



## Productivity Commission Inquiry into Data Availability and Use

Submission from Cancer Council Australia

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**Cancer Council Australia** is Australia's peak national non-government cancer control organisation and advises the Australian Government and other bodies on evidence-based practices and policies to help prevent, detect and treat cancer and also advocates for the rights of cancer patients for best treatment and supportive care.

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### Introduction

In Australia, cancer is the disease group with the highest burden, accounting for 19% of the total disease burden, ahead of cardiovascular disease, mental and substance use disorders, and musculoskeletal conditions and injuries<sup>1</sup>. In 2016, it is estimated that 130,466 new cases of cancer will be diagnosed in Australia, and there will be 46,880 deaths from cancer<sup>2</sup>.

The availability of quality data is critical to the delivery of cancer care, and cancer control services more broadly, and as such there is a pressing need to improve data availability. In 2008, a National Cancer Data Strategy was developed to identify opportunities to develop cancer data capacity in Australia<sup>3</sup>.

A number of barriers to access for cancer-related data in Australia have been identified. These include jurisdictional variations in ethics approval processes, and data access protocols more generally, as well as concerns among some data custodians that researchers may use data inappropriately<sup>4,5</sup>.

The interplay of public and private financing of health services in Australia also presents significant challenges to improving the availability of cancer-related data and health data more broadly.

*ToR 1: Examine the benefits and costs of options for increasing availability of public sector data to other public sector agencies (including between the different levels of government), the private sector, research sector, academics and the community. Where there are clear benefits, recommend ways to increase and improve data linking and availability.*

## **Improving the availability of public sector data**

From a health and medical research sector perspective, it is not possible to provide a comprehensive list of all public sector datasets that should be considered high value. Rather, the assumption should be that all public sector datasets that can be linked on an individual basis with health records are potentially high value. This includes birth, marriage, death, Medicare Australia, hospital, employment, education and welfare records, as well as individually identified records from population surveys conducted by government agencies such as the National Health Survey, which is conducted by the Australian Bureau of Statistics (ABS).

While it is not possible to list all public sector datasets that should be considered high value, there are a number of characteristics that define these datasets:

- the data are accurate, with a known level of accuracy and completeness
- the dataset contains individually-identified records that can be linked to other datasets
- the dataset is comprised of all eligible individuals in a population (such as Medicare Australia data), rather than smaller, ad hoc datasets

In Australia, there are currently two census points where cancer data collection is mandatory, at diagnosis (incidence) and at death (mortality). There are gaps in cancer data, where the data is either not available, incomplete, or not sufficient for national reporting purposes. Improvements in the completeness, quality and availability of cancer data will help strengthen the evidence base on emerging cancer issues, current and planned cancer control interventions, and future trends.

There are specific gaps in health services and expenditure data, and more information is required in order to develop a better understanding of what services are being delivered, how effective they are, and where money is spent. There is also a lack of data relating to patient experiences of care within health services.

With advances in prevention, screening and treatment, many of those affected by cancer are now living longer, either free of disease or with recurrent disease. Despite this, there is little data describing the quality of life of patients after treatment, intermediate and long-term toxicities, or the impact of new treatments and technologies<sup>3</sup>.

There are only limited data available about certain groups in the population, including Indigenous Australians. Importantly, cancer outcomes differ by Indigenous status. For example, in 2008–2012 Indigenous Australians experienced higher mortality rates than non-Indigenous Australians, for all cancers combined; however, information in the National Mortality Database on Indigenous status is currently considered of sufficient quality for

reporting for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory only<sup>6</sup>. Therefore, better quality data are needed to explain the gap in health outcomes between Indigenous and non-Indigenous Australians.

A recent study examined the opportunities and challenges of using data linkage in Indigenous health research, and highlighted the importance of data linkage projects to improving our understanding of Indigenous health outcomes in Australia<sup>7</sup>. Importantly however, while using linked data avoids the time and cost burden of gathering additional and often duplicate data, the process involved in accessing these datasets can be slow and time consuming. This is due largely to the number of ethics committees that are required to approve data linkage proposals, and the fact that proposals need to be cleared by jurisdiction-based data custodians, all operating under different legislative regimes<sup>7</sup>.

