialstyrelsen.se/register/halsodataregister/cancerregistret/inenglish>.

Table D4: Overview of cancer incidence and mortality data quality as at June 2014, United Kingdom

United Kingdom	
Institutional Environment	Commissioning for the provision of the cancer registration system in the UK is shared between the Department of Health in England, the National Assembly for Wales Department of Health and Social Care, the Scottish Executive Health Department, and the Department of Health, Social Services and Public Health in Northern Ireland.
Relevance	Incidence statistics are compiled from data produced by the regional cancer registries in England, and the three national registries in Wales, Scotland and Northern Ireland. Reporting of cancer data is mandatory for all malignant neoplasms, and all carcinoma-in-situ as well as various other benign and uncertain neoplasms. Mortality statistics are derived from the statutory death registrations in the countries of the UK.
Timeliness	Incidence: 1975–2011 (summary data tables published January 2014) Mortality: 1971–2011 (summary data tables published January 2014). The UK Cancer Registry cites the following reason for the delay in the publication of incidence data: *'Incidence statistics presented on our Cancer Statistics website are compiled from data produced by the regional cancer registries in England, and the three national registries in Wales, Scotland and Northern Ireland which means that before we can publish UK statistics we have to wait until all of the data have been published by each country. The process of registering a cancer is complex and there are a number of processes in place to ensure the data are of a high quality but this means there is usually a delay of around 12 to 18 months before the data are complete enough for them to be published.'* As it is a legal requirement to register deaths quickly, the mortality data for the UK can be compiled more quickly. However, there is still a delay of around 12 months before data are published.
Accuracy	England, Northern Ireland and Scotland classified as Group A registries, based on approximately 80% microscopic verification and between 1% and 3% death certificate only cases for 2003–2007 (Forman 2013). Wales had microscopic verification of less than 80%.
Accessibility	*Cancer stats: incidence 2011 – UK* was published in January 2014.
Further information	<http://info.cancerresearchuk.org/cancerstats/> <http://www.ukacr.org/>.

Table D5: Overview of cancer incidence and mortality data quality as at June 2014, United States of America

United States of America	
Institutional Environment	Funding for cancer data collection varies throughout the US and includes a combination of federal, state and private funding. Most state (central) registries are funded to provide data by either the National Program of Cancer Registries (NPCR) or the National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) Program. Five registries are jointly funded. For more information, see ‘Coverage’. Cancer notification to a central cancer registry is mandated in all states, using nationally recognised reporting protocols. The legislation differs between states, as does the operation of the central cancer registry in that state. There is as yet no national collation of those registry data, with two distinct avenues for collection (the NPCR and the SEER program). The North American Association of Cancer Registries works with all registries (including those in Canada) to define standards and process flows, improve quality and timeliness of data and ensure comparability between registries. Reports on cancer incidence and mortality within the United States of America, by the NAACR, are available through the SEER.
Relevance	Cancer data in the United States of America is collected and reported by two main bodies, the National Program of Cancer Registries (NPCR) (96% population coverage) and the National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) Program (28% population coverage). Together, the NPCR and SEER achieve complete coverage of cancer incidence data in the United States of America. The NPCR is federally administered by the Centers for Disease Control and Prevention (CDC), which has since 1992 had the power to make grants to the States for operation of state (central) cancer registries. The NPCR collects data on: the occurrence of cancer, the type, extent, and location of the cancer, and the type of initial treatment, from central cancer registries in those states and territories (jurisdictions) that are funded through the CDC. The SEER Program, federally administered by the NCI, contracts non-government organisations in some states and territories to collect specific patient, tumour, treatment and outcome data among certain demographics and geographic regions. The SEER Program collects data on: patient demographics, primary tumour site, tumour morphology and stage at diagnosis, first course of treatment, and follow-up for vital statistics, from specific geographic areas. The cancer mortality data collected by the SEER Program are complete.
Timeliness	NPCR incidence and mortality: 1999–2010 SEER incidence: 1975–2011 SEER mortality: 1975–2010.
Accuracy	NPCR and SEER classified as a Group A registries, based on approximately 90% microscopic verification and 2% death certificate only cases for 2003–2007 (Forman 2013).
Accessibility	The NPCR produce an interactive web-based report of graphs, tables and maps from state-wide or metropolitan area cancer registries, updated annually. The most recent update presents data for individual years 1999 to 2010 and combined 2006–2010. The SEER *Cancer statistics review* (CSR), a report of the most recent cancer incidence, mortality, survival, prevalence, and lifetime risk statistics, is published annually by the Data Analysis and Interpretation Branch of the National Cancer Institute. The latest edition published in April 2014 includes incidence statistics from 1975 through to 2011, the most recent year for which data are available.
Further information	<http://www.cdc.gov/cancer/npcr/about.htm> <http://seer.cancer.gov/> <http://www.cancer.org/>.

