Australian Government

Cancer Australia

A National Cancer Data Strategy for Australia

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Contents

Introduction

As Chief Executive Officer of Cancer Australia I am pleased to make available this National Cancer Data Strategy for Australia.

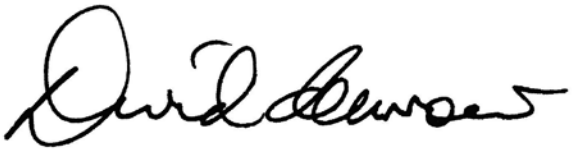
This National Cancer Data Strategy has been prepared by Professor David Roder, who has consulted widely on behalf of Cancer Australia to identify opportunities to develop cancer data capacity in Australia. Consultations have underscored the central importance of data to delivering cancer care and broader cancer control services and a pressing need to improve data availability for this purpose and to inform consumers.

In Australia, there are currently only two census points where cancer data collection is mandatory, at diagnosis (incidence) and at death (mortality). With advances in prevention, screening and treatment, many people affected by cancer are now living longer, either free of disease or with recurrent disease, yet few data exist to monitor quality of life after treatment, intermediate and long-term toxicities, and effects of new treatments and technologies.

Cancer Australia is already taking the initiative to progress a number of priorities that have been identified to date, such as mapping cancer-related data items available nationally through data collections held by the Australian Institute of Health and Welfare, Australian Bureau of Statistics, Department of Health and Ageing, Medicare and other national sources, and taking on stewardship of the existing generic Minimum Data Set (MDS) for clinical cancer registration and seeking advice from stakeholders on need for revision.

This National Cancer Data Strategy has been developed in response to public consultation, to ensure it captures as many as possible of the potential issues, strategies and priorities for action towards improved cancer care. It will be used to provide direction for collaborative effort to increase data availability, consistency and quality in Australia. The overall aim is to improve Australia's efforts in cancer prevention, early detection, treatment, and support for people affected by cancer, including caregivers.

Many thanks to those of you that have taken the time to review and comment on the gaps, issues and potential strategies identified in this foundation work. We value your contribution. I look forward to seeing how this document is used to ensure cancer data activities at the individual jurisdictional and organisational level are progressed within a broader national framework, thus reducing duplication, improving consistency and fostering collaboration.



Professor David Currow
Chief Executive Officer

1. Purpose

This National Cancer Data Strategy for Australia will provide direction for collaborative effort to increase data availability, consistency and quality. The overall aim is to improve cancer prevention, early detection, treatment, and support for people affected by cancer, including caregivers. The Strategy has been developed through an extensive consultation process and therefore represents broad national agreement on the state of play of cancer data in Australia at this time and the priorities for action over the next three to five years.

The role of Cancer Australia is to present this Strategy to the Australian community as a 'living document' that reflects the issues and priorities identified by key stakeholders. Use of the Strategy will ensure that cancer data activities at the individual jurisdictional and organisational level are progressed within a broader national framework, thus reducing duplication, improving consistency and fostering collaboration. It is also anticipated that, where possible and relevant, such efforts will be shared and coordinated nationally, with the opportunity for leadership on these nationally coordinated activities to be generated from any part of the sector.

2. Background

2.1 CANCER AUSTRALIA

Cancer Australia is an Australian Government agency established to provide national leadership in cancer control. It aims to reduce the impact of cancer on the Australian community and to lessen the divide in outcomes for groups of people with cancer whose survival rates or cancer experiences are poorer.

Cancer Australia was established to:

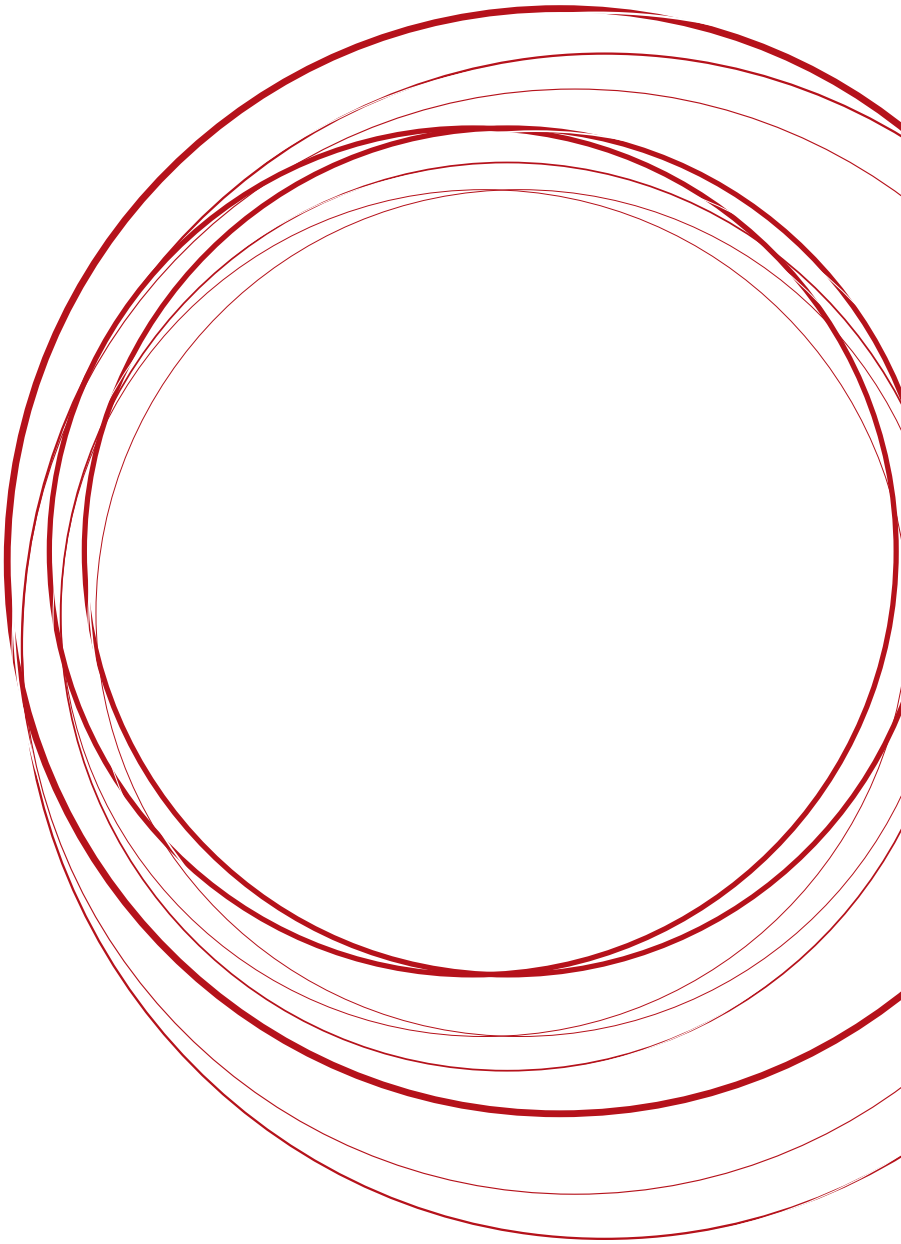
- Coordinate and liaise between the wide range of organisations, groups and service providers with an interest in cancer care and support
- Guide improvements in cancer prevention and care
- Ensure treatments are based on the best available evidence
- Make recommendations to the Australian Government about cancer policy and priorities
- Work with the research community to develop and fund research programs for improving cancer prevention and care
- Help implement Australian Government policies and programs in cancer control.