In this study, where ethics approval was required from 10 state-based human research ethics committees (HRECs) and three Aboriginal HRECs, the time from initiation to completion of the ethics committee approval process ranged from two to 32 months, while the final approval to link and access all datasets took 5 years<sup>7</sup>. Therefore, there is a clear need for a national, streamlined ethics application and approval process.

One of the key concerns with data linkage is the protection of individuals' privacy<sup>4, 5</sup>, and there is a need to address the legislative barriers to data access. It has been suggested that there would be benefits in harmonising Commonwealth and State and Territory legislation in relation to privacy<sup>3</sup>. While the consideration of privacy standards is very important, it is important to note that well-established linkage protocols that are capable of preserving individual privacy already exist in Australia.

A number of high value cancer datasets have been identified, which when linked, will enable better informed health policies and service delivery and more efficient use of health resources<sup>5</sup>:

- *The Australian Cancer Database (ACD)*, a compilation of data from Australian cancer registries.
- *Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits (MBS) data*, which cover private services reimbursed through Medicare, including surgical, radiotherapy and systemic therapies.
- *Australian hospital inpatient data*, which includes treatment statistics on surgery types and in-hospital provision of systemic therapies and other cancer-related procedures.
- *Population-based radiotherapy data*, available from modern radiotherapy machines and compiled in State/Territory databases covering most Australian cancer cases.
- *Screening and vaccination registries data*, which covers population-based cervical, breast and colorectal screening services, plus HPV vaccination data.
- *Self-reported data*, which are available for large nested cohorts (e.g. the Melbourne 20/20 and NSW 45 & Up study cohorts) and include data on cancer risk behaviours and exposures, and medical history information. Collection of patient-reported data on experiences with cancer and the health system is also being trialled for Aboriginal and Torres Strait Islander Australians.
- *Clinical cancer registries and related clinical databases*, which are not population-based, covering approximately 20% of Australian cancer cases. Generally the clinical

data in these registries would be higher in quality than data available as a by-product of administrative data systems.

In addition to privacy concerns related to the linking of multiple datasets, there are a number of other factors that are currently preventing government agencies from making their data available:

- government attitudes and legislation that assume the community would be opposed to greater sharing and use of personal data for research, without any evidence that this is the case
- legislative, logistic and other administrative problems in transferring and exchanging data between states and territories
- internal agency and government culture and policies that have developed over time, that place unnecessary and cumbersome restrictions on the release of data, for example, the Australian Institute of Health and Welfare (AIHW) guidelines on publication of data
- lack of funding for, and failure to prioritise, the development of advanced data systems and infrastructure

The following would greatly assist the collection, standardisation, sharing and release of public data:

- a unique, national, personal identifier (this would reduce costs and errors associated with data linkage)
- standardised protocols for linking individually identified records and making the resulting data available for research in a de-identified format

### **Resource costs associated with improving the availability of public sector data**

It is acknowledged that there will be workforce and financial pressures that the delivery of open data will impose on data custodians; however, the cost to government departments and agencies are small compared with the economic benefits that improved availability of public sector data will drive. In Australia, the estimated economic value of open government datasets range from \$500 million to \$25 billion per year<sup>8</sup>. A report by McKinsey suggests that open data may help create \$3 trillion a year of value in the global economy<sup>9</sup>. How much governments will need to invest will depend on a number of factors, including what infrastructure and expertise is already in place, how much data has already been collected, and which high-value datasets have already been published.

A significant consideration for government is the cost associated with anonymising data. This requires a degree of expertise that not all government agencies and departments will have, and as such, there may need to be some investment in capacity building within government. It will also be important to develop processes for updating data once it is anonymised. Other cost considerations include legal costs to comply with open data legislation, and liability costs to deal with issues that arise as a result of breaches in data security.

As discussed earlier, one of the key concerns with the linking of multiple datasets is the protection of individuals' privacy. Therefore, it is critical that government continues to fund

initiatives such as the Population Health Research Network (PHRN), which is developing and testing leading-edge technology to ensure the safe and secure linking of data collections whilst working to protect peoples' identity and privacy<sup>10</sup>.

