



# **Cancer Australia Submission**

## **Productivity Commission Inquiry – Data Availability and Use**

**July 2016**

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### **Introduction**

Accurate and up-to-date data is critical for evidence-based decision-making in all areas of public policy. In particular, the availability of high quality data across the cancer control continuum (i.e. from prevention, screening and diagnosis, through to treatment and survivorship) is vital to ultimately improving cancer outcomes.

Improving the collection, standardisation, access, linkage (or data integration), analysis and reporting of national cancer data will help us to better understand unwarranted variations in cancer outcomes across the Australian population, and allow for more targeted policy and practice approaches in areas of need. In addition to improving the evidence base for policy decision-making, people affected by cancer see improving the availability and use of data as a priority to improving cancer care and outcomes in Australia.

Cancer Australia welcomes the opportunity to provide input into the *Productivity Commission Inquiry into Data Availability and Use*. Given the broad scope of the inquiry, this submission is structured as follows:

- An overview of Cancer Australia's role and remit;
- An overview of the matters raised in the Inquiry Issues Paper, as they pertain to cancer-related data, including Cancer Australia's program of work in data; and
- Specific issues under Terms of Reference 1, 2 and 4 of the Inquiry, including – as requested in the Issues Paper – examples of best practice.

While this submission focuses on cancer data, many of the issues discussed are common to health data in general. As the subject of data availability and use is both complex and wide-ranging, and given the environment of health data analytics is rapidly changing, this submission and the examples provided are not intended to be comprehensive in addressing all aspects of the Issues Paper.

### **About Cancer Australia**

Cancer Australia is the Australian Government's national cancer control agency and was established in 2006 to benefit all Australians affected by cancer, and their families and carers.

In line with functions specified in the Cancer Australia Act 2006 (Refer Appendix 1), Cancer Australia provides national leadership and coordination in cancer control, and guides scientific improvements across the cancer control continuum, from prevention, screening and early detection, to diagnosis, treatment, follow-up care and supportive care.

The agency undertakes its work in partnership with a wide range of stakeholders, including health professionals and professional colleges, researchers and research-funding bodies, non-government cancer and health organisations, other health portfolio agencies and cancer consumers. Cancer Australia maintains a strategic and inclusive approach to consumer engagement, which ensures that its work is informed by, and responsive to, the needs of people affected by cancer and the broader community.

## Cancer Data in Australia

The projected increase in the number of people diagnosed with, and surviving, cancer<sup>3</sup> will create greater demand across the health system. A better understanding of patterns of care and variations in outcomes will become increasingly important in order to target resources to where they can make the most difference. In order for this to occur, improvements in access and use of data will be required.

Two main types of data used to inform cancer control in Australia are: (1) clinical cancer data, which primarily informs the treatment of individual patients; and (2) population cancer data, which provides a broader picture of cancer control across the country. Given Cancer Australia's role and remit, this submission primarily focuses on population-level data.

Australia is fortunate that – by world standards – there is, at present, comprehensive coverage of data being collected at certain points of the cancer control continuum. For cancer incidence, mortality and survival, mandatory collection of these data allows for comprehensive national reporting of these measures over time and for subgroups of the population.

It should also be noted that recent initiatives, at the Commonwealth level in particular, have increased the availability of public sector data (e.g. the establishment of data.gov.au and the Integrating Authorities). However, there still exist a number of broad issues relevant to the present Inquiry<sup>1</sup>, as summarised below (noting that these issues are also applicable to health data in general):

- Data relevant to cancer control is collected and held by a wide range of different, mostly public sector organisations. These include various Commonwealth and state/territory agencies, and to a lesser extent some non-government organisations. There is no overarching process or mandate for these organisations to share these data, and access is usually predicated on *ad hoc*, bilateral agreements.
- Gaining approval to access data can be resource-intensive. As outlined in *A National Cancer Data Strategy for Australia*: “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”<sup>1</sup>.
- In the cancer field, mandatory collection of data only occurs at two points along the cancer control continuum: (1) at diagnosis of cancer (incidence); and (2) at death due to cancer (mortality). These data are collected by state/territory registrars and collated at the national level. However, critical aspects of cancer control – notably stage at diagnosis (i.e. extent of disease) and recurrences – are not mandated by all governments.
- Gaps remain in standardisation and collection protocols for certain types of emerging or complex cancer-related data. This is particularly the case with respect to

biobanking and bioinformatics (i.e. population data that incorporates information about genetic mutations).