2.2 HOW THIS DOCUMENT WAS DEVELOPED

In Cancer Australia's consultations with Australian, state and territory government bodies, service providers, researchers and community groups, the central importance of data to cancer control and the need to improve data consistency, quality and availability has been widely raised. This has applied both to population data for disease surveillance and service evaluation, and to data for individual patient care. Development of cancer data capacity was nominated as a leading priority in all consultations.

Issues highlighted included the continuing importance of data for broad population health surveillance and research, and in particular the need to increase data availability to improve cancer prevention, screening, treatment, and support for people affected by cancer, including caregivers. Increased data availability was raised as a priority for: monitoring and evaluating cancer service delivery, including assessing patterns of care and outcomes of care in response to policy change; assessing the cost-effectiveness of alternative service models and treatment pathways; and determining the effects of introducing new technologies. Better data availability is being sought to monitor: quality of life, function and other aspects of survivorship after cancer treatment; intermediate and long-term toxicity and other late effects, especially of new treatments; and consumer views on service needs, access and satisfaction with service provision.

Cancer Australia established a National Cancer Data Strategy Advisory Group as one of its five National Advisory Groups, to guide the development of this National Cancer Data Strategy. Membership of this group is listed at Appendix 1. This document has been informed by the *Toward a National Cancer Data Strategy for Australia—Foundation Document* that was released for public consultation from November 2007 to March 2008. Thirty three responses were received during that period and these have been reviewed to develop the Strategy.



3. Why data are important

Health administrators, service providers, and community members require consolidated information on the burden of cancer on the community. There is a need to know how cancer and its risk factors affect different population sectors, how it is being managed, the gaps that exist in service availability, and the impacts of policy initiatives on outcomes. Data on these characteristics are fundamental for effective planning and efficient use of resources for service delivery.

Consultations by Cancer Australia and jurisdictional authorities in their planning processes have highlighted the following, more specific data and information requirements.

FOR POLICY MAKERS, PLANNERS, ADMINISTRATORS AND SERVICE PROVIDERS

While priorities vary with local circumstances, it is normal for data to be required on:

- The prevalence of social determinants of cancer (e.g., socio-economic, ethnic and geographic) and person-centred risk factors (e.g., tobacco smoking, high alcohol intake, poor diet, lack of exercise, excess body weight, excess sun exposure, non-participation in screening, and exposure to environmental carcinogens in occupational and other settings)
- Cancer incidence, mortality, stage at diagnosis, treatment, survival, prevalence, and survivorship
- Population service requirements for prevention, screening, treatment and support
- Projected service requirements
- Service availability and access
- Service participation and disparities in participation across the population
- Service activity and cost
- Service quality, as reflected in service structures, processes (including transition times from presentation with cancer to referral to a specialist and transition times along the treatment pathway, extent of participation in clinical trials, patterns of care, use of multidisciplinary care, provision of palliative care, referral for psychosocial and other support services, extent of care coordination and integration, and survivals and other outcomes)
- Service outcomes
- Resource availability and projected availability in relation to workforce, facilities, equipment and funding
- Consumer views on service needs, satisfaction and experience with services.

FOR RESEARCHERS

- Data on social determinants of cancer and person-centred cancer risk factors, cancer trends, cancer-related policies, and service delivery and outcomes, in order to support effective population health, social, health system and health services research
- Data on clinical care and care outcomes for clinical research, plus bio-specimen data to investigate molecular determinants of cancer risk and effects on treatment outcomes
- Genetic data also are required to investigate genetic determinants of cancer risk and effects of therapies.

FOR THE COMMUNITY AND THEIR ELECTED OFFICIALS

- General information on cancer risk, trends in disease, and service availability and access, both overall and for special populations groups such as the aged, Aboriginal and Torres Strait Islander peoples, ethnically diverse, geographically remote and socio-economically disadvantaged
- Data on service quality and service outcomes
- Information on service availability and access.

FOR CONSUMERS OF CANCER SERVICES

- Data on consumer views on service availability, access, and quality, and their satisfaction with services received
- Data on comparative service outcomes by type of health service, type of provider, and degree of specialisation
- Information on outcomes of services in addition to survival, including quality of life, psychosocial outcomes, and other aspects of survivorship
- Estimates of financial and non-financial costs to consumers of treatment.

4. Data availability in Australia —current status and issues

POPULATION-BASED CANCER REGISTRIES

Australia has comprehensive population coverage with population-based cancer registries in each state and territory. The primary role of these registries is broad population health surveillance and research support, which they perform well. Registry designs and content are similar, although influenced by differences in state and territory legislation, administrative environments, and other historic factors. They are coordinated nationally through the Australian Institute of Health and Welfare (AIHW) and the Australasian Association of Cancer Registries (AACR).

Population-based registries are used for:

- Routine population health surveillance, including monitoring numbers of cancers and cancer deaths, incidence and mortality rates, prevalence and survival by age, sex, country of birth, geographic location, socio-economic status, service access, and diagnostic period
- Comparing Australian cancer incidence, mortality, prevalence and survival with international data, including those provided through publications of the International Agency for Research on Cancer and the International Association of Cancer Registries
- Investigating real and perceived cancer clusters that are often associated with environmental, occupational and related health concerns (e.g., as may pertain to exposures to chemicals, ionising or non-ionising radiation, asbestos or other potential carcinogens)
- Quality assurance activities, including the provision of interval cancer data to screening programs
- Broad service planning, including projections of infrastructure needs in relation to changes in disease prevalence
- Providing representative samples for patterns of care surveys and other research studies (e.g., aetiological, clinical, psychosocial, health-system and consumer research).

While there are differences between jurisdictions in registry methodology, data definitions and currency, the collective value of population-based registry data is supported by a nationally recommended minimum data set (MDS) with accompanying data definitions. Although uptake of the MDS and data definitions has varied by jurisdiction, there is good inter-jurisdictional cooperation. Most data items from jurisdictional registries are sufficiently comparable for national analysis, which is undertaken through the AIHW National Cancer Statistics Clearing House.

Population-based registries often collect breast tumour diameters and nodal status, but rarely do they record ***stage of cancer at diagnosis,*** as needed for assessing stage-specific survivals and effects of screening and

allied early detection programs on the stage for all cancers. This has resulted, for example, in limited evaluation options for the recently introduced bowel screening program, where it has been necessary to resort to local studies for evaluation purposes. NSW is an exception, in that data have been collected at a population level since the 1970s on degree of spread of solid cancers at diagnosis (i.e., whether the spread was local, regional or distant, as used in the USA SEER[1] program).

Indigenous status is recorded by cancer registries, but data quality is poor, as in other health-related statistics collections for this field. This limits capacity to monitor health risk and outcomes of Aboriginal and Torres Strait Islander peoples. Cancer registries obtain data on Indigenous status from hospital and death statistics collections, and other secondary sources. The quality of Indigenous markers in these collections needs to improve if cancer registries are to have better data. Groups representing Aboriginal and Torres Strait Islander peoples have expressed interest in actively supporting improvements in the quality of this data. Data quality is particularly important for Aboriginal and Torres Strait Islander peoples, since they are known to experience more lethal types of cancers, later diagnoses, and poorer treatment outcomes. The health of Aboriginal and Torres Strait Islander peoples is a policy emphasis, underscoring the need for accurate statistical benchmarks for monitoring progress.

While ***coverage and timeliness of Australian population-based data*** compare favourably with most overseas experience, there are differences in timeliness across jurisdictions that affect data availability locally and nationally. In particular, timeliness of the data to support day-to-day service delivery, including monitoring interval cancers for screening programs, or addressing cancer clusters or other community concerns, varies and can be an obstacle for service delivery and research where greater data currency is needed.

Where an increased scope of data collection is needed in addition to that routinely collected by registries, it is often feasible to use ***supplementary data collections*** for time-limited periods. Ad hoc surveys can be undertaken to collect data on risk factors, quality of life, activities of daily living, treatments and other relevant characteristics. Gaining the perspectives of people affected by cancer and their carers through supplementary activities of this type can add great value to routine data collection.