*ToR 2: Examine the benefits and costs of options for increasing availability of private sector data for other private sector firms, the public sector, the research sector, academics and the community. Where there are clear benefits, consider ways to increase and improve availability.*

## **Improving the availability of private sector data**

In Australia, a patient undergoing treatment for cancer may receive services from both public and private providers. Over 47% of Australians hold an insurance policy which offers them some form of hospital cover and in 2012-13, contributions from private health insurers represented approximately 11.5% of Australia's total health expenditure<sup>11</sup>. Therefore, the ability to access, and link, comprehensive, accurate and up-to-date private health sector datasets is critical for policy makers and health administrators, and will enable them to make better informed decisions regarding the delivery of health services.

Currently, private health sector data in Australia is captured in a number of national data collections, including:

- National Admitted Patient Care Dataset
- Hospital Casemix Protocol
- Private Hospital Data Bureau
- National Hospital Cost Data Collection

Importantly however, compared with public sector health data, the availability of private sector data is limited in some areas.

The lack of access to private health sector data has been shown to limit the capacity of emerging cancer databases in Australia. For example, Cancer 2015 is an Australian database that is linked to State and Commonwealth reimbursement datasets, and captures clinical, genomic, quality of life and resource use information, making it one of the most comprehensive cancer databases; however, it is limited due to its use of estimates for private health service delivery<sup>12</sup>.

Internationally, one example of an open access private sector database is the New Zealand Open Companies Register. This register enables private companies to list their business information on an online, searchable database, which improves public access to important company information and facilitates ease of doing business in New Zealand.

The public policy rationale for government-led initiatives to increase the availability of private health sector data in Australia includes:

- social responsibility
- transparency and accountability of service delivery
- competition to drive quality care
- ensuring efficient delivery of optimal care

## *Benefits of improving the availability of private health sector data*

### *Patterns of care*

In order to ensure that health service demands are being met and appropriate care is being delivered, it is critical to understand how people use the health system. The linking of high value health datasets will facilitate a better understanding of how patients with cancer use the health system, from the time of diagnosis, through to the treatment, follow-up, and survivorship phases. Not all of the health services used by these patients will be delivered in the public health system, and therefore data held by private health service providers is critical to our understanding of the complete pattern of health service use in Australia.

### *Performance and quality of care*

Data is essential for the evaluation of health system performance, for both public and private providers. The key benefit of performance measurement is improved accountability and transparency of service provision, which can be used to create incentives for improved service delivery. In addition, information on the effectiveness of policy changes or new programs can be gained by tracking the same performance measures over time. Performance outcomes are important to a range of stakeholders, including governments, service providers, funders (including tax payers), and consumers.

Consumer choice is at the heart of any well-functioning market, and for those with private health insurance, the increased availability of private health sector data on performance and quality of care outcomes will help them make more informed choices about healthcare services.

In Australia, nationally endorsed 'Optimal Cancer Care Pathways' provide an independent benchmark which can be used to evaluate cancer care delivery. This could assist in identifying areas that are delivering high quality care, or areas where there is over-servicing.

### *Patient out-of-pocket costs*

Research has shown that cancer patients in Australia are experiencing significant out-of-pocket costs for their treatment.

In a study of nearly 270 cancer patients receiving treatment in New South Wales and Victorian hospitals, one in three said the out-of-pocket cost of their treatment was placing a significant financial burden on them<sup>13</sup>. Another study has evaluated the economic burden experienced by Australian men after a diagnosis of prostate cancer<sup>14</sup>. This study demonstrated a large variability in out-of-pocket medical costs for prostate cancer treatment, with recently diagnosed men spending a median of \$8000, and 75% of men spending up to \$17,000. Importantly, many participants were well-educated, financially comfortable and two-thirds were privately insured; however, this did not provide adequate protection, with 20% of men reporting that the cost of treating their prostate cancer caused them 'a great deal' of distress<sup>14</sup>.

For patients with cancer living in rural and remote areas of Australia, the closest health service provider may be privately run. Therefore, if a patient is unable, or unwilling, to travel

in order to receive treatment in a public health facility, they may be forced to pay a high premium for their treatment, or choose to forgo optimal care.

The National Cancer Data Strategy identified the increasing proportion of cancer care being provided through the private health sector as one of the barriers to access to data on the complete treatment pathway<sup>3</sup>. While Medicare Australia data can provide an accurate picture of the types of health services and drugs patients are using, it does have some limitations. For example, it does not include information on the rebates received by patients from private health insurance funds. Therefore, for privately insured inpatients, while Medicare Australia data can identify the type and number of services used, the provider fee charged and the government benefit paid, it cannot identify the patient out-of-pocket costs. Given the considerable impact that out-of-pocket costs are having on cancer patients in Australia, this is one example where a significant community benefit could be derived from increased availability of private sector data.