There have been some recent advances towards overcoming barriers relating to the access and use of cancer data (see next section). Although well-established processes are in place to access public sector datasets, more efficient linking and sharing of data relevant to cancer control could optimise the resources used by data custodians to provide data and limit the costs paid by organisations accessing the data. Assuming appropriate ethical and privacy standards are maintained, this would allow for a continued sustainable and cost-effective approach to ensuring evidence-based policy approaches are applied to cancer control in Australia.

### **Cancer Australia's work in data**

As the national cancer control agency, Cancer Australia developed a program of work under its *Strategic Plan 2014-2019*<sup>2</sup> which aims to address some of the issues noted above. Cancer Australia works in collaboration with stakeholders to increase national cancer data availability, consistency and quality. The overall aim is to improve cancer outcomes through data-informed and targeted strategies such as:

- Developing a framework of **National Cancer Control Indicators**. This framework identifies key indicators (and associated measures) across the continuum of care. Monitoring these indicators will support evidence-based decision-making for improved policy and practice towards better cancer outcomes, and provide a better understanding of unwarranted variations in cancer outcomes. The framework also provides a platform for bringing together cancer-specific data from different sources, and will facilitate the use of different data sets relevant to cancer control.
- Addressing critical data gaps through the **Stage, Treatment and Recurrence (STaR)** project. This is a multi-phase project, in collaboration with multiple stakeholders, to develop high-quality, comprehensive national data on the stage (Tumour, Node, and Metastasis - TNM) of cancer at diagnosis, the treatments applied to cancers and the frequency of recurrence of cancer after treatment. Collation, analysis and use of STaR data will allow for more targeted policy and practice across the cancer care continuum, including understanding unwarranted variations in cancer outcomes across different population groups.

## **Terms of Reference 1: Availability of Public Sector data**

Terms of Reference 1 of the Inquiry is to examine the benefits and costs of options for increasing availability of public sector data to other public sector agencies, the private sector, research sector, academia and the community. Due to the broad scope of Terms of Reference 1, the sections below are provided in reference to selected questions presented on page 14 of the Issues Paper.

### **1.1 Benefits from increasing availability of public sector data**

Government departments and agencies collect and hold, through their activities, large volumes of cancer-related data. At the Commonwealth-level these are primarily the Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS), and the Department of Health. These data span the cancer control continuum, from data about

risk factors, vaccination programmes, screening and detection programmes, and disease incidence, admitted patient care, cancer treatments and medicines (including associated costs), mortality and survival.

From a cancer control perspective, there are a relatively small number of national datasets that provide particular value to other public sector agencies, researchers and the community, such as:

- Cancer incidence data, which provide a complete picture of cancer diagnoses in Australia. These are collected by state/territory population-based cancer registries and collated into the AIHW Australian Cancer Database;
- Medicare Benefits Schedule (MBS) data, which provide information about national outpatient treatments such as radiotherapy;
- Pharmaceutical Benefits Scheme (PBS) data, which provide information about dispensing for PBS-listed pharmaceutical cancer treatments such as chemotherapy and systemic therapies;
- Admitted patient care data, which provide a complete picture of inpatient treatments for cancer (e.g. many surgical procedures). These are collected by state/territory data custodians and collated into the AIHW National Hospital Morbidity Database ;
- Cancer mortality data, which provide information regarding cause of death, and allow for the calculation of relative survival by cancer type. These are collected by state/territory registrars and collated by the ABS, and linked to the AIHW Australian Cancer Database via the National Death Index).

