

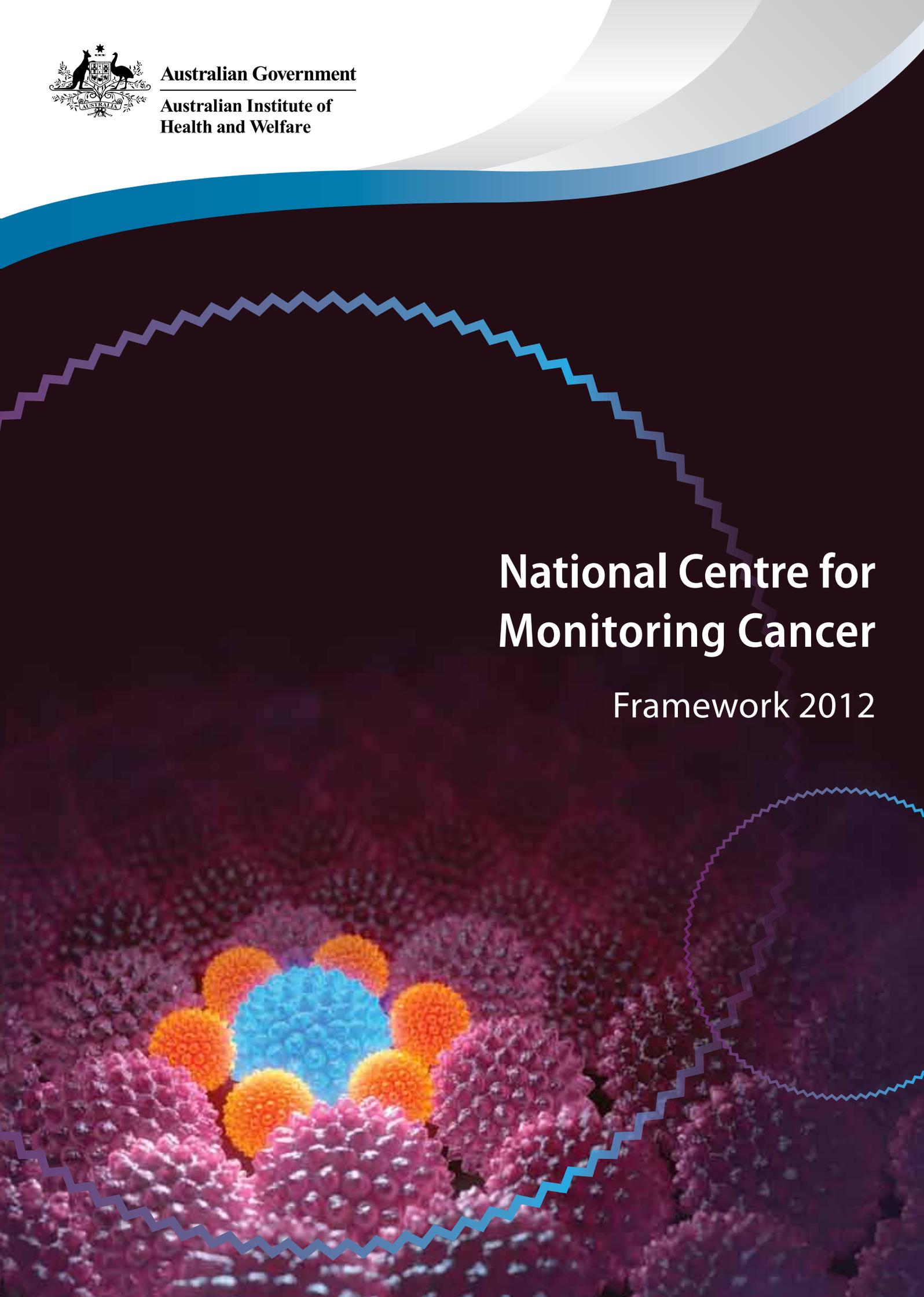


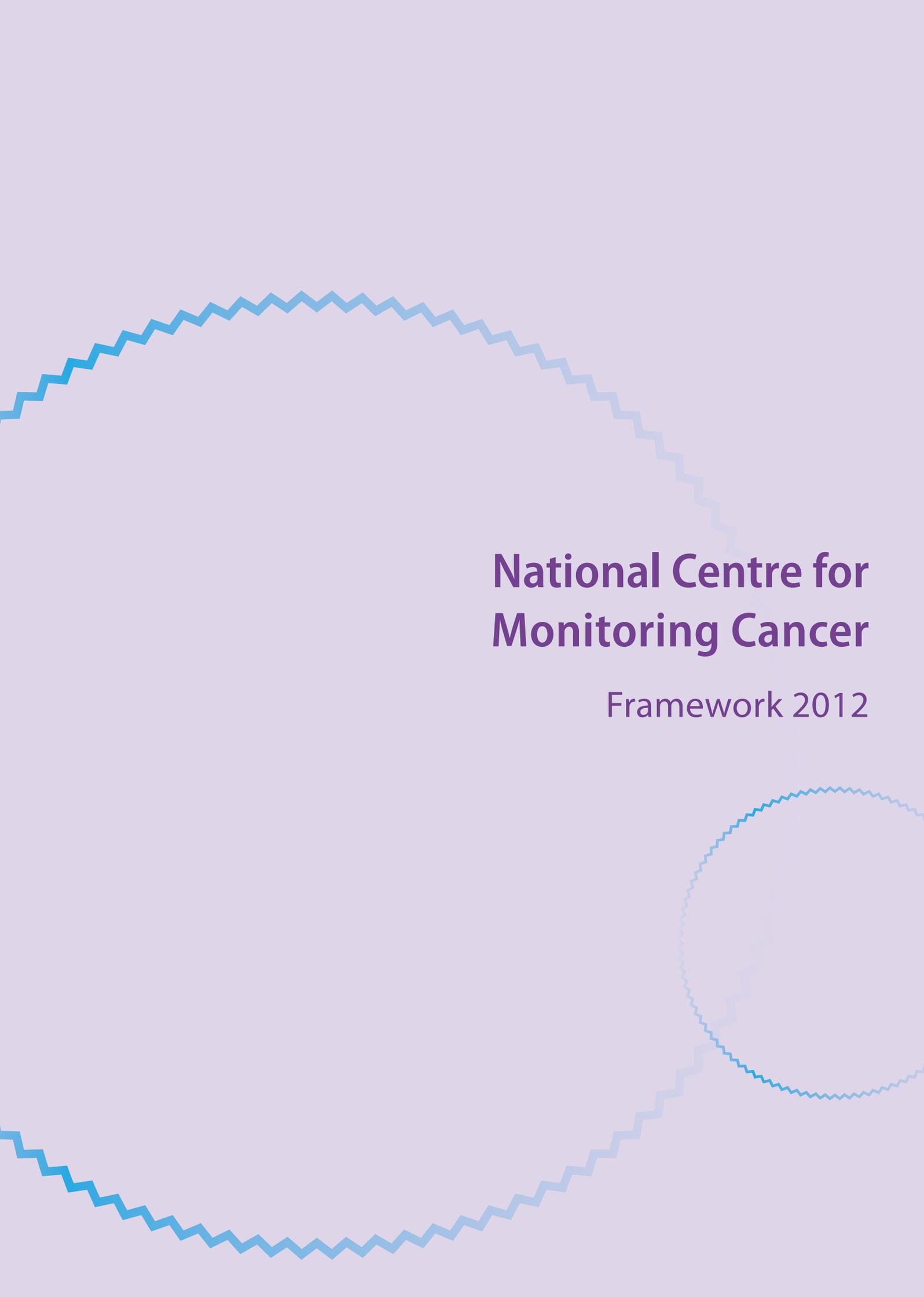
**Australian Government**

**Australian Institute of  
Health and Welfare**

# National Centre for Monitoring Cancer

Framework 2012





# National Centre for Monitoring Cancer

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The Australian Institute of Health and Welfare is a major national agency which provides reliable, regular and relevant information and statistics on Australia's health and welfare. The Institute's mission is *authoritative information and statistics to promote better health and wellbeing.*

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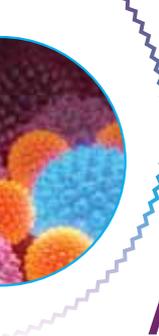
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# Contents

<b>Acknowledgments</b> .....	iv
<b>Abbreviations</b> .....	v
<b>Summary</b> .....	vi
<b>1 Introduction</b> .....	1
<b>2 The importance of cancer data in Australia</b> .....	2
2.1 The burden of cancer	2
2.2 Cancer control and the need for cancer data	3
2.3 The cancer data cycle	4
2.4 Sources of cancer data	5
2.5 National population-based cancer and screening data	6
2.6 Cancer data along the cancer pathway	10
2.7 Data linkage to enrich cancer data	13
<b>3 The National Centre for Monitoring Cancer (NCMC)</b> .....	14
3.1 Establishment of the NCMC	14
3.2 The NCMC Framework	15
<b>Appendix A: Cancer Monitoring Advisory Group initial terms of reference (2009)</b> .....	22
<b>Appendix B: Cancer Monitoring Advisory Group members</b> .....	24
<b>References</b> .....	25
<b>List of tables</b> .....	26
<b>List of figures</b> .....	26



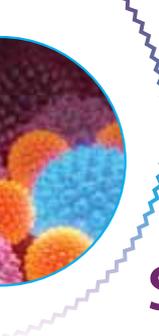
## Acknowledgments

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# Abbreviations

AACR	Australasian Association of Cancer Registries
ABS	Australian Bureau of Statistics
ACD	Australian Cancer Database
AIHW	Australian Institute of Health and Welfare
CMAG	Cancer Monitoring Advisory Group
COAG	Council of Australian Governments
NCMC	National Centre for Monitoring Cancer
NCSCH	National Cancer Statistics Clearing House