Appendix E: Jurisdictional approval matrix

Table E1: Jurisdictional approval matrix for AIHW to release jurisdictional incidence and mortality data from the ACD

	State/territory							
	NSW	**Vic**	**Qld**	**WA**	**SA**	**Tas**	**ACT**	**NT**
Geographic levels[(a)]								
National	✓	✓	✓	✓	✓	✓	N	✓
Whole of state	✓	✓	✓	✓	✓	✓	N	✓
SLA or LGA	N	N	N	N	N	N	N	E
CCD or Mesh Block	N	N	N	N	E	N	N	E
Age group levels								
5 year age group	N	✓	S	S	S	S	N	N
Screening target groups	N	✓	S	S	S	S	N	N
Survival data	S	S	S	S	S	S	N	N
Unit record data	N	N	N	N	N	N	N	N
Contacting cases	✗	✗	✗	N	N	✗	✗	✗

✓ Yes, unrestricted.
✗ No, not permitted.
N Negotiation. Must be discussed with individual registry, may or may not require ethical approval.
S State Only. Available at whole state level only.
E Ethics. Jurisdictional and AIHW ethics approval required.

(a) Geographic levels based on Australian Standard Geographic Classification: SLA (statistical local area); LGA (local government area); CCD (census collection district); Mesh Block (smallest geographical unit).

Appendix F: Key stakeholders

It is important to note that the following key stakeholders are only those involved from the collection of data by jurisdictional cancer registries through to the compilation of, and dissemination of data from, the ACD.

No specific mention is made of the role of pathologists or professional organisations in collecting these data, or of the patients from whom these data are collected, because these steps occur earlier in the process—nevertheless, their contribution to the data collection process is acknowledged as essential.

Table F1: Overview of key stakeholder groups for the ACD, as at August 2014

Stakeholder Group	Key position or person	Jurisdiction	Interest
Australian Government Department of Health	Ms Alice Creelman, Assistant Secretary Cancer and Palliative Care Branch Associate Professor Rosemary Knight, Principal Medical Adviser Ms Kate Jorgenson, Director (Bowel Screening Section) Population Health Programs Branch Ms Tracey Bessell, Director (Screening) Cancer and Palliative Care Branch	National	Key consumer of cancer data, including contractual work
Australian Institute of Health and Welfare	AIHW Board Dr Mukesh C Haikerwal, AO (Chair) Mr David Kalisch, Director (CEO) Ms Justine Boland, Head, Statistics and Communication Group Ms Lisa McGlynn, Head, Health Group Mr Justin Harvey, Head, Cancer and Screening Unit Dr Phil Anderson, Head, Data Linkage Unit Mr David Whitelaw, Statistical Advisor Staff, Cancer and Screening Unit	National	ACD compilation, governance, statistical review and dissemination
State and territory health departments	Director General, NSW Health Chief Health Officer, NSW Health Chief Health Officer, Victorian Department of Health Director-General, Queensland Health Executive Director (Public Health), WA Department of Health Director (Epidemiology) SA Department for Health and Ageing Director of Public Health, Tasmanian Department of Health and Human Services Chief Health Officer/Deputy Director General, ACT Health Directorate Chief Health Officer, NT Department of Health	Australian states and territories	Legislated responsibility for mandated notification and collection of cancer data, funding, data custodianship