The ***range of data*** collected by population-based registries is adequate for broad public health surveillance, but too narrow for clinical and other more specific service applications. In particular, these registries rarely collect data on stage of cancer at diagnosis, treatment information, time from diagnosis to first recurrence, and other outcomes apart from survival. While histological sub-types of cancers are identifiable, other sub-types defined by receptor status, biochemical and other markers are not routinely collected.

1 The Surveillance Epidemiology and End Results (SEER) program provides information on cancer statistics to help reduce the burden of cancer on the USA population.

As stand-alone facilities, population-based registries have only a limited application beyond their principal public health surveillance and research role, and can only monitor quality of care indirectly. They have a central contribution to make, however, in the ***development of data networks*** that serve broader purposes. Some jurisdictions are developing systems to integrate staging, treatment and related clinical data into their population-based cancer registry data, whereas others are complementing their population registry data through data linkage or clinical registration.

CLINICAL CANCER REGISTRATION

Clinical registries have provided the complementary staging, treatment and allied clinical data required to monitor clinical care and outcomes. In many instances, they provide data on cancer recurrence, which give an earlier indication than death data of outcomes. Generally these registries can be linked to population-based registries.

Clinical registries, either alone or in combination with other data sources, can be used to monitor and assess:

- Effectiveness of new treatment protocols, to compare this with the efficacy demonstrated in clinical trials with a highly selected group of participants
- Patterns of care compared with guideline recommendations, to find opportunities to improve care
- Economic characteristics of alternative treatment pathways, to find means of increasing efficiency
- Survival effects of different diagnostic and treatment practices, to determine best practice
- Patterns of care and survivals for high-risk groups, to address inequalities
- Intermediate and long term toxicity effects of different treatment protocols, to find means of improving patient safety
- Operational characteristics of the health system, including patient flows between the public and private sectors, to identify opportunities for system improvement
- Case loads by cancer type, to facilitate service planning and estimate accrual opportunities for clinical trials.

There is a strong interest in using clinical cancer registration in Australia to collect stage, treatment and other clinical characteristics. Major developments are occurring in NSW, Queensland, Victoria and Western Australia, but only a very small proportion of cancers are covered by these additional data fields at present, such that only limited population-based data inferences can be drawn.

Issues relating to broader collection of data include legislative, information technology and data manager support. Pathology data are indispensable for clinical cancer registration and reliant upon expert pathology input. The pathology workforce and complexity of pathology reporting need to be taken into account when considering data supply for clinical cancer registration.

As with population-based registries, clinical registry developments have mostly been a jurisdictional responsibility, or a local health agency matter. As such, they reflect local legislative and administrative influences, and local opportunities to retrieve data from other data systems. Unlike population-based cancer registries, clinical registries are not coordinated nationally (i.e., not through the AIHW/AACR or other means). Yet, there is a strong argument for access to population-based clinical registration data that cover all treatments, whether inpatient, outpatient, community or home-based.

Opportunities exist to increase the quality of data provided nationally from clinical cancer registries by ***ensuring the existing Clinical Cancer Core Data Set, originally developed under the aegis of the National Cancer Control Initiative (NCCI), is maintained for currency and relevance,*** and gaining agreement on more consistent data collection processes and definitions. This was highlighted at a "measuring cancer" workshop at the Clinical Oncological Society of Australia's Annual Scientific Meeting in November 2006.

Clinical registry models vary by state/territory. For example:

- Western Australia and South Australia have hospital-based registries administered by teaching hospitals but linkable to the respective state population-based registries. The South Australia registries were introduced in the 1980s and the Western Australia registries in the 1990s. Data sources included population-based registries, hospital-based electronic information systems, case notes and clinician reporting. These registries are mostly restricted to the larger teaching hospitals. More recently in Western Australia, a re-engineering of the state's population-based cancer registry has commenced. There are plans to extend the registry role as part of a broader Western Australian Clinical Cancer Data System, with links to hospital-based registries and other tumour-specific databases.
- New South Wales has a pilot clinical registry program involving five Area Health Services. Emphasis has been placed on data extraction from existing inpatient and other administrative databases, using electronic data retrieval. There is also an interest in NSW in integrating staging, treatment and related clinical characteristics into a re-engineered population-based cancer registry.
- Queensland has a recently introduced web-based data system, accessible across the public sector and linkable to the state population-based registry. There has also been a separate lung cancer registry, covering the public sector.

- Victoria has introduced legislative provision for the central collection of NCCI Clinical Cancer Core Data Set items in its population-based registry and is developing electronic means of receiving these data.

National initiatives in clinical cancer registration have included:

- ***The Australian Paediatric Cancer Registry.*** This is located at the Queensland Cancer Registry. It supplements data on cancers in children less than 15 years of age, obtained from state/territory population-based registries, with data on stage and clinical management obtained directly from treatment centres. An interest has been expressed in extending this Registry to cover older teenagers and young adults, in accordance with an increased policy emphasis on this age range. A major challenge in the continued operation of this registry has been obtaining the necessary administrative and ethics approvals across jurisdictions.
- ***The Australian Blood Cancer Registry.*** This was developed as a "proof of concept" initiative by a coalition of stakeholders, including consumers, clinicians, researchers, and healthcare and pharmaceutical organisations, with the objective of supporting best practice and better informed policy making. Data collection and classification standards have been defined, so as to take advantage of existing pathology reporting. There has been the promotion of automated electronic decision support within patient management systems. The development of structured pathology reporting that offers opportunities for automated data collection for registry purposes is underway.
- ***The NCCI Clinical Cancer Core Data Set.*** This focuses on the primary course of care. It was released in 2004 along with data definitions. The objective of the Data Set was the collection of enough data to be informative for service monitoring, without imposing an unsustainable burden of data collection. A larger number of data items were thought to be potentially counterproductive, predisposing to gaps in data entry and unacceptable data quality.

  Exclusions from the Clinical Cancer Core Data Set include data items on specialist referral, diagnostic procedures, multidisciplinary case reviews, shared decision-making, care co-ordination, treatment complications, quality of life and other aspects of survivorship. Such characteristics and others can be the subject of ancillary studies. Data requirements vary from time to time. As far as possible, the Clinical Cancer Core Data Set should remain stable, with priority given to core items that will always be relevant. The AIHW has asked that Cancer Australia takes on the stewardship of this Clinical Cancer Core Data Set. Ongoing stewardship will be important, if the Data Set is to remain current and credible.

BIO-SPECIMEN DATABASES

Most cancer registries have undertaken *ad hoc* linkages with bio-specimen data to support research studies. Generally the aim has been to determine how therapies might be customised to molecular and other biological features of cancers to improve patient outcomes. Considerable linkage activity has taken place in Victoria, for example, as in the support of family/genetic studies and the Melbourne Collaborative Cohort Study.

Registries also have supported studies into biomarker predictors of cancer development and of treatment outcomes by stage and other prognostic factors. The supply of bio-specimen data for these studies depends on pathologist input. Again, any changes in the pathology workforce will impact on this work. Optimising the efficiency of bio-specimen banking and the automation of data management will be important to reduce the impost on pathologists' time.