# Summary

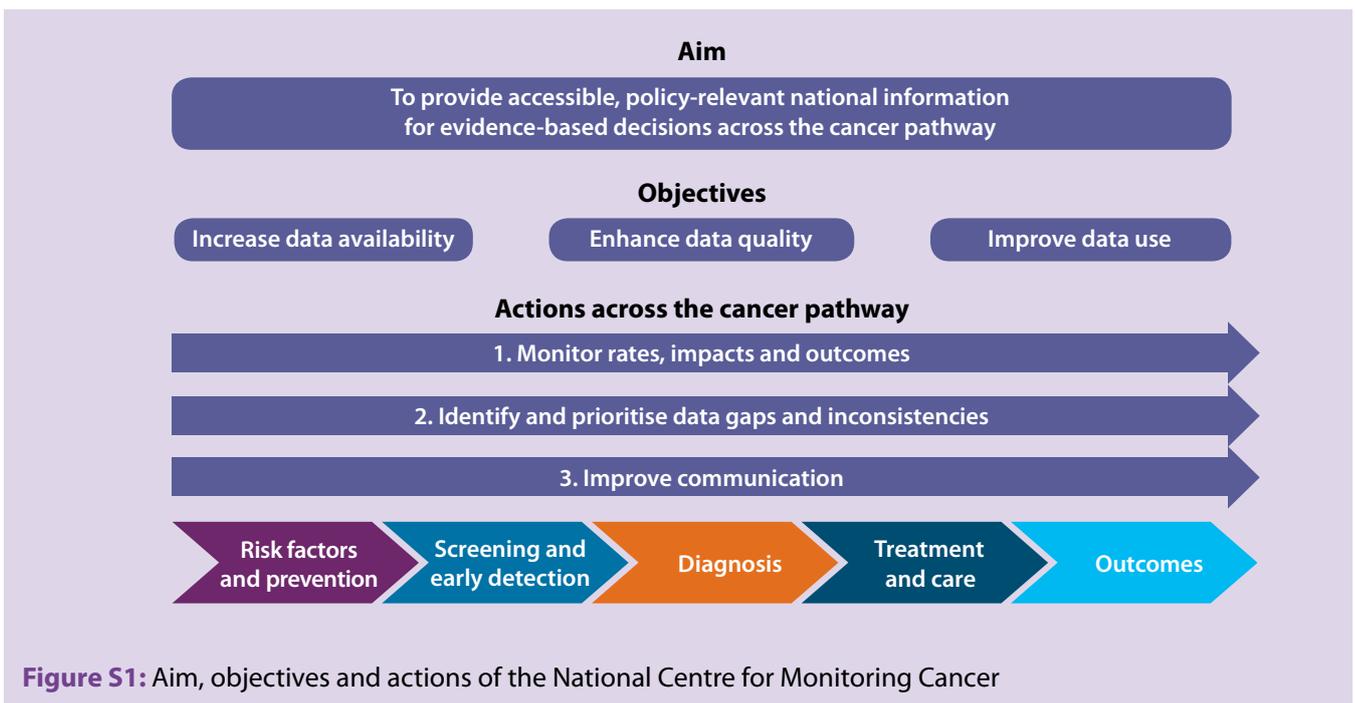
Summary

The National Centre for Monitoring Cancer (NCMC) was established in 2009 to monitor cancer rates and their impact and outcomes, as well as to identify and address priority gaps and deficiencies in population-level cancer and related data. The NCMC is located and managed within the Australian Institute of Health and Welfare (AIHW) in accordance with AIHW policies, procedures and legislation, and is advised by a multidisciplinary Cancer Monitoring Advisory Group.

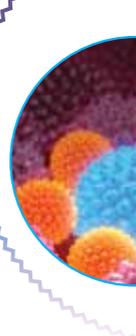
The NCMC aims to provide accessible, policy-relevant national information for evidence-based decisions across the cancer pathway. NCMC initiatives will be undertaken by:

- monitoring rates, impacts and outcomes
- identifying and prioritising data gaps and inconsistencies
- improving communication.

These actions are applied at every stage of the cancer pathway—from risk factors and prevention to screening and early detection, diagnosis, treatment and care and, finally, outcomes—to form NCMC activities that address cancer information needs. Figure S1 provides a graphical conceptualisation of the aims and objectives for the NCMC.



The NCMC Framework guides and organises the systematic planning, implementation and evaluation of NCMC activities. These are prioritised according to the criteria of relevance, strengths, feasibility and partnerships. Through these initiatives, the NCMC assists health professionals, researchers, policy makers and the general public, and contributes towards informed health system planning and effective service delivery to reduce the burden of cancer in Australia.



# 1 Introduction

Cancer is the leading cause of burden of disease in Australia and has a major impact on individuals, families and the health-care system. A policy-relevant evidence base, built on accessible and high-quality data, is essential for informing and strengthening effective cancer control. A number of data and information gaps currently exist, as well as opportunities to develop cancer data capacity at the national level. Areas of need that have been previously identified include collecting national data on stage and treatment, as well as measuring the management of cancer, prevention activities and social determinants of cancer. Further opportunities also exist for maximising the use of national cancer data collections in relation to specific population subgroups and for improving data accessibility, as well as developing data linkage resources (Cancer Australia 2008a).

In response to the increasing burden of cancer and the ever-growing demand for cancer information, the Australian Institute of Health and Welfare (AIHW) received funding as part of the Australian Government's 2009–10 Budget to establish a National Centre for Monitoring Cancer (NCMC). The aim of the NCMC is to provide accessible, policy-relevant national information for evidence-based decisions across the cancer pathway. Accordingly, NCMC initiatives will be undertaken by:

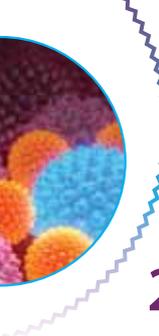
- monitoring rates, impacts and outcomes
- identifying and prioritising data gaps and inconsistencies
- improving communication.

This document is intended to be a comprehensive outline and framework of the NCMC. It was developed during the NCMC's initial funding period, and will continue to be updated as the NCMC develops.

Chapter 2 provides background information to set the context for the NCMC: it presents a snapshot of cancer epidemiology in Australia, summarises the need for data in cancer control policy, and ends with an overview of cancer data sources in Australia.

Chapter 3 presents information about the NCMC, including its governance and scope. The NCMC Framework is provided, which aims to guide and organise the systematic planning, implementation and evaluation of NCMC activities.

Governance details, including the initial terms of reference, of the NCMC Cancer Monitoring Advisory Group (CMAG) are provided in Appendix A. Appendix B lists members of the CMAG involved in the development of the framework.



## 2 The importance of cancer data in Australia

### 2.1 The burden of cancer

#### Box 2.1: Cancer facts

- Cancer has a greater overall impact on the health of Australians than any other disease group, and is the second most common cause of death in Australia.
- One in two Australians will be diagnosed with, and 1 in 5 will die from cancer before their 85th birthday.
- The most common cancers diagnosed in Australians are non-melanoma skin cancer, prostate cancer, breast cancer, melanoma of the skin and lung cancer.
- Cancer rates and outcomes differ by age, sex, indigenous status, remoteness area and socioeconomic status.

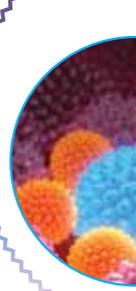
Cancer has a major impact on the health of Australians. It was estimated to be the leading contributor to burden of disease in 2010, accounting for about one-fifth of the total burden (AIHW & AACR 2010). Despite a lowering of cancer mortality and an increase in survival over time, one in two Australians will be diagnosed with a notifiable cancer and one in five will die from the disease before the age of 85 (AIHW & AACR 2010).

In 2008, more than 112,000 Australians were diagnosed with a notifiable cancer, representing an age-standardised incidence rate of 490 cases per 100,000 people (AIHW 2012a). This incidence rate has increased over time, up 28% from 1982. The most commonly reported cancers diagnosed in Australians were prostate cancer, bowel cancer, breast cancer, melanoma of the skin and lung cancer, which together made up 62% of all cancers diagnosed.

Data on cancer incidence do not include basal and squamous cell carcinomas of the skin (BCCs and SCCs)—the most common types of non-melanoma skin cancer—because registration of these cancer cases is not legally required. The national incidence of these cancers is estimated from periodic national household surveys (NCCI 2003; Staples et al. 2006). Based on the most recent survey in 2002, about 474,000 new cases of these cancers are expected to be diagnosed in 2012 (AIHW 2012a).

In 2009, more than 41,000 Australians died from cancer, representing an age-standardised mortality rate of 174 deaths per 100,000 people (AIHW 2012a). Cancer accounted for approximately 3 in 10 deaths in Australia, making it the second most common cause of death; however, the rate of cancer deaths has decreased by 17% since 1982.

In line with decreasing mortality, increases in survival have been observed for many cancers; notably, prostate cancer, breast cancer in females, and bowel cancer, although for others, such as brain and lung cancer, survival has remained low (AIHW, Cancer Australia & AACR 2008).



Despite improvements in cancer control, cancer incidence and mortality rates differ by Indigenous status, remoteness area and socioeconomic status. Indigenous Australians experienced higher incidence and mortality from cancers of the cervix, lung and unknown primary site, and higher all-cancer mortality compared with non-Indigenous Australians, based on data from selected jurisdictions in 2003 to 2007. Incidence and mortality for cancers of the cervix, lung and unknown primary site also rose with increasing remoteness and with decreasing socioeconomic status (AIHW & AACR 2010).

This snapshot highlights a number of important issues for cancer control in Australia. There are continuing challenges to prevent more cancers, diagnose cancers earlier and treat cancers more effectively. Cancer interventions also need to ensure that gains in cancer control are distributed equally across different population subgroups. With a growing and ageing population, the number of cancer cases and deaths is expected to lead to a greater impact on the health-care system. To address these issues, effective cancer control needs to be informed by an accessible, reliable and policy-relevant evidence base, which can detect cancer trends, strengthen cancer interventions, prioritise and allocate resources and identify improvements.

## 2.2 Cancer control and the need for cancer data

Cancer has been a prominent policy issue in Australia for decades. In 1996, cancer control was declared a National Health Priority Area by Australian health ministers in an initiative to focus public attention and health policy on areas which contributed significantly to the burden of disease in Australia and for which there is potential for health gain (AIHW & DHFS 1997).