Increasing the availability of public sector cancer data, such as those listed above, entails encouraging the public release of de-identified data. From a cancer control perspective, including socio-demographic information (where data quality allows) in publically available data is useful for understanding inequities in cancer outcomes between population groups. Where detailed, de-identified data is not released routinely, increasing the ease with which data requests for such information can be made, or provision of access to the actual data, should be encouraged.

The benefits of increasing the availability and use of data include improving its utility and value. Data quality issues can be identified and more readily addressed, and as a result of this 'positive feedback loop', higher quality data can be used more effectively in identifying areas of need and thus enable the progressing of positive health outcomes.

Access to timely data allows for ongoing monitoring and evaluation of national programs; increased value for the health system through better use of existing resources (i.e. existing data); enhanced health system responsiveness; greater transparency and accountability for governments and other service providers; and improved outcomes through monitoring the impact of policy interventions over time.

More accessible data will also be exposed to a wider range of innovative ideas and approaches ('the marketplace of ideas'), ranging from new and varied data analysis techniques to the development of better targeted programmes and policy initiatives for improving public health outcomes and disparities<sup>4</sup>. In addition, increasing the availability of data inherently leads to a culture of collaboration, where researchers and public/private

organisations can make use of collected data, and can collaborate to answer specific research questions<sup>4</sup>.

Ultimately, increasing the availability and use of data can improve cancer outcomes through improved clinical decision-making and strengthened evidence-based policy decisions. This in turn can reduce the incidence of cancer, increase cancer survival, and improve long-term outcomes for people affected by cancer.

### **Best Practice Examples**

#### *National Statistical Service*

The National Statistical Service (NSS), in collaboration with government agencies and data custodians, acts as a peak coordinator/forum regarding public sector data in Australia<sup>5</sup>. The NSS supports the Essential Statistical Assets for Australia initiative, which acts as a framework for providing a more seamless national statistical system<sup>6</sup> (e.g. by minimising the risk of duplicating data collections).

#### *Data.gov.au*

Data.gov.au was established as a central hub for public sector datasets, in order to encourage the use of government data<sup>7</sup>. In addition to open datasets, the catalogue includes unpublished data and data available for purchase. A related website – nationalmap.gov.au – provides access to spatial data from Australian government agencies<sup>8</sup>.

## **1.2 Factors impeding government agencies from making their data available**

As mentioned above, some public sector agencies which hold data may adopt cautious approaches towards the release of data, even to agencies and departments within the public sector. The influence of privacy legislation, or concerns about how the data will be used, can also heighten the tendency of data custodians towards being risk-averse. This can cause subsequent delays for users in accessing low-risk, de-identified data. The time required for committee approvals, pulling-out the data and cost-recovery processes may also add significant costs and delays in the process of accessing data from custodians – factors which may have significant opportunity costs for those requiring certain data.

Some broad approaches to assist in addressing these problems include:

- Prioritise and promote – across government – collaboration and openness as values inherent to public data custodianship. Organisations which hold public data could also review their use of data approval committees and limit the need for them to approve straightforward or common data requests.
- Where required, encourage data users and custodians to maintain formal ongoing communication regarding use of the data, outputs of data analysis, and broader project governance, so as to assuage any concerns about how data is being used.
- Encourage the development and use of remote data access infrastructure. This would allow for users to directly access detailed, de-identified data in a timely fashion, and would limit costs on the part of data custodians by reducing the production of similar data multiple times. It would also reduce costs for those

accessing data. It would also allow data custodians to pre-emptively address mitigation strategies for data requests where privacy issues may be a genuine risk.

#### **Best Practice Example**

##### *Data Cubes and Remote Access Data Laboratories*

Various products of varying complexity are currently available that allow users to access public sector data. Many Commonwealth agencies such as the AIHW and ABS provide free access to users of limited amounts of data via spreadsheets and online data cubes. For a nominal fee, some ABS data is available through 'TableBuilder' products that allow users to select their required variables. Finally, remote access data laboratories allow users to interrogate data sets directly (which usually requires some knowledge of statistical software programming)<sup>9</sup>.