There are examples of linked bio-specimen/cancer registry platforms that can be used by external researchers, including:

- **The Research Tissue Network** in Western Australia—The network includes data on over 3000 cancers with stored tissue and/or blood. Administrative and ethics approval has been given to link the bio-specimen data to the Western Australia population-based registry and to clinical registries in the public sector. De-identified data sets can be generated for use in approved research studies.
- **BioGrid Australia** (formerly known as The Molecular Medicine Informatics Model (MMIM))—Biomarker, proteomic, imaging, co-morbidity, environmental, screening, clinical and other data can be linked to the state cancer registry and to clinical databases and official death registrations. However, unlike the Western Australian model, linking to Medicare data at the individual person level has not yet been approved. Much value is seen in the BioGrid Australia model in collecting data across multiple tumour streams and across different types of data domains (i.e., population and clinical registries, bio-specimen databases, etc.). De-identified data sets are being generated through this process for use in approved research studies.
- **Other bio-specimen networks** provide open access for external researchers to biological specimens for peer-reviewed research, including research involving cancer registry linkage, when approved by research ethics committees. They include the Australasian Biospecimen Network (ABN) that comprises six tissue banks and which aims to strengthen tissue banking and foster standard processes. Other tissue banks can also be connected to the ABN. At present, there are 10–15 tissue banks that have established these links. There are also other networks of tissue banks around Australia for haematological, breast, ovarian, prostate and skin (melanoma) cancers that provide specimens for research that may involve cancer registry linkage. The Victorian Cancer Biobank is another important tissue banking initiative. It operates a "hub and spoke" model around four main hubs in Melbourne, with links to source hospitals, and to the ABN.

- **The 45 and Up Study**—This is a large cohort of NSW residents aged 45 years and older that is being followed prospectively. Data from questionnaire surveys, bio-specimens and other sources are being linked with NSW population-based cancer registry data. De-identified data sets will be available for approved research studies.

Bio-specimens are frequently collected in clinical trials to address specific research questions. The experimental nature of trials increases opportunities for effective secondary research. The feasibility of secondary research could be increased, if attention were given to broadening the consent process for trials to include further research questions.

To be useful for translational research, bio-specimen data need to be supplemented with data on demography, histology, stage and other prognostic indicators, treatment, and follow-up recurrence, relapse and survival outcomes for periods of up to 10 years from treatment. This can be facilitated through linkage with cancer registries and other clinical databases. These linkage processes would be greatly facilitated by increasing inter-operability of databases. Ideally, Australian data systems would be compatible with the USA cancer Biomedical Informatics Grid™ (caBIG™), so as to increase opportunities for international collaboration.

OTHER CANCER-RELATED DATABASES

Other data sources used by cancer services and researchers have included:

- **The Mesothelioma Cancer Registry** previously located with the National Institute for Occupational Safety and Health. It collected environmental exposure data for mesothelioma cases. Operation of the Registry has ceased, largely as a consequence of privacy and related administrative issues.
- **National Health Survey data (ABS):** Sample surveys are used to collect self-reported data on health conditions, use of health services, and health-risk behaviours. Risk factor data are rarely collected by cancer registries, although nested surveys of sub-sets of cancer cases and controls may be undertaken for comparative analysis.
- **National skin-cancer survey data:** Periodic sample surveys of the self-reported incidence and prevalence of non-melanoma skin cancers have been implemented to assess the burden of these cancers, generally with follow-up medical verification of data accuracy. Population-based registries generally are unsuitable for collecting data on these cancers, although this is undertaken in Tasmania.
- **Cancer screening data (AIHW):** These data are obtained from state and territory breast and cervical screening programs, and more recently from the National Bowel Screening Register. They enable screening coverage and performance to be monitored.

  Deficiencies are present, as for example in gaining data on colonoscopy outcomes following bowel screening. Although BreastScreen services collect data on Indigenous status, such data are not available from cervical screening databases, which rely on cytology and histopathology reporting that do not include these data.

Through linkage of screening data to cancer registries, the effects of screening services on cancer outcomes can often be assessed and cancer incidence and outcome data used to identify population sub-groups most in need of increased screening.

- **Demographic data (ABS):** These data are essential as denominators for calculating cancer rates. The ABS Act has prevented linkage of census data with external files at a unit record level, which limits research opportunities. Such linkages have proved beneficial in the United Kingdom, other parts of Europe, and New Zealand. In Australia, ecological studies using ABS data also have been limited by the absence of a consistent small-area locator. "Mesh blocks", each based on approximately 50 households, are being introduced by the ABS to address this problem and will complement the geo-coding presently underway in some cancer registries.
- **Mortality data (AIHW):** These data are available for the period since 1968 through General Record of Incidence of Mortality (GRIM) books, which allow menu-driven assessments of mortality trends by age, sex, jurisdiction and cause of death for major cancers and other causes. A similar facility is now available for incidence data.
- **Hospital inpatient morbidity data (AIHW):** These data are episode-centric, not person-centric. They cover public and private hospital inpatients for the period since 1994–1995. Since most cancer surgery is undertaken on an inpatient basis, data linkage to cancer registries would enable monitoring of most surgical activity by cancer site and histology. This would not apply to radiation and medical oncology services, which often involve ambulatory care.
- **Medicare data:** Pharmaceutical Benefits Scheme (PBS) data have been available to the AIHW from 2004, although only Western Australia has PBS and Medical Benefits Schedule (MBS) data that could be linked at a unit-record level to cancer registry and other disease databases. While lacking the value of linked data, unlinked Medicare data have been used in ecological studies, including evaluations of effects of breast and other cancer screening services on cancer mortality, and of associations of Prostate Specific Antigen (PSA) testing with prostate cancer incidence and mortality. Databases held by private health insurers also have been used to complement Medicare data in some of these studies.
- **Allied health registries:** Examples of their applications have included the use of midwives data to explore associations of obstetric history and birth outcomes with childhood cancer risk; and the use of infectious-disease registries to investigate links of human immunodeficiency virus (HIV), hepatitis B and C, and other infections with some cancers. Renal transplant registry data have been linked to cancer registries to quantify associations of transplantation with cancer risk. The human papillomavirus (HPV) vaccine registry, presently under development, has the potential to facilitate evaluation of preventive effects of this vaccine on the incidence of cervical and other cancers.
- **Allied population files:** Extracts from Electoral Rolls and Medicare files have been used for sampling controls and identifying comparative cohorts in epidemiological studies.

- **Other data,** including:
  (1) *general practice data* (i.e., the Bettering the Evaluation and Care of Health (BEACH) survey data for the period since 1994 (AIHW))
  (2) *health and welfare expenditure data* (AIHW)
  (3) *medical and nursing labour force data* (AIHW)
  (not cancer specific, but including data on some cancer specialties)
  (4) *national drug survey data* (AIHW)
  (5) *national disability survey data* (ABS)
  (6) *infrastructure data*, i.e., data on workforce, facilities and equipment
  (miscellaneous state/territory databases)
  (7) *clinical trials register data* (Australian New Zealand Clinical Trials Registry)
  (includes details of registered trials)
  (8) *patient- safety indicator data* (includes adverse events related to surgery, medical oncology, radiotherapy and other treatments)
  (9) *data sets* on cancer research activity (miscellaneous data sets held by government agencies, professional bodies and Non-government Organisations (NGOs))
  (10) *Linked data sets* (see page 17)

5. Data gaps, inconsistencies and implications

POPULATION-BASED CANCER REGISTRATION

The absence of data on tumour, node, metastases (TNM) or equivalent stage is a fundamental gap that seriously limits capacity to interpret survival outcomes and the impact on stage of screening and other early detection initiatives.

Another gap is the lack of information on family history of cancer and the consequent inability to quantify associated risks without special purpose studies. Similarly, occupational data collected by these registries are sparse or non-existent, limiting quantification of occupational contributions to cancer risk.

Generally population registries do not collect data on precursor lesions, although pre-cancerous abnormalities are recorded in cervical cytology registers. There is not, for example, a register of adenomatous polyps, which would have greatly assisted evaluation of the bowel screening program.