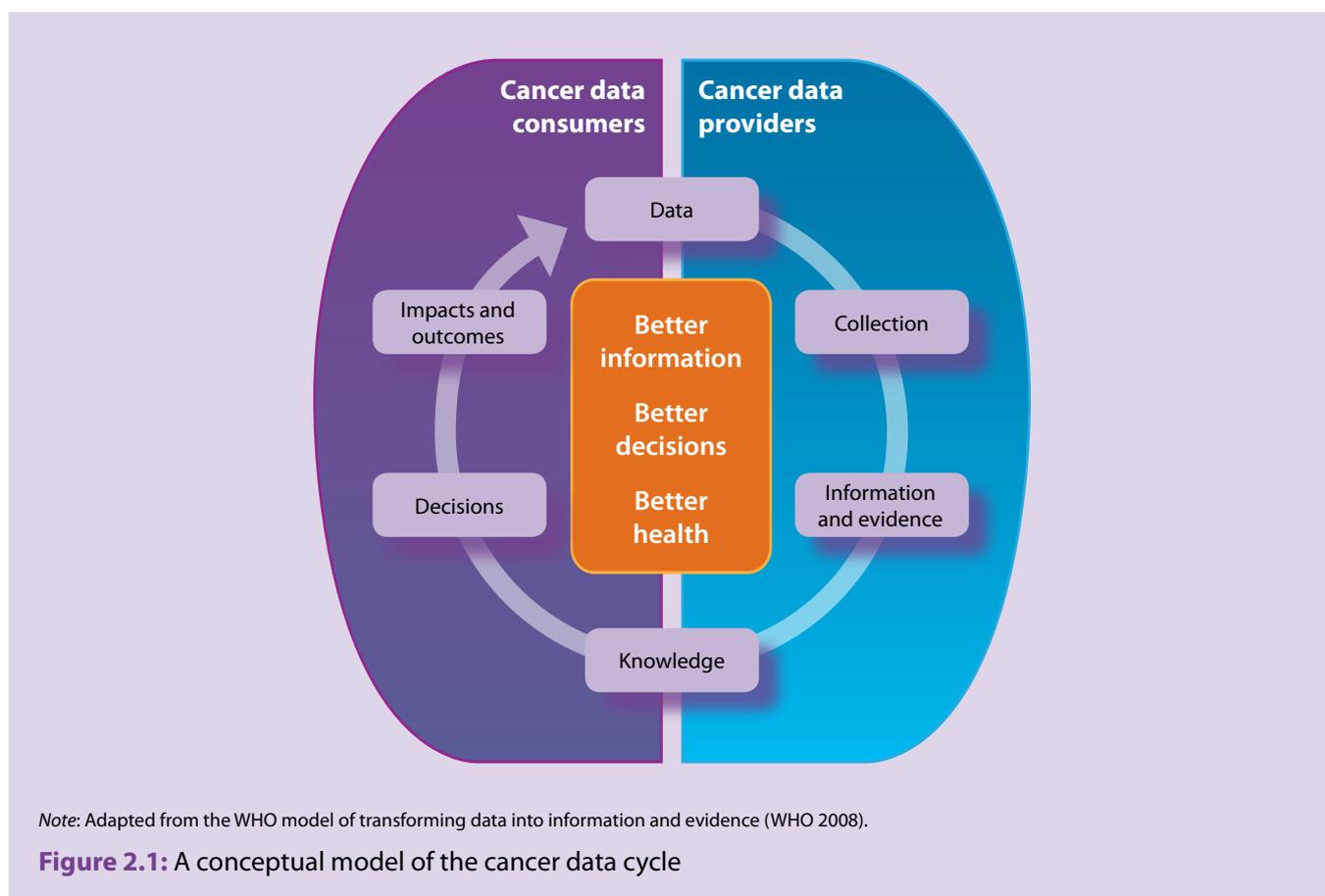
Over the years, a number of national efforts have targeted cancer, focusing on prevention, detection, treatment and research. Some of the major initiatives that have highlighted the role of cancer data in evidence-based policy in recent years include the National Health Priority Area cancer control report (DHFS & AIHW 1998) and the *National chronic disease strategy* (NHPAC 2006a) and *National service improvement framework for cancer* (NHPAC 2006b).

More recently in Australia, the Council of Australian Governments (COAG) introduced a new set of health performance indicators (PIs), which aim to report on the goals of the health system and reflect the roles and responsibilities of governments in managing and providing health services (AIHW 2010). Australian and state and territory health authorities have committed to regularly report on these performance indicators and benchmarks, five of which relate to cancer and are reported by the AIHW. The five cancer-related performance indicators are incidence of selected cancers (PI 4), 5-year relative survival of people diagnosed with cancer (PI 44) and screening participation rates for cervical, breast and bowel cancer (PIs 10, 11 and 12, respectively).

Many national cancer initiatives highlight data collection and reporting as an essential component to measuring need and effectiveness. In general, these initiatives identify a number of critical intervention points for reduction of cancer risk, prevention of cancer, early detection of cancer and more effective treatment and support during cancer care and highlight data collection and reporting as an essential component to measuring need and effectiveness at all points along the cancer pathway.

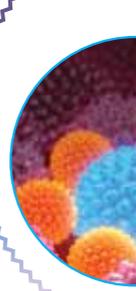
## 2.3 The cancer data cycle

The role of cancer data in producing accessible, policy-relevant national information can be best understood through a cancer data cycle, as illustrated in Figure 2.1. The cancer data cycle is adapted from the World Health Organization (WHO 2008) and is intended to be a conceptual model describing how data can be transformed into information and evidence to influence decisions and policy. The cycle is split into two, with one half representing the supply of cancer data by providers, such as state and territory cancer registries and the AIHW, and the other half representing the use of data by consumers, such as the general public, researchers, health professionals and policy makers.



The cycle illustrates how data are collected and analysed to form information and evidence, which in turn are transformed into knowledge to guide decisions towards better health outcomes. These outcomes can be measured by data, which are collected for monitoring, thus restarting the cancer data cycle. The model also illustrates the value of data currency: increased timeliness of data collection and reporting at the beginning of the cycle would lead to better outcomes earlier at the end of the cycle.

Policy interest in prevention, early detection and equitable cancer services has led to an emphasis on addressing national data gaps and limitations of cancer data collection in Australia. Improving cancer data allows a better understanding of how cancer could be prevented, detected or treated. It also enables a closer monitoring of outcomes and the impact of policies—in particular, how these differ across population subgroups and trends over time. Through these efforts, cancer data contribute towards informed health system planning and effective and efficient service delivery to reduce the burden of cancer in Australia.

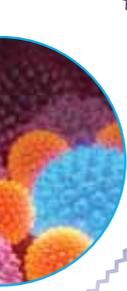


## 2.4 Sources of cancer data

Cancer (excluding basal and squamous cell skin cancers) is a legally notifiable disease in Australia. State and territory population-based cancer registries receive information on cancer diagnoses from a variety of sources, such as hospitals, pathology laboratories, radiotherapy centres, and registries of births, deaths and marriages. These data are compiled at the jurisdictional level and are then supplied annually to the AIHW for inclusion in a national database of cancer incidence. There are also three national population-based cancer screening programs for which data are compiled and reported nationally by the AIHW. Other cancer data collections, while not population-based, record more detailed clinical, staging and treatment data and there are also a growing number of biospecimen databases in Australia. Table 2.1 provides a summary of the most common Australian cancer data sources.

**Table 2.1:** Summary of the most common Australian cancer data sources

Major Australian cancer data sources	Data collected	Uses
State and territory population-based cancer registries, Australian Cancer Database (AIHW)	Demographic information, incidence (including cancer site and morphology), follow-up for vital status, mortality. Differences exist across jurisdictions in methodology and data currency, but data are generally comparable for national analysis when they are provided to the AIHW for inclusion in the Australian Cancer Database.	Routine population health surveillance and research support, including epidemiological research, service planning, quality assurance activities, comparing Australian cancer data with international data, investigating real and perceived cancer clusters and other reporting and monitoring.
Australian Paediatric Cancer Registry (APCR)	Demographic information, incidence, stage, treatment and survival. The APCR is one of the few national registries of childhood cancer in the world and covers all Australian children aged 0–14 years.	Population health monitoring, epidemiological and clinical research.
Clinical cancer registries	Demographic information and other identifiers (including Medicare number), cancer site and morphology, stage, hormone receptor status, initial treatment and treatment outcomes (including cancer recurrence). Consistency in data collection is maintained through the Clinical Cancer Core Data Set.	Monitoring of patterns of care and treatment, and evaluation of outcomes, epidemiological research to identify individuals diagnosed with specific types of cancer.
Biospecimen databases	Various cancer data and biological samples, from collections such as the Western Australian Research Tissue Network, BioGrid Australia, Australasian Biospecimen Network and Victorian Cancer Biobank.	Research into biomarker predictors of cancer; customising therapies to molecular and biological features of cancers.
Cancer screening registries	States and territories maintain demographic, screening and outcome data in registries for the National Cervical Screening Program and BreastScreen Australia. The Australian Government Department of Human Services maintains similar data in the National Bowel Cancer Screening Program Register.	Follow-up of participants with results requiring further investigation and monitoring of the programs and other reporting.



**Table 2.1 (continued):** Summary of the most common Australian cancer data sources

Other Australian cancer data sources	
Australian Mesothelioma Registry	General practice data (AIHW)
National Health Survey data (ABS)	Health and welfare expenditure data (AIHW)
National skin cancer survey data	Medical and nursing labour force data (AIHW)
Demographic data (ABS)	National drug survey data (AIHW)
Mortality data (AIHW)	National disability survey data (ABS)
Hospital inpatient morbidity data (AIHW)	Infrastructure data
Medicare Benefits Schedule data	Clinical trials register data
Allied health registries	Miscellaneous cancer research and survey data sets
Allied population files	Linked data sets

*Note:* Based on *A national cancer data strategy for Australia* (Cancer Australia 2008a) and *Data sets for cancer control and research in Australia* (Cancer Australia 2008b), interpreted and updated by the AIHW.