(continued)

Table F1(continued): Overview of key stakeholder groups for the ACD, as at May 2012

Stakeholder Group	Key position or person	Jurisdiction	Interest
Australasian Association of Cancer Registries	Australian state and territory cancer registries: • New South Wales Central Cancer Registry • Victorian Cancer Registry • Queensland Cancer Registry • Western Australian Cancer Registry • South Australian Cancer Registry • Tasmanian Cancer Registry • Australian Capital Territory Cancer Registry • Northern Territory Cancer Registry New Zealand Cancer Registry	Australia states and territories, New Zealand	Data quality and coherence
Jurisdictional cancer registries: director, data managers, coding staff	New South Wales Central Cancer Registry Victorian Cancer Registry Queensland Cancer Registry Western Australian Cancer Registry South Australian Cancer Registry Tasmanian Cancer Registry Australian Capital Territory Cancer Registry Northern Territory Cancer Registry	Australian states and territories	Data collection, coding, quality assurance, provision and approval
Cancer Monitoring Advisory Group	Professor Jim Bishop (Chair) Ms Lisa McGlynn Professor Ian Olver Professor David Roder Ms Julie Marker Mr Neville Board Associate Professor Claire Vajdic Associate Professor Christopher Stevenson Dr Helen Zorbas Dr Timothy Threlfall Associate Professor David Ellis Dr Debra Graves Ms Alice Creelman Ms Helen Farrugia Dr Cleola Anderiesz Professor David Hill Professor Janet Hiller	National	Expert advisory group to the National Centre for Monitoring Cancer at the Australian Institute of Health and Welfare

(continued)

Table F1(continued): Overview of key stakeholder groups for the ACD, as at May 2012

Stakeholder Group	Key position or person	Jurisdiction	Interest
Cancer Australia	Professor Helen Zorbas, CEO Dr Cleola Anderiesz, General Manager Knowledge Management	National	Key consumer of cancer data, including contractual work
Cancer Institute NSW	The Hon Morris Iemma, Board Chair Professor David Currow, Chief Cancer Officer, CEO	NSW	Manages NSW Central Cancer Registry on behalf of NSW Health
Cancer Council Australia	Mr Stephen Foster, Board President Professor Ian Olver, CEO	National	Advocate for improvements in cancer data availability
Cancer Council Victoria (Anti-Cancer Council Victoria)	Professor Margaret Hamilton, Council President Mr Todd Harper, CEO	Victoria	Majority funder, responsible body for Victorian Cancer Registry
Users of cancer data (ad hoc requests)	Cancer charities/support groups/advocacy groups Doctors and other health care workers Epidemiologists Government agencies Life insurance companies Members of the public Pharmaceutical companies Students	Various: including international	One-time clients; annual return customers; dedicated users of cancer data with multiple requests each year.
International bodies	WHO IARC	International	Comparable Australian cancer incidence and mortality data for global research and analysis.
National Data Standards Committees	National Health Information Standards and Statistics Committee (NHISSC) Dr David Filby, Chair National Health Information and Performance Principal Committee (NHIPPC) Mr David Swan, Chair	National	Data standards, NMDS

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This report presents the 'current state' of the Australian Cancer Database (ACD), and identifies and presents approaches for the continued development and enhancement of the database towards the defined 'goal state'.

To ensure that the ACD continues to supply national, responsive, policy-relevant cancer incidence, prevalence, survival and mortality data, the AIHW, with the support and cooperation of state and territory cancer registries, examined all governance arrangements and end-to-end data processes that affect the quality and currency of the ACD. The goal state for the collection is defined, specific points of influence identified, and potential next steps towards achieving the goal state are presented as points for consideration and discussion among ACD stakeholders and contributors.