#### *Improved clinical trial transparency*

Another area where a substantial societal benefit could be obtained from increased availability of private sector data is clinical trials. The results from a significant proportion of clinical trials are never published and those that are published are more likely to report positive results. Clinical trials of cancer drugs represent a significant share of all trials. Therefore, it is likely that a large amount of clinical trial data in this area never reaches the public domain.

In an effort to improve transparency in clinical trials research, the US Department of Health and Human Services and the National Institutes of Health have recently proposed policy changes aimed at expanding clinical trial registration requirements and promoting the sharing of trial data<sup>15</sup>. In addition, trial sponsors are responding to calls for greater research transparency. For example, a data-sharing platform called ClinicalStudyDataRequest.com, developed by GlaxoSmithKline in 2013, is now used by some of the world's largest pharmaceutical companies to share information on clinical trials<sup>15</sup>.

While data-sharing platforms are promising, they may be limited in both their scope and access to data. The high cost of these platforms is another potential barrier. As such, it has been suggested that hosting open data is a role that government is uniquely placed to undertake, given its resources and regulatory monopoly<sup>15</sup>.

#### *ToR 3: Identify options to improve individuals' access to public and private sector data about themselves and examine the benefits and costs of those options.*

The My Health Record is a secure online summary of an individual's health information, including allergies, existing health conditions, general practitioner and other healthcare provider consultations, hospitalisations, prescribed drugs and medical test results. Originally introduced by the Australian Government in 2012 as an opt-in personally controlled electronic health record (PCEHR), it has been re-launched recently, and individuals will now have to opt-out if they do not wish their personal health information to be available in this form.

PCEHRs such as this have many benefits, including helping consumers become more proactive participants in the management of their own health, as well as improved consumer-provider communication, access to data in medical emergencies and chronic disease management. In the case of cancer, best practice care is delivered by a multi-disciplinary team, which ensures that the treatment, psychosocial, and supportive care needs of the patient are addressed in a timely manner. The use of PCEHRs will facilitate multi-disciplinary care, enabling the sharing of data across different healthcare providers and organisations.

There are also challenges to the use of PCEHRs. Individuals are able to remove clinical or Medicare documents from their My Health Record at any time, and as a result these documents may no longer be accessible, even in an emergency. If individuals remove information without consulting with the relevant healthcare professional(s), this raises concerns about the accuracy and reliability of the data contained within the record. This issue needs to be explored further, as it may have an impact on how the My Health Record is viewed by healthcare professionals, and as a consequence its utility in clinical practice.

*ToR 4: Examine the options for, and benefits and costs of, standardising the collection, sharing and release of public and private sector data.*

In Australia, private hospitals are required to contribute to a number of mandatory national data collections; however, outside of these mandated obligations, there are also voluntary data collections that report on important health system data. One example is the private sector National Hospital Cost Data Collection (NHCDC), which produces a range of hospital cost and activity information<sup>16</sup>. The most recent NHCDC report contained data from 96 private hospitals in Australia, representing 41% of eligible hospitals and 60% of eligible separations<sup>16</sup>.

The reporting requirements of national data collections incur a cost to private hospitals. Specifically, the diverse range of reporting required for these data collections, the duplication of requirements among collections, as well as the complexity of data supply chains, all contribute to a significant reporting burden for private hospitals<sup>17</sup>. It has been suggested that the simplification and harmonisation of private hospital data collections may help reduce this burden, and enable performance comparisons to be made across all Australian hospitals, both public and private<sup>17</sup>.

Therefore, there are opportunities for government to improve the accuracy and timeliness of private health sector data in Australia, by standardising the collection of private hospital data. There may also be an opportunity for government agencies such as the AIHW to play a greater role in private health sector data collection. Stakeholders in this sector have previously indicated that they were comfortable with the AIHW operating as a collection agency for private hospital data, given the level of data protection offered by its governing legislation, and its well established and effective protocols for providing access to data, while protecting privacy and confidentiality<sup>17</sup>.



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