### **1.3 Using data more efficiently and effectively**

As highlighted in Box 2 of the Issues Paper<sup>10</sup>, agencies and departments could explore opportunities to collaborate and co-operate in developing approaches to maximise the utility of the data, by developing approaches for its efficient use (e.g. by identifying research topics; undertaking linkage/ integration). Although there are exceptions, on the whole there is not an environment of collaboration or partnership between data custodians and those seeking to access and use data. Rather, this relationship is often framed as that of a service provider and service user. However, opportunities exist to develop these types of partnerships, especially between government agencies with a common goal to maximise the utility of public sector data.

As discussed above, efficient use of data can be optimised by exposing it to a greater breadth of innovative ideas, exploration, research and analyses. One improvement in this area could be, in addition to encouraging the provision of publicly available data (e.g. on data.gov.au), that data custodians could explore ways to more clearly communicate and promote exactly which data are publicly available. From a user's perspective, public data custodians should provide as much detail as possible on what data is available, and how to access and interpret their data. This will help educate and build data capabilities among users, and help reduce unnecessary data requests, so data can be used more efficiently and effectively.

The Issues Paper<sup>10</sup> also addresses the efficient and effective use of individual data (e.g. collected through personal devices). Although this is an important area, a better understanding of population-level data, well-organised and analysed to make meaningful information, provides a stronger evidence base for priority research, directed clinical interventions, and the development of best practice in cancer care and informed cancer policy.

### **Best Practice Examples**

#### *'Cd-link' in Ontario*

'Cd-link' is a cancer-specific, de-identified data linkage/data release mechanism developed in collaboration between the Ontario Institute for Cancer Research, Cancer Care Ontario and the Institute for Clinical Evaluative Sciences. It aims to safely link tumour-specific clinical registry data with administrative data. Providing a cost-effective, accessible platform for linked cancer data aims to "bring the creativity of the broader research community" to the study of cancer, and to "attract new researchers into the field of cancer health services research"<sup>11</sup>.

## **1.4 Sharing and linking of public sector data**

Data linkage involves combining information about people, places or events from within or across multiple data sets, while still protecting privacy.

Cancer Australia supports statements in the Issues Paper that 'health-related research, in particular' could benefit from greater [data] integration'<sup>10</sup>. Data linkage is an efficient and powerful method to add value to existing data, whether administrative or from surveys; and to increase its usefulness for informing population health and policy development (such as health monitoring, health service planning, and program evaluation).

From a cancer control perspective, data linkage is the only way to combine the information being collected across disparate data sets at different points of the cancer control continuum. Linking these datasets can provide an understanding of, for example, patient journeys through the health system. It enables researchers, policy makers and governments to answer questions about the health of cancer patients, groups or populations at one point in time, as well as over time. Linked data can help identify at a population-level inappropriate practices, inefficiencies across the health system, and variations in practice and care received. In particular, data linkage is cost-effective, as new datasets can be created without the expense of actually collecting new data.

### **Best Practice Examples**

#### *Accredited Integrating Authorities (linkage)*

The establishment in 2014 of Integrating Authorities by the Commonwealth has allowed for a clear framework when using Commonwealth data for data linkage projects deemed to be 'high risk'<sup>12</sup>. The NSS also maintains a register of data integration projects to avoid duplication of effort.

#### *ABS Mental Health data linkage*

The ABS Mental Health Services and Census project integrates 2011 Census data with administrative information on people accessing subsidised mental health-related Medicare Benefits Schedule (MBS) services and Pharmaceutical Benefits Scheme (PBS) prescription medication<sup>13</sup>. The analysis of the integrated data provides insights into the relationship between mental health-related services, medication use, and key socio-economic information such as education, employment and housing. This information can assist policy and decision makers in the development and evaluation of mental health programs and support services.