LIMITED CLINICAL CANCER REGISTRATION

Gaps in data collection and feedback are common in clinical registries, largely due to a shortage of adequately trained and experienced people for data collection, database development and management, and analysis and dissemination of the data collected. Clinicians frequently lack time to do this work and rarely get required data feedback.

Clinical cancer registration covers only a small fraction of cancers in Australia. The result is a very limited availability of national data on cancer stage, co-morbid conditions, other prognostic indicators, treatment, recurrences and other outcomes. Data on other characteristics often collected through clinical registration, such as trial participation, exposure to multidisciplinary care, provision of specialist palliative care, and referral for psychosocial support, also are lacking.

Without staging data, it is not possible to evaluate early detection initiatives or assess whether increases in measured survival are due to earlier detection or better treatment outcomes. Without treatment and treatment-outcome data, and long-term survival data, the impact of treatment guidelines on practice and cancer outcomes cannot be evaluated. These treatment data, if available, could also be used in assessments of intermediate and long-term toxicities of new treatments, plus the cost-effectiveness of new technologies and of alternative treatment pathways.

While surveys of patterns of care have been undertaken to address this deficiency, they provide only a "snap shot", and due to sample-size limitations, rarely can be used to monitor services at a local level. Also, they can impose an unsustainable data collection burden on service providers. That said, if carefully targeted, they have

an important contribution to make in scoping cancer management practices and outcomes at a national as well as state and territory level. Generally more detailed data can be sought through them than is available in clinical registries. Cancers investigated successfully through these surveys have included lung, breast, colon/rectum, prostate, ovary, oesophagus, and brain cancers, and non-Hodgkin's lymphomas.

The NCCI Clinical Cancer Core Data Set for clinical registration was intended for generic service monitoring and does not address the more detailed data needs of specialists for service audit and clinical research. Specialist groups are creating their own data sub-sets for this purpose. Examples include the Royal Australasian College of Surgeons National Breast Cancer Audit data set, and in NSW, extended minimum data set items (i.e., additional to the Clinical Cancer Core Data Set) for gynaecological oncology, haematological cancers, colorectal cancers, upper gastrointestinal cancers, and melanoma.

The National Breast and Ovarian Cancer Centre (NBOCC) has developed a specialist breast-cancer minimum data set with data definitions, to complement generic clinical cancer registration. This has been field-tested in two NSW locations prior to finalisation. The aim is to produce a national guideline to increase national comparability of data. Guidelines for specialist registration also are needed for other cancers. Otherwise specialist data sets will develop in a disparate manner, such that opportunities for their collective use for external benchmarking, service monitoring and research will be limited.

Where clinical registries exist, survival outcomes can be tracked through linkage with population-based registries and the National Death Index at the AIHW. Additional data linkage is also pursued to fill data gaps, although this is often *ad hoc* and with mixed success. An exception is the WA Data Linkage System that enables linkage of cancer registry data with the range of clinical and socio-demographic data required for effective service monitoring and quality assurance. This Linkage System is a major resource, covering seven core population health databases that include 35 years of data. There are also additional links to external research and clinical databases. Similar linkage is being pursued in NSW, Queensland and Victoria. For example, in NSW, there is a Centre for Health Record Linkage (CHeReL) and a special interest in data linkage to monitor and evaluate outcomes of bowel screening, including effects of this screening on need for colonoscopy services.

There is much to be gained in improving data support for patient care and broader cancer control from data linkage, although linked data sets are limited by the level of data quality in source databases. Also, linkage can be sub-optimum where uniform patient identifiers do not exist. Another weakness is the scarcity of data available from available data sources for linkage in some areas (e.g., psycho-oncology).

Clinical cancer registries have been used for decades in the USA and elsewhere. They are a proven means of capturing the staging and other prognostic data needed to complement population registry data. Demonstration models have existed on a limited scale in Australia for up to 20 years. Case survivals have been monitored through these registries by stage and other prognostic indicators to assess service quality. There are many examples of these applications described in government reports and in the scientific literature. Increased emphasis is now being given in these registries to a more timely collection and analysis of data for decision support in day-to-day practice.

COLLECTION OF TREATMENT DATA

The collection of treatment data is more problematic at a population than institutional level. People with cancer are frequently treated through both the public and private sectors, such that patterns of care cannot be assessed with data from one sector alone. As a consequence, clinical registries in the public sector that only collect public-sector data can only have a limited role in treatment monitoring. At present, most clinical registries in Australia are located in the public sector.

DATA LINKAGE

Both MBS and PBS Medicare claims data are available in Western Australia at a de-identified level through the WA Data Linkage System. Similar linkage opportunities are being pursued in other jurisdictions. Such linked files ideally would include:

- Cancer types, dates of diagnosis and death, and causes of death (from population registries)
- Staging, other prognostic data, and public-sector treatment data (from clinical registration)
- Private treatment data, including radiation oncology and medical oncology data (from Medicare records).

For effective service monitoring and for supporting day-to-day patient care and broader service delivery, data need to be linked from the public and private health sectors, and across administrative jurisdictions. This can raise significant legal, ethical and administrative issues. Many of these issues need a national solution, guided by experience with the Western Australian linkage model, CSIRO privacy-preserving linkage methodologies, and other linkage models in the United Kingdom and North America.

There would be much "value adding" if data from BreastScreen and other screening programs also could be included in these de-identified linked data files. This would enable analyses of performance along the full screening pathway. Also, the inclusion of bio-specimen data would facilitate translational research.

Privacy could be addressed through careful linkage system design, leading to de-identified data sets at a sufficient level of aggregation to render inference of a person's identity impossible. Such approaches have been used in the WA linkage system, by the CSIRO in Queensland and Victoria, by the CHeRel linkage facility in NSW, and in various projects in other jurisdictions. A carefully planned national protocol is needed to optimise the significant public benefit to be gained from data linkage, while optimising privacy. Meanwhile, the more inter-operable the existing data systems, and the greater the use of standard data definitions, the greater will be the efficiency and utility of linkage, and the lower the need for extensive data mapping.

VARIABLE CANCER REGISTRATION

The clinical registration that does exist in Australia is based on variable data collection models and standards, which limit the collective value of the data. The Clinical Cancer Core Data Set under the aegis of the NCCI was released with minor revision in 2004 as the national data set specification for generic clinical registration. By comparison, specialist clinical minimum data set modules are mostly being developed without guidance from national standards.

Cancer registration is heavily reliant on histopathology/haematology reporting. Variable content in reporting by laboratories complicates cancer registration and leads to data inconsistencies. It is expected that the move towards structured ("synoptic") reporting will assist cancer registration by ensuring that key characteristics are reported in a common manner and in a more readable form. National guidelines for structured reporting have an important contribution to make in furthering this process.

SURVEYING THE INCIDENCE OF NON-MELANOMA SKIN CANCER

In the past there have been periodic surveys of non-melanoma skin cancer incidence and prevalence. These cancers are much more common than all other cancers combined and impose a large burden on the population and treatment services. They are not recorded in cancer registries, except in Tasmania. Data are needed on these cancers for targeting and evaluating skin cancer-prevention initiatives and for more general service planning. The aim should be to gather complementary data to those collected on these skin cancers through the Tasmanian Cancer Registry.