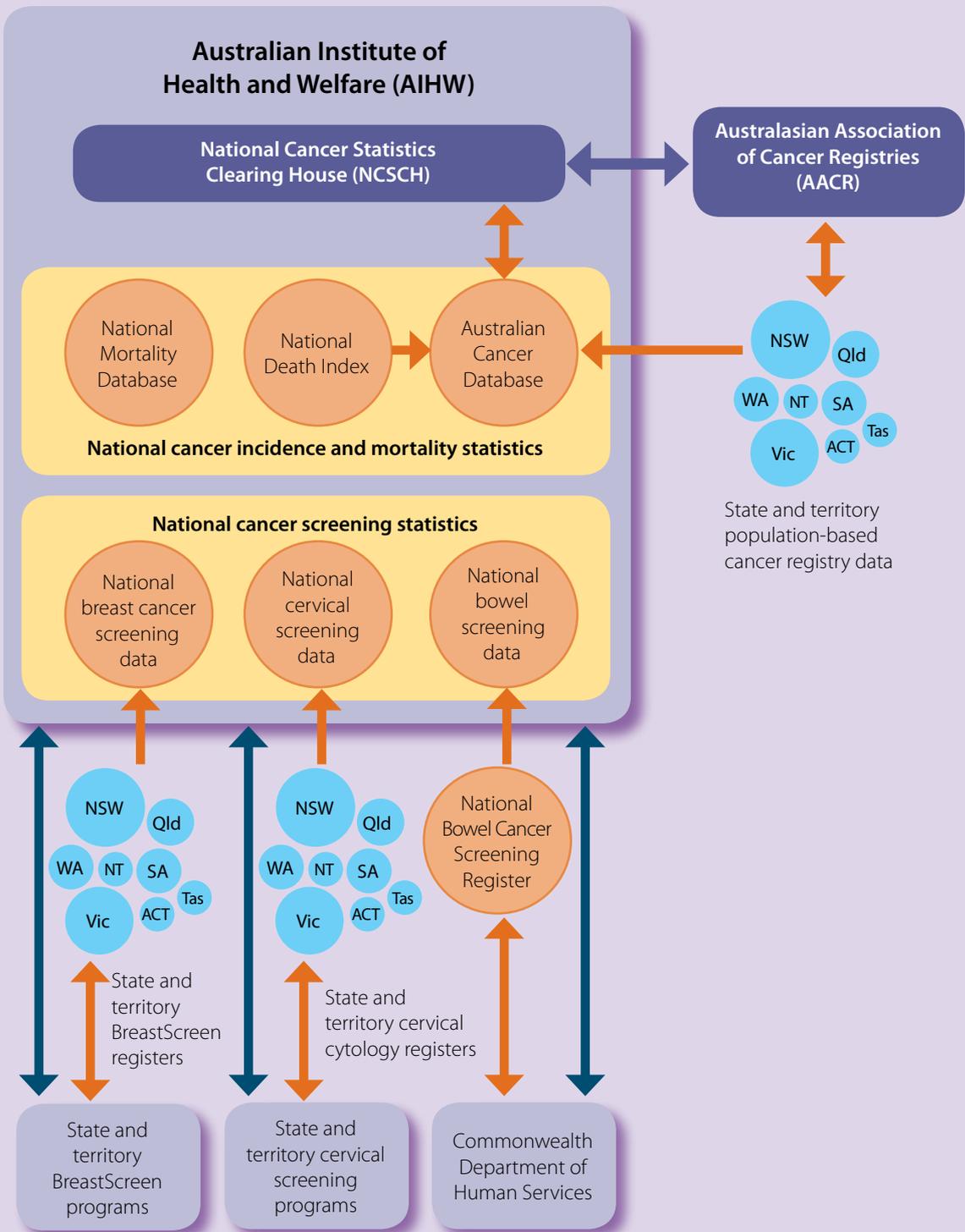
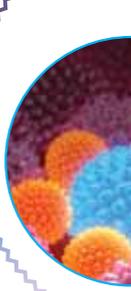
## 2.5 National population-based cancer and screening data

This section concentrates on the data sources for national population-based cancer and screening data in Australia, and the role of the AIHW in collating and reporting these data.

The major source of national, population-based cancer data is the Australian Cancer Database (ACD), compiled at the AIHW from state and territory cancer registry data. The AIHW works in collaboration with the Australasian Association of Cancer Registries (AACR) through the National Cancer Statistics Clearing House (NCSCCH). The NCSCCH is a collaborative agreement between the AIHW and the AACR to disseminate national cancer incidence and mortality data, support research based on these data, and to develop and improve cancer statistics generally.

In addition to the ACD, the AIHW maintains three major sources of national, population-based screening data for BreastScreen Australia, the National Cervical Screening Program and the National Bowel Cancer Screening Program. These data are respectively collected by the state and territory BreastScreen and cervical screening programs and the Australian Government Department of Human Services, and are sent to the AIHW for national monitoring and reporting.

The relationships and the flow of data between these organisations are presented in Figure 2.2 and described in detail below.



Note: Rectangles and dark arrows respectively represent organisations and relationships between them. Circles and light arrows respectively represent national cancer and screening data sources and the flow of data between them.

**Figure 2.2:** Organisations and data collections involved in national, population-level cancer and screening data in Australia

### 2.5.1 The Australian Institute of Health and Welfare

The AIHW is a major national agency established by the Australian Government as an independent statutory agency in the Health and Ageing portfolio to provide reliable, regular and relevant information and statistics on Australia's health and welfare.

The AIHW, as custodian of major national data collections, is committed to providing high-quality, national data and analysis across the health, housing and community services sectors, presented in meaningful and relevant ways and delivered in a timely manner. These data and analyses support an increased understanding of health and welfare issues and are critical to good policy making and effective service delivery, both of which can have a direct impact on the lives of Australians. The AIHW's statistics and information also play an important part in informing community discussion on health, housing and community services matters.

The Health Group of the AIHW develops and maintains national data to support monitoring and reporting on the health of Australians. This includes monitoring the determinants of health, health status and diseases, and related quality of life. The group reports on the health of populations and chronic disease monitoring, including cardiovascular disease, diabetes, cancer, kidney disease, arthritis and asthma. It also reports on related health services such as cancer screening and primary care.

The AIHW has a unique role in coordinating national cancer data. The AIHW monitors and reports on national cancer statistics supplied by state and territory population-based cancer registries, as well as collaborating with the Department of Health and Ageing to provide statistical information for the national population-based cancer screening programs. In addition, the AIHW works with other cancer bodies, such as Cancer Australia to develop cancer information to assist policy makers, researchers, service delivery planners and consumers.

The AIHW houses major data collections used to provide national cancer information—these are listed below. The data collections can be grouped into those used to report cancer incidence and mortality, and those used to monitor population-based screening programs. Other data collections also used regularly to report on various aspects of cancer include the National Hospital Morbidity Database, the Disease Expenditure Database and population data.

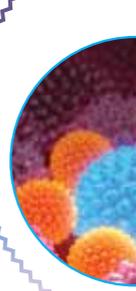
#### The Australian Cancer Database (ACD)

The AIHW, in partnership with the AACR, maintains this national collection of approximately 2 million cancer cases diagnosed in Australia since 1982. Data are submitted annually to the AIHW by state and territory cancer registries and reflect the availability of population-based registry data. Mortality data for records in the ACD are provided by cancer registries, as well as through record linkage to the National Death Index, also held at the AIHW. This enables calculation of survival and prevalence. Projections of incidence are also derived from incidence data in the ACD.

One of the limitations of the data received from some of the state/territory cancer registries is the quality and coverage of data on Indigenous status, which precludes comparison of cancer incidence and survival by Indigenous status at a national level. However, a subset of registries provide data deemed of sufficient quality to report Indigenous status. Similarly, country of birth includes a large amount of missing data which limits analysis.

With increasing focus on monitoring cancer across population subgroups, incidence data can be analysed by socioeconomic status and geographical area using the postcode or Statistical Local Area at diagnosis and Australian Bureau of Statistics (ABS) concordances.

Currently there are no national data on tumour grade, stage or treatment. Tumour size (thickness) is collected nationally for melanoma of the skin and national data on tumour size and nodal status are sometimes requested from registries on an ad-hoc basis for particular solid-state tumours.



Several projects have already been established to improve national cancer data. Cancer Australia is currently undertaking work to develop methodologies for complementing existing population-based incidence and mortality data with data on stage, recurrences and treatment. The Royal College of Pathologists of Australasia is also working on improving diagnostic, staging and other prognostic data through its National Structured Pathology Reporting of Cancer Project.

### **The National Mortality Database**

National cancer mortality statistics are included in this database maintained by the AIHW. This is a historical register of all deaths in Australia since 1964. The database comprises information about the cause of death and other characteristics about the person, such as sex, age at death, area of usual residence and Indigenous status. The information is sourced from the Registrars of Births, Deaths and Marriages in each state and territory and the National Coronial Information System.

The ABS compiles and codes the data to a national file. Information about the causes of death are coded (using an automated process) to an international standard—currently, the International Classification of Disease and Related Health Problems 10th revision (ICD-10).

Mortality data are an important indicator of cancer control initiatives. Regular and timely provision of cancer mortality information is critical to ensure accurate reporting of these indicators.

Similar to incidence data, cancer mortality data have data quality limitations for Indigenous status, restricting analysis to a subset of jurisdictions. Unlike incidence data, cancer mortality statistics cannot be broken down by histology, as this is not collected for deaths data.

### **BreastScreen Australia monitoring data**

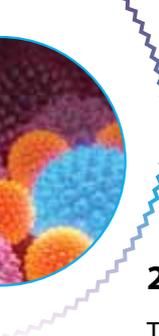
The AIHW reports BreastScreen Australia screening indicators for participation, cancer detection, sensitivity, ductal carcinoma in situ detection, recall to assessment and rescreening. These are computed from de-identified unit record data or compiled from aggregated data provided by state and territory BreastScreen programs. Participation data have been collected since 1996–1997 and are analysed by sociodemographic variables such as age, state and territory, geographical area, socioeconomic status, language spoken at home, and Aboriginal and Torres Strait Islander status.

### **National Cervical Screening Program monitoring data**

The AIHW also reports on screening indicators for the National Cervical Screening Program, including participation, rescreening, cytology and histology. These are compiled from aggregated data provided by state and territory cervical cytology registries. Participation data have been collected since 1996–1997 and are analysed by sociodemographic variables such as age, state and territory, geographical area and socioeconomic status. However, cervical cytology registers cannot yet record Aboriginal and Torres Strait Islander status, or language spoken at home.