## 1.5 Data linkage initiatives in Australia

As the Terms of Reference 1 seeks to identify characteristics of high-value public sector datasets, it should be noted that Australia is currently well-resourced with data linkage facilities. Each state/territory has a dedicated data linkage unit to integrate health-related data for research and policy making purposes. Additionally, three Commonwealth agencies including the ABS, the Australian Institute of Family Studies and the AIHW (see Table 1) have the authority to integrate data collected by the Commonwealth Government.

From the perspective of using public sector health data therefore, Australia has an excellent base of data linkage infrastructure and expertise on which to facilitate further improvements in data linkage processes.

**Table 1: Examples of health data linkage facilities in Australia**

Data Linkage Unit	Geographic Scope
ABS	National
Australian Institute of Family studies	National
AIHW	National
Population Health Research Network	National
WA Data Linkage Centre	Western Australia
SA-NT DataLink	South Australian and Northern Territory
Centre for Health Record Linkage (CHeReL)	New South Wales and Australian Capital Territory
Centre for Victoria Data Linkage	Victoria
Tasmanian Data Linkage Unit	Tasmania
Queensland Research Linkage Group	Queensland

## 1.6 Data linkage across levels of government

Given that the Australian public health system is primarily regulated by the Commonwealth and state/territory governments, cancer-related administrative or survey data are often held by different levels of government. As previously noted, the Commonwealth collects or collates administrative data related to cancer incidence and mortality, treatments (MBS and PBS), as well as 'minimum data sets' related to cancer registration and hospital admissions. The states and territories collect more detailed data regarding cancer registrations and hospital admissions. In addition, both levels of government run regular or *ad hoc* surveys across a range of health topics in order to address specific policy goals.

In the context of cancer, data linkage between these various datasets could be better harnessed to look at relationships between incidence and mortality data, and patient experience data (collected at the state/territory level) with patterns of MBS/PBS treatment



data (collected by the Commonwealth). Any consideration of increasing the use of data linkage must, therefore, take into account ways to facilitate cross-jurisdictional linkage.

### **Best Practice Examples**

#### *State/Territory data linkage centres*

The SA NT datalink was established in 2009 as a collaboration between the Northern Territory and South Australian partners<sup>14</sup>. The linkage centre enables the integration of administrative and clinical datasets with the aim to provide evidence base for researchers and policy makers to better understand and monitor the population health and wellbeing impacts of policy and investment decision for South Australians and Northern Territorians.

The WA Data Linkage Centre was established in 1995 as a collaboration between four agencies: Department of Health WA, University of Western Australia, Telethon Kids Institute and Curtin University<sup>15</sup>. The linkage centre develops and maintains a system of linkages connecting data about health events across all individuals in Western Australia.

## **Terms of Reference 2: Availability of Private Sector data**

Terms of Reference 2 of the Inquiry is to examine the benefits and costs of options for increasing availability of private sector data for other private sector firms, the public sector, research sector, academia and the community.

Many of the issues mentioned in this submission apply to data generated in both the public and private health sectors. More than 50% of cancer care is provided in the private health sector. Additionally, patients often move between the private and public sectors at different times during the course of treatment. Accessing and using private health sector data is thus critical to better understanding cancer care in Australia, and in particular the costs of cancer care to both the patient and the health system overall.

Certain data collected in the private health sector are commercially valuable (e.g. the outcomes of clinical trials in the development of cancer medicines) and also a repository of great public value for the development of best practice care and policy decision-making (e.g. data on patient experiences collected by private hospitals). Greater access to private sector data would increase the amount of available information to combine with public sector data. This would provide governments with access to different types of data not currently accessible, as well as more statistical power for decision-making in health via larger combined datasets. Access to, and inclusion of standardised private sector data with matching public sector data, is important to assist evidence-based decision-making to improve cancer control across the continuum.