MONITORING CANCER TRENDS AND OUTCOMES IN ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

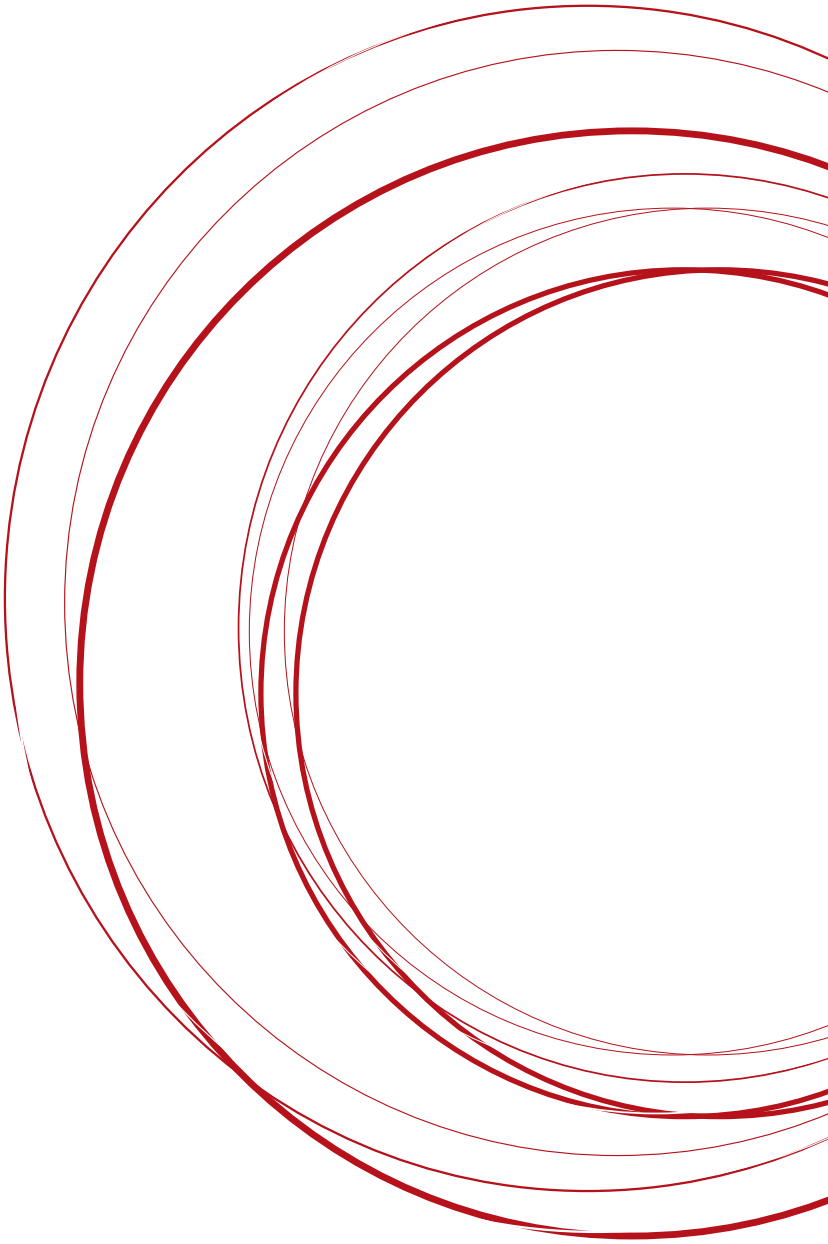
Research studies in a number of Australian locations show that Aboriginal and Torres Strait Islander peoples have particularly adverse cancer outcomes. Indigenous identification has been poor in health records generally, including cancer registries, and requires upgrading if cancer trends and outcomes for Aboriginal and Torres Strait Islander peoples are to be monitored and addressed effectively.

OTHER DATA COLLECTION GAPS

Population and patient/carer surveys have been a useful means of data collection on: risk behaviours; community views on service needs, availability, and access, and on satisfaction with services; and survivorship and the availability of community support services. National indicators and normative standards for these characteristics would greatly assist data interpretation. These surveys have been *ad hoc*, sporadic, and uncoordinated. Similarly, while data on workforce and other infrastructure needs exist, there are significant gaps that limit their usefulness for ongoing monitoring and planning.

There is much data collection in Australia, but as in most other countries, it is frequently service-activity centred rather than person centred. Without linking data from multiple databases at the person level, the collective value of these data cannot be realised.

Another issue is the absence in many cancer data systems of information on co-morbidity and broader health issues. This prevents the assessment of cancer in a broader health context.



6. Proposed strategic directions

INTRODUCTION

Data on the burden of cancer on the population are fundamental to target control programs effectively and reduce inequalities. There is a clearly identified need for these data for governments, health service administrators, service providers, consumers, community organisations and researchers.

Data collection needs to be integral to the ordinary business of providing cancer services, with its own planning and funding. Data are needed on socio-demographic descriptors to monitor health inequalities according to geographic remoteness, socio-economic disadvantage, exposures to occupational hazards, ethnicity and Indigenous status. The cancer burden also needs to be monitored by disability status, service availability and access, and by tobacco use and other risk behaviours. With an increased age profile of the Australian population, it will be important to monitor cancer management practices outcomes in the aged sector of the community.

There is a need to better define key cancer-control questions, the data available to address them, how to access these data and how to provide a coordinated response. Data gaps need to be identified and appropriate priorities agreed upon for filling them. The steps needed to improve data quality and data consistency need to be defined, along with the research required to develop effective data-collection models and technologies.

Cancer Australia has a focus on improving cancer outcomes. A key role will be to ensure the national health-data collection and reporting effort optimally uses existing data in a coordinated way. This includes data on factors ranging from environmental risk factors, and means of identifying population sub-groups exposed to unacceptable environmental risks, to data on behavioural risk factors, service availability and access, quality and appropriateness of care, and care outcomes.

The National Cancer Data Strategy provides a framework to address these needs in a prioritised manner, with guidance from the National Cancer Data Strategy Advisory Group and consultation more broadly. Operational plans also will reflect broad consultation with other partner organisations and stakeholders. Cancer Australia will work with these bodies in a planned and coordinated manner to ensure that cancer data needs are addressed.

It is not the role of Cancer Australia to lead each of these strategic initiatives. Rather, its role is to identify opportunities where the best placed agencies or groups can drive specific initiatives.

The following strategies and activities will need prioritisation for implementation. They provide a direction for collaborative effort to improve data development for the Australian community.

IMPROVE DATA AVAILABILITY

1. Assess and prioritise data needs for cancer care and broader cancer control applications

This should cover data needs for:

- Public health surveillance, including surveillance of the health of Aboriginal and Torres Strait Islander peoples and other groups at special risk
- Health policy development and administration
- Cancer prevention, including assessing cancer risk factors and broader social determinants of cancer
- Service delivery, including delivering preventive, early detection, treatment, supportive, palliative, and terminal care to individuals and population groups
- Research.

2. Map data availability in relation to these needs, identify and prioritise gaps, and collaborate with data collection agencies in closing gaps

This should include consideration of the data gaps highlighted in consultations to date, including gaps in the data needed for assessing:

- Appropriateness of treatment and broader service delivery, as related to best-practice guidelines, and service quality
- Survival rates, quality of life, psychosocial and other treatment outcomes by stage
- Intermediate and long term toxicity of new treatments
- Performance of new technologies
- Cost-effectiveness of alternative service models/interventions
- Disparities in service access, utilisation and quality
- Disparities in cancer risk, prevalence, outcomes and survivorship
- Consumer satisfaction with service availability and provision.
- Effectiveness of communications of health care professionals with consumers and of meeting consumer demands for information on service performance by health-service and provider type by degree of specialisation

A balance needs to be struck between the routine collection of data and the use of supplementary time-limited collections and surveys targeted to close gaps (as has been used to good effect, for example, in evaluating bowel screening). Data linkage also offers opportunities to bring data together from different sources to close gaps. This is relevant for addressing a wide range of purposes, including assessing effects of current screening initiatives on cancer incidence, stage and survival by socio-demographic sub-group.

Data collection comes at a financial cost, which often deters data-system development. On the other hand, the cost of not collecting data needs to be considered, including unguided health services that lead to inequitable or unknown health outcomes.