### **National Bowel Cancer Screening Program data**

The AIHW routinely reports on the National Bowel Cancer Screening Program. The National Bowel Cancer Screening Register maintained by the Australian Government Department of Human Services, holds complete data on invitations and faecal occult blood test results. Data on follow-up assessment, colonoscopy and histopathology are requested from health care providers and specialists, but are not mandatory. Data such as participation, screening outcomes and follow-up of positive test results are analysed by sociodemographic variables such as age, sex, state and territory, geographical area and socioeconomic status. Data on language spoken at home, disability status, and Aboriginal and Torres Strait Islander status are also supplied and analysed. These data rely on self-identification at the time of screening.



### 2.5.2 The Australasian Association of Cancer Registries (AACR)

The AACR is a collaborative body representing the eight Australian state and territory cancer registries, the New Zealand Cancer Registry and the AIHW. It was formed in 1982 to provide a formal mechanism for promoting uniformity of collection, classification and collation of cancer data. The AACR Executive Committee provides advice to the AIHW on the direction of the NCSCH work program, development of publication topics and strategies, and ongoing technical advice on the operation of the NCSCH. The objectives of the NCSCH are to analyse and report on the data in its national repository of cancer incidence and mortality statistics, support research based on these data, and develop and improve cancer statistics generally.

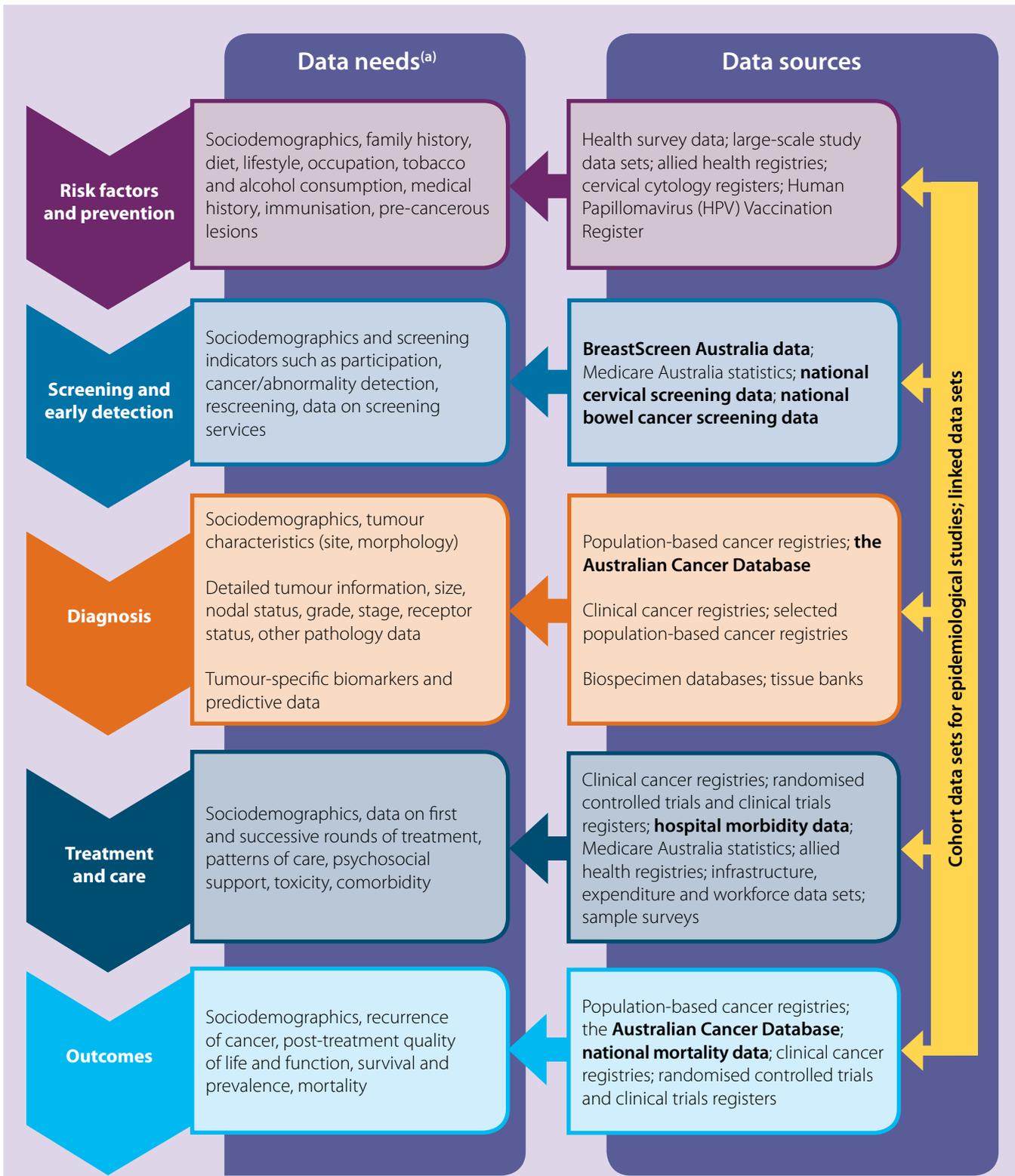
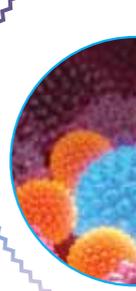
## 2.6 Cancer data along the cancer pathway

### 2.6.1 A summary of cancer information needs

Cancer is a multifaceted disease and its impact on the population occurs in many ways. The key areas of cancer control, data collection and cancer monitoring can be represented by a pathway, beginning with risk factors and prevention, followed by screening and early detection, diagnosis, treatment and care, and ending with cancer outcomes. Opportunities for cancer control exist at each point in this pathway, by implementing changes at both at a societal and individual level. However, these changes need to be driven by sound scientific evidence. At each point on the pathway, there are different health priorities and information needs for a variety of data consumers, such as patients and their families, researchers, health professionals, service planners and policy makers.

Figure 2.3 presents a summary of the cancer data needs distributed along the cancer pathway, and data sources currently collecting this information. It is worth noting that population-based and mandatory collection of cancer data occurs at only two points along the pathway: diagnosis and outcomes, both of which contribute towards national data at the AIHW.

This diagram serves as a reference to Australian cancer data sources mapped along the cancer pathway, as well as a guide for shaping the framework of cancer data activities in the NCMC.

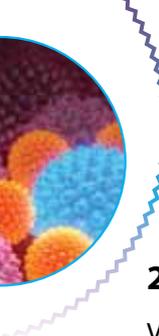


(a) Some of the identified data needs are currently collected and others are not.

Notes

1. Sociodemographic data include information on age, sex, geographical area, socioeconomic status, Indigenous status and ethnicity.
2. Data sources in bold represent those located at the Australian Institute of Health and Welfare.

**Figure 2.3:** Australian cancer data needs and sources along the cancer pathway



## 2.6.2 Opportunities for monitoring and data improvement

Various points exist along the cancer pathway where further work could be done to improve cancer data and monitoring. A number of data gaps and inconsistencies have been previously documented in Cancer Australia's *A national cancer data strategy for Australia*. These include, but are not limited to (Cancer Australia 2008a):

- tumour stage data at the national, population-based cancer registration level
- host risk factor information. While a range of host risk factor information for each notified case of cancer at the population-level is not feasible, separate data collections or ecological analyses of incidence trends against population-level risk factor data could be investigated.
- clinical cancer registration
- cancer treatment monitoring, especially at the population level
- longer-term outcomes, including recurrence and time-to-relapse
- variation in cancer registration
- surveying the incidence of non-melanoma skin cancer, given that basal cell and squamous cell carcinoma of the skin are not legally notifiable and data are not collected at a national level
- monitoring of cancer trends and outcomes in Aboriginal and Torres Strait Islander peoples.

Accordingly, Cancer Australia has identified a number of initiatives that require a collaborative effort to improve cancer data. These recommendations focus on data availability, reporting, quality and consistency, and research in data collection and use. In particular, there are a number of opportunities using data linkage methodology that could bridge such data gaps. It is worth noting that some data development work is already in progress with the National Structured Pathology Reporting of Cancer Project, undertaken by the Royal College of Pathologists of Australasia, to improve diagnostic, staging and other prognostic data.

Further opportunities exist for cancer monitoring at a later stage of the data cycle where data are shaped into information and evidence. Information gaps exist with respect to cancer in particular population subgroups, such as Aboriginal and Torres Strait Islander peoples and young Australians. In addition, information measuring the management of cancer, prevention activities and social determinants of cancer are not easily obtainable. There is also a need for in-depth monitoring of specific cancers at a national level, as well as information on broader aspects of cancer, such as comorbidity, late effects of cancers and multiple cancers. While there are many sources of cancer information, opportunities still exist for improving the consistency, coverage, timeliness and currency of national, population-based disease monitoring across the cancer pathway.

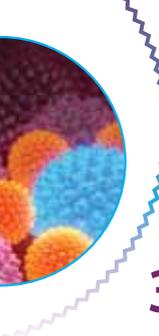
The new performance and accountability reporting arrangements being implemented under the National Health Reform should provide opportunities to improve cancer data and monitoring. Under the Performance and Accountability Framework agreed between governments, the National Health Performance Authority will develop and produce hospital performance reports and healthy communities reports, which will report across a range of performance indicators that will initially be drawn, where possible, from performance standards and targets agreed by the COAG in the National Healthcare Agreement 2011. The performance indicators will include population health indicators, access indicators and indicators that measure best practice more locally. For the first time, there will be nationally consistent and locally relevant reporting on the performance of health-care providers. As this new performance reporting arrangement develops, it will provide an additional source of data along the cancer pathway illustrated in Figure 2.3.



## 2.7 Data linkage to enrich cancer data

Linking data from more than one source is becoming an increasingly important tool in health information. Data linkage (or data integration) is a method of bringing together information about people, places and events in a way that protects individual privacy. Data linkage is a powerful way of adding value to data. Research supported by linked data can help identify cause and effect relationships, or explain the nature of relationships over time and across different contexts. The use of data linkage in the cancer information environment provides opportunities to expand on the data available in the many and varied repositories outlined in Section 2.4.