An example of progress being made in this area is in the use of structured pathology reporting of cancer, funded by the Commonwealth Department of Health<sup>16</sup>. This program of work is overseen by the Royal College of Pathologists Australasia in collaboration with various stakeholders. This project has developed a suite of guides for pathologists working in both the public and private sectors, so that pathological assessments of tissue biopsies are recorded in a similar fashion across the country. Having an inter-sectoral system of standardised cancer pathology reporting contributes to cancer control through improvements in clinical management of patients. Access to and linkage of these to treatment and outcomes will

assist in identifying patterns of care by diagnosis and variations in treatment at the population-level.

As with public sector data, there are however, multiple areas along the cancer control continuum where further progress on greater data access and standardisation could be made. For example, there is little incentive for the large amounts of industry-related data regarding cancer clinical trials to be released or combined with public sector data. The profile of clinical trial participation (which is often associated with improved patient outcomes<sup>17</sup>) is a significant gap in our understanding of cancer control in Australia. In the absence of a firm evidence-base, governments are unable to determine if policy interventions are required to ensure equitable access to clinical trials.

#### **Terms of Reference 4: Benefits and costs of sharing and release of data**

This submission has addressed the issue of the potential benefits of, and current barriers to, sharing and releasing data throughout. Assuming standard de-identification is maintained for non-linked data, in most cases *not* making data available has greater opportunity costs than making data available, primarily through projects being delayed, and evidence-generation, improved policy and better health outcomes being foregone. As well as opportunity costs, there are also monetary costs associated with inefficient data access arrangements, primarily through unnecessary investment in new data collections and duplicate costs paid by organisations accessing data (i.e. paying the labour costs for processing each data request).

Two opportunities for maximising the benefits of sharing data more widely would be:

- Encourage the development of remote data access infrastructure; and
- Support training for workforce skills in data management and analytics to ensure that the increasing amounts of open and linked data are being used and managed correctly and effectively.

#### **Summary**

By international standards, Australia generally has excellent data to monitor and report on key indicators of cancer control. These data are, however, held by several different entities, mostly in the public sector but also in the private sector, and are not currently effectively utilised for this purpose.

A detailed understanding of cancer control across the continuum - over time, between population groups, and within an international context – is critical for the development of evidence-based policy. Improving access to, and where necessary, linkage of, these data is seen as a priority by Cancer Australia. Among many other public policy benefits, whole-of-government approaches to efficiently increasing the access and use of available public sector data in the first instance would ultimately assist in improving cancer outcomes.

Although Australia has comprehensive population coverage – state/territory population-based cancer registries – of cancer incidence, as well as national data on health behaviours, treatments and mortality (refer page 4), more value can be added by linking different datasets relevant to cancer. Doing this would improve our ability to more accurately identify health-risk factors, patterns of care, use of health services, and how these relate to outcomes.

In addition, data linkage could be used more widely to integrate data from the public and private health sectors, and across administrative jurisdictions for effective service monitoring and for supporting broader service delivery. Although there are significant legal, ethical and administrative considerations, best-practise examples from Australia and overseas show that de-identified data can be used in an ethical fashion which protects individual privacy and improved health outcomes.

Likewise, recent initiatives show that there is broad government support for improving data linkage capacity, both at the Commonwealth (e.g. Integrating Authorities) and state/territory-level (e.g. the Western Australian linkage model). These initiatives will not only improve the use and impact of existing data, but also influence the opportunity and physical costs associated with inefficient data access/use arrangements.

Increased availability and use of cancer data in Australia will boost innovation, improve collaborative research, and better inform clinical decision-making and policy development. In particular, taxpayer-funded, de-identified health data should be seen as a public good, and its widespread use is the most powerful tool that we have to directly improve outcomes for Australians affected by cancer.