An collation of currently available national data sets has been compiled by Cancer Australia and is available at www.canceraustralia.gov.au

3. Address deficiencies in Indigenous identification in cancer registries and allied databases

Cancer registries obtain these data from hospital admission and death records. The quality of data on Indigenous status from these sources is generally poor and needs upgrading if cancer and broader health-related needs of this sector of the population are to be addressed effectively. The Northern Territory has invested in improving Indigenous identification in its cancer registry. There may be methodological lessons from this experience for other states and territories.

4. Maximise data use

Maps of data resources and contact people should be disseminated to potential data users. These users could be identified from lists of existing users; national, state and territory health agencies; professional health-provider groups; lists of cancer researchers; and "snowball sampling" techniques, beginning with identified users. An open access data system, housing only de-identified data, could assist in improving health outcomes. Opportunities to bring data together from separate databases, as for example through NCRIS (National Collaborative Research Infrastructure Strategy) and other initiatives, need to be pursued to maximise the collective value of these data.

Data analysis is needed to distil information from databases for regular feedback to providers, such that their use can be maximised. Small-area data availability is important to avoid masking inequalities at a local level. Small-area data also are useful for ecological studies to identify at a population level determinants of cancer and poor cancer outcomes.

Data users need to be referred to relevant data reports, already published in the peer-reviewed literature or in government reports, such that additional analyses can build on past results.

5. Barriers to data use

There is a need to address legislative barriers to data access and requirements for researchers to gain approval from multiple ethics committees. While due regard for ethical standards and privacy protocols is very important, the need for multiple clearances and multiple approval processes is a major source of inefficiency and often, a barrier to progress. Mutual recognition and other means of streamlining ethics committee approval processes need to be pursued.

Use of health consumers' information requires careful balancing with privacy requirements. There is a need to respect individual privacy and arrange for "opt in" and "opt out" provisions, as appropriate. Community awareness of the use of identified data by registries and other data systems is important, together with the legislative and governance frameworks in which they operate.

A position paper could be developed on data access, the integration of public and private data for service improvement, and consistency in data access across institutions. The paper should address interactions with privacy law and the Tissue Act, and be available as a basis for comment on reviews of the Privacy Act.

Registries need to cover all cancers, if their purpose is to define incidence, mortality and survival. Legislation to mandate reporting is often necessary in these circumstances. When legislation applies, there should be broad dissemination of information on this practice, such that it is known to consumers. Alternatively, where registries are directed at service quality improvement, an "opt out" or "opt in" approach may be more appropriate.

There would be benefits in harmonising Commonwealth/State/Territory legislation and policy in relation to privacy, ethics and informed consent. It is notable that privacy issues have raised recent challenges for existing registries (e.g., the Mesiothelioma Registry and the Australian Paediatric Cancer Registry).

The wide variations in ethics approval processes, and data access protocols more generally across Australia, constitute a barrier to data use. Cancer registry data may be currently under-utilised as a result of some of these barriers.

The increasing proportion of cancer care provided through the private as well as public sector presents complications for access to data on the complete treatment pathway. It is important that this is addressed as it runs counter to safety and quality monitoring requirements.

6. Promote awareness among funding bodies of data applications in cancer control

Information on data requirements and applications should be collected so that funding bodies can consider these matters when making funding decisions. There has been a major increase in demand for data in response to trends towards evidence-based practice. The associated resource requirements need to be considered.

7. Ensure key data collection activities are continued

Priority data collections need to be sustained. Data collections can be vulnerable at times of organisational change. Also, alternative means of data collection, such as use of sentinel practices and laboratory data repositories, need to be explored. Such practices are relevant for non-melanoma skin cancers, which are easily the most prevalent type in Australia, but are generally not amenable to cancer registration.

IMPROVE DATA REPORTING

8. Promote the production of data reports that address key cancer questions

There needs to be ongoing consultation and review of key cancer-control questions to guide data analysis and reporting. These questions need to be defined through a consultative process involving health administrators, health professionals and consumers. Report production could be collaborative ventures between data-collecting bodies and data users. Australia-wide standards for reporting incidence, mortality and survival should be developed, to assist the production of a regular coherent national picture.

IMPROVE DATA QUALITY AND CONSISTENCY

9. Maintain the MDS developed by the NCCI for generic clinical registration

The currency of the NCCI Clinical Cancer Core Data Set should be maintained. There has been recent concern, for example, that participation in a clinical trial is not included as an item. Revisions need guidance from clinical authorities. The process should be undertaken in collaboration with the AIHW, the Statistical Information Management Committee and related standards-setting bodies, and with consumer involvement.

10. Promote the development of MDS modules for specialist clinical registration

This development is important if data consistency is to be increased. Specialist bodies (e.g., tumour stream specialists) need to lead these developments, working with the AIHW, the Statistical Information Management Committee, and related standards-setting bodies, and with consumer involvement. Priorities need to be established for developing MDS modules for this purpose.

11. Seek approval for minimum data sets for cancer registration, with nationally authorised data-dictionary definitions, from the Australian Health Ministers Council

Approved minimum data sets could be incorporated into Australian Health Care agreements between the Australian government and the jurisdictions to support their adoption. Apart from this, their use and common interpretation could be promoted through cancer-service accreditation.

12. Develop a framework document to support development of specialist minimum data sets along common pathways

Until specialist MDS modules can be developed across the full spectrum of cancers, specialists (i.e., tumour stream specialists) will create their own data sets independently. A framework document has been developed to guide this process to achieve greater data consistency and is available at www.canceraustralia.gov.au

13. Determining data requirements with administrators and users of major tissue banks

Administrators and users of major tissue banks should jointly determine data requirements. Tissue banks have a central role to play in genetic and other molecular research. There is a need to optimise their development and availability for this purpose. Bio-specimen databases need to be developed that can be inter-linked and linked with clinical and population health databases for research translation. Infrastructure available internationally should be considered for Australian applications. This should include the Netherlands PALGA network, the European Biobanking and Biomolecular Resources Research Infrastructure, the EuroBioBank, the USA caBIG™ project and the Canadian Tissue Repository Network, CTRNet.

RESEARCH IN DATA COLLECTION AND USE

14. Promote innovation in data collection

Traditional methods of clinical cancer registration are likely to be too labour-intensive to be sustainable in many contemporary health-service environments, particularly where patients are treated through multiple public and private service outlets. There needs to be experimentation with alternative models, including models that extract data from existing databases. The development of electronic health records, apart from improving individual patient care, is likely to greatly increase the availability of timely data for clinical safety and quality monitoring.

Where data of adequate quality have already been collected in other clinical and administrative data systems, it would reduce the burden of data collection if these data were used, rather than undertake repeat data collection. A universal health identifier would facilitate the linkage process and the value of linked databases would be enhanced if data were collected according to national standards, thus reducing the need for data mapping.

Research into alternative data collection models is needed. Research settings could include:

(1) ***The WA Data Linkage System,*** which links health-related data from multiple sources, including Medicare, for research purposes and to support cancer care delivery

(2) ***The CSIRO/Queensland Government E Health Research Centre,*** which supports health data integration programs around Australia and has undertaken research into the auto-coding of stage from pathology and other record sources, the development of privacy-preserving analytics, and other innovations

(3) ***The NSW Centre for Health Record Linkage (CHeReL),*** which is partnering with the NSW Cancer Institute for pursuing cancer data linkage to monitor cancer care and service outcomes, and support cancer care delivery

(4) ***BioGrid Australia*** (formerly known as the Molecular Medicine Informatics Model (MMIM)) which links genetic, proteomic and other molecular data with clinical, population health and other data for research purposes

(5) ***The NSW Clinical Cancer Registry Model,*** which extracts data weekly for notifiable patients from existing "live feeds" from the NSW Health Admitted Patient and Radiotherapy statistics. Demographic data are imported directly from hospital systems using secure HL7 messaging.