While data linkage provides opportunities to explore the cancer pathway and identify outcomes additional to those available in current datasets, the procedures and processes are complex. Best-practice linkage protocols safeguard individual privacy and provide accurate methodologies for matching data within legislation and with appropriate consent and human ethics committee and data custodian approval. In Australia's federated system this can make undertaking data linkage an intricate and time-consuming task. Efforts are underway to support and facilitate data linkage both within the AIHW and in the broader data community. The NCMC is well placed to work with existing and future data linkage processes, procedures and initiatives to seek additional cancer information to inform policy, service provision and prevention activities.



## 3 The National Centre for Monitoring Cancer (NCMC)

### 3.1 Establishment of the NCMC

In response to the increasing burden of cancer and the ever-growing demand for cancer information, \$4.2 million was invested by the Australian Government in the 2009–10 Budget to improve the range of cancer data and related evidence available at a population-level in Australia (Commonwealth of Australia 2009). Half of this funding was allocated to the AIHW to establish the NCMC, which will monitor cancer rates and their impacts and outcomes, as well as identify and address priority gaps and deficiencies in population-level and related cancer data to improve the evidence base. The information and improved data produced by the NCMC will assist health professionals, researchers, policy makers, service planners, consumers and the general public and increase public awareness, knowledge and understanding about national cancer trends and patterns.

The second half of the funding was allocated to Cancer Australia for the development of data sets relating to stage, treatment and recurrence, and combining these with existing population-based incidence and mortality data. To date, this has led to the establishment of a Cancer Data Working Group in 2009 and the commencement of pilot projects examining ways to collect stage, treatment and recurrence data with the aim of expanding the methodology to national data (Cancer Australia 2010).

#### 3.1.1 Governance

The NCMC is located and managed within the Health Group of the AIHW in accordance with AIHW policies, procedures and legislation. The work of the NCMC is guided by the Cancer Monitoring Advisory Group (CMAG), a multidisciplinary committee providing expert advice to the AIHW on national information needs and requirements for cancer data, strategic directions, the overall work program and the conduct of individual projects of the NCMC. The group includes members who are familiar with one or more of the following areas: the cancer data environment, current cancer-related priorities, policies and clinical practices, and emerging issues. The terms of reference for the CMAG as well as a list of CMAG members are included in Appendixes A and B, respectively.

In order to ensure that NCMC projects complement other cancer activities being undertaken beyond the AIHW, the work of the NCMC will be done in close consultation with major stakeholders, in particular the AACR, the Department of Health and Ageing and Cancer Australia.



### 3.1.2 Scope

While the NCMC is established to be a major authority on all Australian cancer data, its expertise and efforts are concentrated around national, population-level cancer data. NCMC work will not be separate from the extensive cancer monitoring and data improvement activities currently being undertaken by a range of cancer bodies, including cancer registries and universities as well as within the AIHW itself. Hence, NCMC work will be undertaken using a two-pronged approach:

- developing, collecting and analysing new data
- analysing existing data in new and meaningful ways.

A major part of NCMC work will involve improving national cancer data collections located at the AIHW, with additional work exploring how these can be combined with existing data to bridge gaps and to extend the evidence base along the cancer pathway. While the NCMC will explore, identify and prioritise data gaps and inconsistencies, it is not the role of the NCMC to drive every initiative. Instead, the NCMC will highlight opportunities for data development and support best-placed agencies or groups in order to improve the evidence base.

## 3.2 The NCMC Framework

The NCMC Framework has been developed in consultation with the CMAG and aims to guide and organise the systematic planning, implementation and evaluation of NCMC activities. Figure 3.1 presents the aim and objectives of the NCMC, and illustrates how these are translated into actions that apply across the cancer pathway.

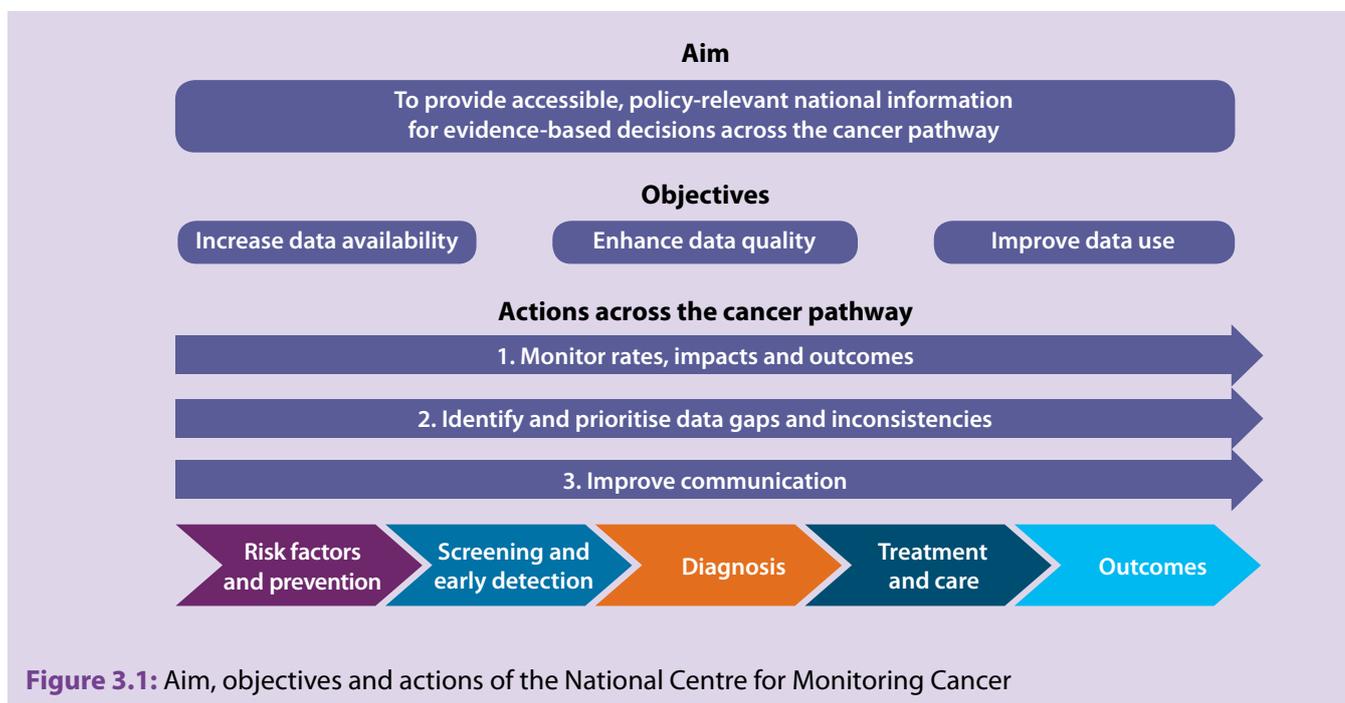
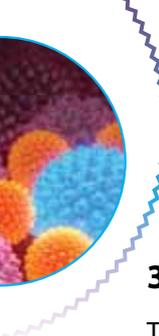


Figure 3.1: Aim, objectives and actions of the National Centre for Monitoring Cancer



### 3.2.1 Aim

The aim of the NCMC is:

To provide accessible, policy-relevant national information for evidence-based decisions across the cancer pathway

The NCMC will collate, interpret, analyse and disseminate information relating to cancer prevention, early detection, diagnosis, treatment and outcomes. Where necessary, the NCMC will identify, prioritise and work towards closing data gaps and inconsistencies in order to improve the evidence base.

The NCMC will play an important role as a leading authority and comprehensive resource for cancer data in Australia. Its cancer monitoring work, in combination with its data improvement activities, will help transform data into evidence to inform policy and health decision making.

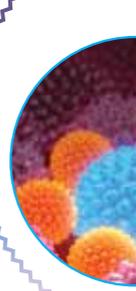
### 3.2.2 Objectives

- **Increase data availability:** sought-after and relevant data are collected, validated and made available to meet the needs of cancer data consumers in a timely and responsive fashion; data are made accessible while maintaining ethical standards and privacy protocols.
- **Enhance data quality:** data are accurate, coverage is complete, and there is clarity and consistency in national cancer data collection; the evidence base is reliable and valid.
- **Improve data use:** cancer data are analysed and presented in meaningful and effective ways; the use of national cancer data collections and linked data resources are optimised to address areas of need; the cancer evidence base plays a valuable role in informing policy and guiding decisions.

### 3.2.3 Actions across the cancer pathway

Three major actions have been developed to meet NCMC objectives and provide direction for NCMC work.

- **Monitor rates, impacts and outcomes:** the NCMC will build on the existing monitoring of disease frequency and outcomes, such as monitoring of cancer incidence, mortality, survival and prevalence, and various screening indicators. This also involves focusing on specific cancers, as well as identifying trends and differences by sociodemographic factors and population subgroups. Further work will be extended towards monitoring new data, such as risk factors and impacts from cancer control interventions, and developing methodologies for monitoring existing data in new ways.
- **Identify and prioritise data gaps and inconsistencies:** the NCMC will be involved in data development activities to identify and, where possible, close data gaps and resolve inconsistencies. This may involve addressing deficiencies in data availability, accessibility, timeliness and quality, as well as gaps in data content where reporting has not previously taken place.
- **Improve communication:** the NCMC will enhance communication about cancer data findings to accurately and effectively guide decision making, service planning and policy. This involves selecting the most relevant issues to report on, analysing data in meaningful ways, presenting messages effectively and ensuring that sources of cancer data are accessible to a wide audience in a variety of formats.



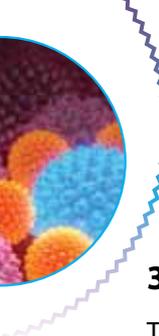
### 3.2.4 Criteria

Five key criteria prioritise and guide decision making to reduce the volume of potential cancer monitoring and data activities to a feasible and effective work plan (Table 3.1). Potential activities will be applied and judged by the NCMC in close collaboration with the CMAG. As projects arise, they will be scored and ranked to determine whether they are undertaken. By using the criteria to assess competing potential projects, the NCMC and CMAG can strategically position work around national clinical, research and policy priorities.