## **Abbreviations**

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
MBS	Medicare Benefits Schedule
NSS	National Statistical Service
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
SA	South Australia
STaR	Stage, Treatment and Recurrence
WA	Western Australia

## References

1. Cancer Australia 2008. A National Cancer Data Strategy for Australia. Available from: [https://canceraustralia.gov.au/sites/default/files/publications/ncds\\_final\\_web1\\_504af02093a68.pdf](https://canceraustralia.gov.au/sites/default/files/publications/ncds_final_web1_504af02093a68.pdf) (Accessed 6 July 2016).
2. Cancer Australia, 2014. Cancer Australia Strategic Plan 2014–2019, Cancer Australia, Surry Hills, NSW.
3. Australian Institute of Health and Welfare 2012. Cancer incidence projections: Australia, 2011 to 2020. Cancer Series no. 66. Cat. No. CAN 62. Canberra: AIHW.
4. Commonwealth of Australia, Department of the Prime Minister and Cabinet, Public Sector Data Management, 2015, [https://www.dpmmc.gov.au/sites/default/files/publications/public\\_sector\\_data\\_mgmt\\_project.pdf](https://www.dpmmc.gov.au/sites/default/files/publications/public_sector_data_mgmt_project.pdf) (Accessed 13 July 2016).
5. National Statistical Service <http://www.nss.gov.au/> (accessed 11 July 2016).
6. Australian Bureau of Statistics 2015. 1395.0 - Essential Statistical Assets for Australia. See <http://www.abs.gov.au/ausstats/abs@.nsf/mf/1395.0> (accessed 11 July 2016).
7. Australian Government – data.gov.au <https://www.data.gov.au/> (accessed 11 July 2016).
8. Australian Government – National Map <https://nationalmap.gov.au/> (accessed 11 July 2016).
9. Australian Bureau of Statistics 2016, Microdata Entry Page. <http://abs.gov.au/websitedbs/D3310114.nsf/home/Microdata+Entry+Page> (last accessed 13 July 2016).
10. Productivity Commission Issues Paper – Data Availability and Use, p.7. April 2016.
11. Earle CC 2014. Ontario Cancer Data Linkage Project: "cd-link". *Healthcare Quarterly* 17(1):11.
12. National Statistical Service – Accredited Integrating Authorities <http://www.nss.gov.au/nss/home.nsf/pages/Data%20Integration:%20Accredited%20Integrating%20Authorities> (accessed 6 July 2016).
13. ABS 2016 4329.0.00.003 – Patterns of Use of Mental Health Services and Prescription Medications, 2011. <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4329.0.00.003~2011~Main%20Features~Introduction~1> (accessed 12 July 2016).
14. SA NT Datalink 2016 <https://www.santdatalink.org.au/> (accessed 12 July 2016).
15. Data Linkage WA <http://www.datalinkage-wa.org.au/> (accessed 12 July 2016).
16. The Royal College of Pathologists of Australia, 2016. Structured Pathology Reporting of Cancer. <http://www.rcpa.edu.au/Library/Practising-Pathology/Structured-Pathology-Reporting-of-Cancer> (last accessed 13 July 2016).
17. CC Chow et al. 2013. *Does Enrollment in Cancer Trials Improve Survival?* J Am Coll Surg. 216(4): 774–781. doi:10.1016/j.jamcollsurg.2012.12.036.

## **Appendix 1: Cancer Australia Act 2006**

The Cancer Australia Act 2006 (Part 2, Section 7) specifies the following functions for Cancer Australia:

- a) to provide national leadership in cancer control
- b) to guide scientific improvements to cancer prevention, treatment and care
- c) to coordinate and liaise between the wide range of groups and health care providers with an interest in cancer
- d) to make recommendations to the Commonwealth Government about cancer policy and priorities
- e) to oversee a dedicated budget for research into cancer
- f) to assist with the implementation of Commonwealth Government policies and programs in cancer control
- g) to provide financial assistance, out of money appropriated by the Parliament, for research mentioned in paragraph(e) and for the implementation of policies and programs mentioned in paragraph (f)
- h) any functions that the Minister, by writing, directs Cancer Australia to perform.