In addition, research into automated data collection from structured ("synoptic") reports should be given priority.

15. Develop and test options for data collection

Data linkage has been highlighted as an important methodology to increase data capacity. The NCRIS initiative is proposing a network of state data linkage units, and a national unit, to facilitate the linkage of clinical and population health data for research. Any opportunities to link cancer data through this initiative would be important to follow up.

On other occasions, alternatives to data linkage would be more appropriate, including sample surveys or sentinel data collection. Data on quality of life of health consumers are important for health-service evaluation and may require customised surveys, since these data would rarely be obtainable through linkage. Investigations to identify the best data-collection options for specified purposes and settings would be of value. In 1997, one-off national funding was provided to cancer registries to collect additional data for breast-screening evaluation.

Pilot testing is needed to determine how existing population-based cancer registry data can be extended and complemented with more clinically orientated data, taking advantage of eHealth and related data initiatives. Through this means, broader data on patterns of care, referral patterns, disease recurrence, treatment, co-morbidity and related health matters could be collected. The Australian Commission on Safety and Quality in Health Care is piloting clinical quality registry projects. This will be an opportunity to test methods of cancer-data collection and dissemination.

16. Include data on ethnicity in cancer data collections

Apart from Indigenous status, there is a need to record ethnicity, given the multicultural character of Australia. Often country of birth or main language spoken at home is used for this purpose although these data are not universally recorded and better descriptors are needed.

17. Promote data collection on the prevalence of metastatic cancer

Cancer registries do not collect these data. Yet, with increases in survival of people with metastatic disease, the need for data on prevalence at diagnosis and recurrence, and on effectiveness of treatment, has increased. As an interim measure, statistical modelling projects need to be supported to estimate prevalence nationally and regionally, so as to assist service planning. It will be important to ensure, however, that this initiative not impede the collection of metastatic data by registries, as a basis for research and outcome monitoring.

18. Develop a national platform for cancer registration and to support cancer care delivery

The present population-based cancer-registration system is susceptible to data inconsistencies and inefficiencies. Conversely, it provides for a close proximity between data collectors and data users at a jurisdictional level, which would be conducive to local data use, and it enables comparison between different registration models.

There would also be value in reviewing prospects for a national IT platform, as an option for cancer registration. This option could be taken up by states and territories on an "opt in" basis and might be particularly useful for jurisdictions that lack the resources to develop their own customised products.

Also, electronic means of extracting clinical registry data from local databases for national compilation need to be explored, such that national comparison and benchmarking would be facilitated.

19. Improve collaboration and dissemination of research and development results

Australia has a history of independent development of data systems, with suboptimal inter-jurisdictional collaboration in the development process. The development of a collaborative framework to facilitate the promotion and sharing of experience across Australia would be of value, so that opportunities for mutual learning and collaboration can be realised.

20. Improve efforts to distil and communicate key messages from the data

Communication strategies are required to ensure that feedback reaches decision makers. Data analysts are needed to distil messages from available data for these communications. Outputs need to be customised to the needs of laypeople as well as policy makers, service personnel and researchers. Feedback needs to cover the primary health care providers, as well as specialist groups.

Communication needs to be balanced and complete, such that truly informed decisions can be made. Effective feedback is an investment in evidence-based decision making and improved health returns on health investment. Opportunities for web based technologies need to be pursued for clinical registration, with data output also transmitted on the web. An excellent outcome would be for Australians to be able to view their own data on the web, in the same way that they now can view American data.

Appendix 1:

NATIONAL CANCER DATA STRATEGY ADVISORY GROUP— THIS LIST REFLECTS MEMBERSHIP OVER THE LIFE OF THE GROUP. NOT ALL THOSE LISTED ARE CURRENT MEMBERS.

Ms Deborah Baker	Manager—Monitoring, Evaluation, e-Research, Cancer Institute NSW
Ms Jacqueline Ball	Department of Health and Ageing
Ms Catriona Bate	Australian Bureau of Statistics
Associate Professor John Bass	Menzies Research Institute, University of Tasmania
Mr Neville Board	Information Systems Manager, Cancer Institute NSW
Ms Denise Carlton	Director, Australian Bureau of Statistics
Ms Shoni Colquist	Queensland Cancer Control Analysis Team, Queensland Health
Mr Greg Coombs	Assistant Secretary, Economic & Statistical Analysis Branch, Department of Health and Ageing
Professor David Currow (Chair)	CEO, Cancer Australia
Mrs Jurina Demaine	Consumer
Dr Rhys Francis	Executive Manager, The National Collaborative Research Infrastructure Strategy (NCRIS)
Associate Professor Lin Fritschi	Head, Cancer Epidemiology, Western Australian Institute for medical Research
Professor Graham Giles	Australasian Association of Cancer Registries
Mr John Harding	Head, Health Registers and Cancer Monitoring Unit, Australian Institute of Health and Welfare
Dr Marienne Hibbert	Project Director, BioGrid Australia (previously MMIM—Molecular Medicine Informatics Model)
Dr David Joske	Australian Blood Cancer Registry
Ms Andriana Koukari	Assistant Secretary, Population Health Programs Branch, Department of Health and Ageing
Dr Huw Llewellyn	The Royal College of Pathologists of Australasia
Mr Gary Morgan	Chief Executive, e-Health Research Centre

Mr Peter Morris	Assistant Secretary, Population Health Strategy Unit, Department of Health and Ageing
Professor Ian Olver	CEO, Cancer Council Australia
Professor David Roder	Data Manager, Cancer Australia
Ms Rada Kusic	Clinical Oncological Society of Australia—Clinical Research Professional Group
Professor Bernard Stewart	Head, Cancer Control Program, South East Sydney and Illawarra Area Health Service
Ms Christine Sturrock	Head, Health Registers and Cancer Monitoring Unit, Australian Institute of Health and Welfare
Dr Paul Tridgell	Australian Commission on Safety and Quality in Healthcare
Ms Clare Vivian	Consumer
Ms Anne Woollett	Clinical Oncology Society of Australia—Clinical Research Professional Group
Professor Patsy Yates	Director of Research, Centre for Health Research—Nursing, Queensland University of Technology
Dr Helen Zorbas	Director, National Breast and Ovarian Cancer Centre

Appendix 2:

ACRONYMS AND ABBREVIATIONS

ABN	Australasian Biospecimen Network
ABS	Australian Bureau of Statistics
AACR	Australasian Association of Cancer Registries
AIHW	Australian Institute of Health and Welfare
BEACH	Bettering the Evaluation and Care of Health
caBIG™	cancer Biomedical Informatics Grid™
CSIRO	The Commonwealth Scientific and Industrial Research Organisation
CHeReL	Centre for Health Record Linkage
GRIM	General Record of Incidence of Mortality
HIV	Human immunodeficiency virus
HL7	Health Level Seven
HPV	Human papillomavirus
MBS	Medical Benefits Schedule
MDS	Minimum Data Set/s
NBOCC	National Breast and Ovarian Cancer Centre (previously known as the National Breast Cancer Centre)
NCCI	National Cancer Control Initiative
NCRIS	National Collaborative Research Infrastructure Strategy
NGO	Non-government Organisation
PALGA	Pathologisch Anatomisch Landelijk Geautomatiseerd Archief (Dutch National Pathology Information System)
PBS	Pharmaceutical Benefits Scheme
PSA	Prostate Specific Antigen
SEER	Surveillance Epidemiology and End Results
TNM	Tumour Node Metastasis