Four criteria represent the NCMC priorities and considerations of relevance, strengths, feasibility and partnerships. Given that the NCMC was established with funding from the Australian Government's 2009–10 budget in response to the increasing burden of cancer and the demand for cancer information, its key criterion of relevance ensures that its activities address areas of clinical, policy and/or research interest and will provide useful information for planners and service providers. In addition, the NCMC promotes responsiveness to changing or emerging policies, supports data access and optimised use of national cancer data resources, emphasises and prioritises areas of need, and promotes harmonisation among stakeholders to achieve a collaborative approach to monitoring and data development. A fifth criterion represents other significant issues that may be considered when evaluating potential NCMC activities. For example, projects may be of a horizon-scanning nature that identify areas of future importance to address longer-term monitoring and data needs.

**Table 3.1:** Criteria for National Centre for Monitoring Cancer decision making

Key criteria	Description
Relevance	There is strong interest in the project from a clinical, policy and/or research area and the project will address an area of need or provide information pertaining to a data gap. The timing is appropriate and it will facilitate decision making. This approach may include responding to emerging issues. High..... Medium.....Low
Strengths	The project capitalises on existing strengths or builds new strengths that highlight efficient methods of cancer data storage, validation or analysis and takes advantage of the AIHW's position as custodian of the central national cancer data repository. High..... Medium.....Low
Feasibility (including costs)	The project is capable of being implemented from an operational, legislative and financial perspective. High..... Medium.....Low
Partnerships	The project uses, enhances or builds partnerships with internal and/or external stakeholders that lead to meaningful improvements in the cancer data environment. High..... Medium.....Low
Other issues	Other significant issues for consideration in project proposed. Please provide details. High..... Medium.....Low



### 3.2.5 Implementation strategy

The implementation strategy of the NCMC (Figure 3.2) brings together the priorities of the NCMC, available resources and NCMC work boundaries to produce key cancer monitoring and data improvement activities. The implementation strategy is applied at every point of the cancer pathway and draws upon:

- **Criteria** that guide decision making and prioritise the work of the NCMC. By determining which projects are undertaken, these criteria form the mechanism of cancer monitoring and data activities.
- **Data** that represent the resources drawn upon to meet NCMC objectives. Most of these are already collected to some extent in Australia, although not necessarily at a national, population-based level.
- **Boundaries** that are important considerations for defining the scope of NCMC data activities, but are not limitations or challenges per se. They also identify work by other agencies and organisations and their relationship to NCMC work.
- **Actions** that represent major activities linking cancer questions to data outcomes. They are formed based on the NCMC objectives of increasing data availability, enhancing data quality and improving data use.
- **Objectives** that represent higher-level outcomes to be achieved through NCMC activities. They reflect the NCMC's aim of providing accessible, policy-relevant national information for evidence-based decisions across the cancer pathway.

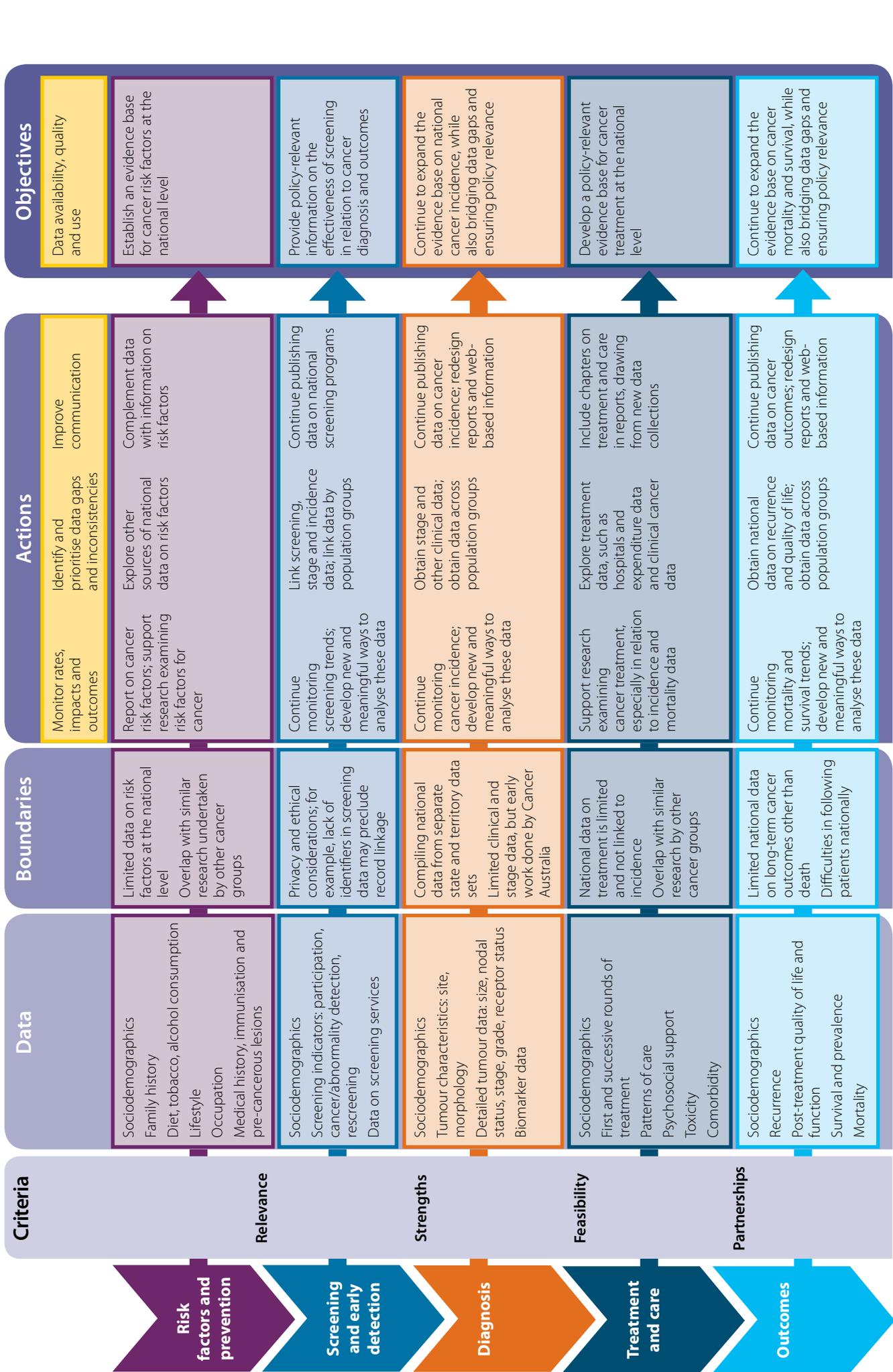
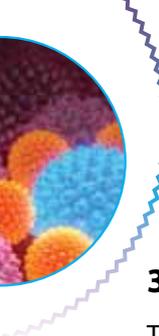


Figure 3.2: The National Centre for Monitoring Cancer's implementation strategy



### 3.2.6 Potential key activities across the cancer pathway

The implementation strategy illustrates opportunities for monitoring, addressing data gaps, and improving communication at each point of the cancer pathway. Other activities apply across the entire cancer pathway, for example, data linkage opportunities exist to join various points of the pathway and could be harnessed by the NCCMC to improve data availability and use. As part of its monitoring activities, the NCCMC will produce a number of comprehensive reports focusing on specific cancers and on cancer in specific population subgroups that would extend along the entire pathway.

#### Risk factors and prevention

Traditionally, data on risk factors and prevention have been outside the scope of national cancer data reporting at the AIHW. While a substantial amount of research is undertaken on cancer risk factors and prevention beyond the AIHW, relatively little data exist at the national level. The NCCMC will work towards improving national data about risk factors and prevention—for example, by including this information in major cancer reports, as well as by conducting and by supporting research examining risk factors for cancer. By maintaining strong relationships with other cancer research bodies, to engage in collaborative research as well as to avoid duplication of work, the NCCMC's activities will align with the objectives of the National Collaborative Research Infrastructure Strategy to provide major research infrastructure that is national and strategic, and to foster research activity that is collaborative and world-class. There are also many related data sources at the AIHW, such as the National Health Survey data, that would complement national incidence data.

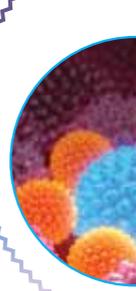
#### Screening and early detection

A number of screening monitoring activities are already undertaken at the AIHW for the national population-based breast, bowel and cervical screening programs. The NCCMC will prioritise data gaps, such as data by population subgroups, as well as link screening and cancer incidence data together to monitor the impact of screening on cancer trends. The NCCMC will also engage in horizon-scanning of the rapidly evolving nature of cancer diagnostics and emerging new techniques.

#### Diagnosis

Diagnosis is a major stage of the cancer pathway where there is mandatory, population-level data collection. As a result, there are a number of monitoring and data activities already taking place, both at the AIHW and in other cancer organisations. The NCCMC provides the opportunity for more detailed analysis and reporting on specific cancer types or cancer in specific population subgroups. Further data improvement activities will be directed towards filling data gaps and addressing inconsistencies, such as the currency of cancer incidence data, structured pathology reporting, and the availability of data by population subgroup. Projects on population-level collection of stage data are currently being undertaken by Cancer Australia, and the NCCMC will support this work. Similarly, the NCCMC will support the work of the Royal College of Pathologists of Australasia in undertaking the National Structured Pathology Reporting of Cancer Project to improve diagnostic, staging and other prognostic data. The College has also been working on standardising diagnostic and prognostic data as a prerequisite for benchmarking Australian performance in cancer management through the International Collaboration on Cancer Reporting. Further activities will also focus on new cancer data initiatives that were previously beyond the scope of national cancer data, such as clinical cancer data.

Opportunities also exist for collecting biomarker and predictive data for individual cancers. As targeted therapies and companion diagnostics develop, there is a need to systematise collection of this class of data to electronically enhance collection and to improve timeliness of collection and analysis.



## Treatment and care

While there are currently no linked national and population-based cancer incidence and treatment data, the NCMC will support Cancer Australia's work in developing data sets to collect information on initial treatment modalities. Additional data activities will involve examining relevant data collections, such as hospitalisations, and exploring clinical cancer registry data. Data improvement opportunities also exist in linkage to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data collections, as well as to other databases.

## Outcomes

At present, national data on cancer outcomes have concentrated on mortality and survival, with little information on other patient experiences such as recurrence and post-treatment quality of life. The NCMC will build on the routine work of the AIHW in monitoring cancer mortality and survival by analysing data in new and meaningful ways, as well as undertaking comprehensive reports on selected cancer topics. Gaps in the data, such as recurrence and quality of life, will be addressed by exploring new data sources such as patient journey data, and examining large-scale cohort studies to assess how these could complement existing national cancer data.

### 3.2.7 An example of the implementation strategy

**Project:** Review and redesign of *Cancer in Australia*

**Stages of the cancer pathway:** Diagnosis and outcomes

**Criteria:** The review has high relevance (there is a strong interest in cancer data), strengths (the review capitalises on the AIHW's strengths to provide national health statistics) and is feasible. Through consultations, the review would also build on the partnerships between the AIHW and its stakeholders.

**Data:** Sociodemographics and tumour characteristics (site, morphology) are available on the Australian Cancer Database (ACD). Cancer mortality data, including sociodemographics, are available on the National Mortality Database (NMD).

**Boundaries:** Data need to be compiled at the national level from the state and territory cancer registries and checked for consistency; limited data on stage and treatment prevent further reporting.

#### Actions:

- **Monitor rates, impacts and outcomes:** report on cancer incidence and mortality rates and trends, particularly for the latest year of data available
- **Identify and prioritise data gaps and inconsistencies:** illustrate the lack of quality data for comparing cancer rates by Aboriginal and Torres Strait Islander status and country of birth, and show the limitations of allocations of socioeconomic status quintile and geographic area by postcode

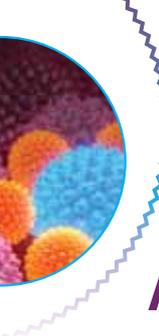
**Improve communication:** redesign publication to improve readability and access.

**Key activity:** redesign, production and release of *Cancer in Australia*.

#### Objectives achieved:

- **Data availability:** data are made available to the general public, are easy to access and easy to understand
- **Data use:** data are presented in new and meaningful ways in the report.

**Goal:** The redesign and release of *Cancer in Australia* is a key activity of the NCMC which helps expand the evidence base on cancer in Australians while also bridging data gaps and ensuring policy relevance.



# Appendix A: Cancer Monitoring Advisory Group initial terms of reference (2009)

## Background

Cancer is the leading cause of the burden of disease and injury in Australia and it has a major impact on individuals, families and the health-care system. In light of this, as well as the ever-growing demand for cancer information, the Australian Institute of Health and Welfare (AIHW) received 4 years of funding as part of the Australian Government's 2009–10 Budget to improve population-level cancer data and related evidence in Australia. This funding will be used to establish a National Centre for Monitoring Cancer (NCMC) within the AIHW. An advisory group is being formed to provide expert advice on the work of this Centre. The aims of the NCMC are described in this document, as are the terms of reference for the advisory group.

Cancer Australia also received funding to improve population-level cancer data as part of the Australian Government's 2009–10 Budget. The work that Cancer Australia is undertaking with these funds is focused on how to best capture national data on stage at diagnosis and on cancer treatments. The Cancer Data Working Group has been established to guide Cancer Australia's work in these areas.

## Aim of the National Centre for Monitoring Cancer

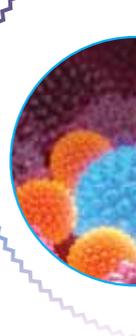
The aim of the NCMC is twofold: to monitor cancer rates and their impact and outcomes, as well as to identify and address priority gaps and deficiencies in population-level cancer and related data in order to improve the evidence base. The information and improved data produced by the NCMC will assist health professionals, researchers, policy makers, service planners, consumers and the general public to better understand national cancer trends and patterns. Areas that will be considered include (but are not limited to) incidence, risk factors, screening, diagnoses, health service use and health outcomes.

The plan is to undertake this work using a two-pronged approach: developing and collecting new data, and analysing existing data in unique and different ways. While the NCMC is a new initiative, it is not separate from the extensive work already undertaken at the AIHW in the areas of cancer and cancer screening. Further information about this work can be found on the AIHW website <[www.aihw.gov.au](http://www.aihw.gov.au)>.

## Governance of the National Centre for Monitoring Cancer

An advisory group—which will be referred to as the 'Cancer Monitoring Advisory Group' (CMAG)—will be established to provide expert advice to the AIHW regarding the activities of the NCMC. The composition of the CMAG will include members who are familiar with one or more of the following areas: the cancer data environment; current cancer-related priorities, policies and practices; and emerging issues.

In order to ensure that the work of the NCMC complements other activities being undertaken, the work of the NCMC will be done in close collaboration with major stakeholders; in particular, the Australasian Association of Cancer Registries (AACR), the Department of Health and Ageing and Cancer Australia.



## **Operation of the Cancer Monitoring Advisory Group**

### **Membership**

The Cancer Monitoring Advisory Group will comprise up to 15 members including the Chair. The Chair and members of the CMAG will be appointed by the Director of the AIHW. The CMAG will be a multidisciplinary committee, and members will be appointed because of their individual expertise and/or as a representative of an organisation or group. The period of appointment will be 2 years initially with the option to extend at the end of that time.

The group may consult with or co-opt relevant technical experts as required and additional members may be invited from time to time as need dictates.

### **Terms of reference**

The role of the Cancer Monitoring Advisory Group role will be to provide expert advice to the Australian Institute of Health and Welfare on the direction and work program of the NCMC.

Specifically, the terms of reference for the CMAG are to:

- provide expert advice to the AIHW on national information needs and requirements for cancer and related data that fall within the scope of the NCMC
- provide expert advice on the strategic direction of the NCMC including objectives and core activities
- participate in work program planning and priority setting for the NCMC, including identifying opportunities for improving cancer data
- provide expert advice on the conduct and reporting of individual projects in the NCMC work program.

### **Procedural rules**

The CMAG will meet face-to-face approximately twice a year, with additional meetings held via teleconference, as required. The meeting schedule will be determined by the AIHW in consultation with the advisory group. Out-of-session consultation may be undertaken, as required.

Agenda papers will be sent to members of the CMAG at least one week prior to each meeting.

Key decisions and advice of the CMAG will be recorded in minutes and circulated to members for ratification.

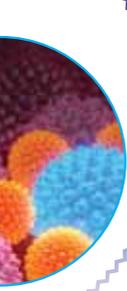
Members of the CMAG may, at times, be provided with information which is not in the public domain and is confidential. Members will thus be asked to enter into an agreement with the AIHW regarding confidentiality of information. Members will also be asked to declare any conflict of interest.

Once established, the CMAG may establish additional rules of procedure, as required.

### **Secretariat**

The Secretariat for the advisory group will be provided by the AIHW.

Travel, accommodation and any other reasonable expenses for non-government members to attend meetings will be paid by the AIHW.



# Appendix B: Cancer Monitoring Advisory Group members

**Table B1:** Cancer Monitoring Advisory Group members (and proxies) involved in the development of the National Cancer Management Centre Framework

Member	Representing
Professor Jim Bishop AO (Chair)	Executive Director of the Victorian Comprehensive Cancer Centre and University of Melbourne Chair of Cancer Medicine
Dr Cleola Anderiesz	Cancer Australia
Dr Tracey Bessell	Department of Health and Ageing
Mr Neville Board	Australian Commission on Safety and Quality in Health Care
Ms Melinda Bromley	Department of Health and Ageing
Ms Helen Catchatoor	Department of Health and Ageing
Associate Professor Stephen Fox	Royal College of Pathologists of Australasia
Professor David Hill AM	Cancer Council Victoria
Professor Janet Hiller	Academic/Australian Catholic University
Dr Sanjiv Jain	Royal College of Pathologists of Australasia
Associate Professor Rosemary Knight	Department of Health and Ageing
Ms Lisa McGlynn	Australian Institute of Health and Welfare
Ms Julie Marker	Consumer/Cancer Voices South Australia
Professor Ian Olver AM	Cancer Council Australia
Mr Andy Paras	Department of Health and Ageing
Dr Joanne Ramadge	Cancer Australia
Professor David Roder AM	Cancer Australia
Dr Chris Stevenson	Academic/Monash University
Ms Chris Sturrock	Australian Institute of Health and Welfare
Dr Tim Threlfall	Australasian Association of Cancer Registries
Associate Professor Claire Vajdic	Academic/Lowy Cancer Research Centre
Professor Alison Venn	Australasian Association of Cancer Registries
Dr Helen Zorbas	Cancer Australia

Appendix



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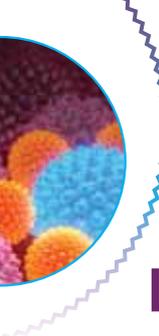
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## List of tables

- Table 2.1: Summary of the most common Australian cancer data sources (page 5)
- Table 3.1: Criteria for National Centre for Monitoring Cancer decision making (page 17)
- Table B1: Cancer Monitoring Advisory Group members (and proxies) involved in the development of the National Cancer Management Centre Framework (page 24)

## List of figures

- Figure S1: Aim, objectives and actions of the National Centre for Monitoring Cancer (page vi)
- Figure 2.1: A conceptual model of the cancer data cycle (page 4)
- Figure 2.2: Organisations and data collections involved in national, population-level cancer and screening data in Australia (page 7)
- Figure 2.3: Australian cancer data needs and sources along the cancer pathway (page 11)
- Figure 3.1: Aim, objectives and actions of the National Centre for Monitoring Cancer (page 15)
- Figure 3.2: The National Centre for Monitoring Cancer's implementation strategy (page 19)

## List of boxes

- Box 2.1: Cancer facts (page 2)

The National Centre for Monitoring Cancer (NCMC) was established by the Australian Government in 2009 to monitor cancer rates, impacts and outcomes in Australia. The centre is located and managed within the Australian Institute of Health and Welfare. The NCMC Framework guides and organises the systematic planning, implementation and evaluation of NCMC activities.

