

# Consultation on the Data Availability and Transparency Bill 2020



5<sup>th</sup> November 2020

Cancer Council 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.

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Cancer Council Australia thanks the National Office of the Data Commissioner for involving our organisation in various consultation elements of this work. While acknowledging that the Data Availability and Transparency Bill (the Bill) is not restricted to health information, this submission focuses on health data, specifically related to cancer and the ability to use data to inform the delivery of care. In addition to addressing the data sharing elements within the Bill, Cancer Council has provided information for consideration of the Office of the Data Commissioner for future improvements in data in Australia.

## Overall intent of the Bill

Cancer Council supports the intent of the Bill and recognises that the key feature of accrediting users and data service providers will hopefully streamline access to publicly held data for purposes which promote the use of data for public benefit. This is an important step towards building a mature data system.

In parallel to this Bill, an additional significant advancement in the use of data would be an agency such as the Australian Institute of Health and Welfare or the Australia Bureau of Statistics maintaining an enduring periodically updated linked data set for cancer. This dataset could comprise of the Australian Cancer Database, Admitted Patient Data Collection, Emergency Department Data Collection, radiotherapy data, data from the National Screening Programs, Medicare Benefits Schedule and Pharmaceutical Benefits Schedule and the National Death Index. This is happening in a similar capacity at a state level. Cancer Institute NSW is establishing the [Enduring Cancer Data Linkage \(CanDLe\)](#) for health services research in New South Wales. It will provide linked unit record cancer data to a network of approved researchers, aiming to advance the pace, quantity and quality of population-wide cancer research that is aligned to the goals of the NSW Cancer Plan.

## Enabling a mature data system

Between 2019 and 2020, Cancer Council developed a vision for cancer data in Australia using a maturity model approach. A mature data system which enables a routinely updated national master linked dataset fed by State, Territory and Commonwealth data collections, held in a secure research environment accessible by accredited and accountable analysts and researchers, with simplified data custodianship and further capacity to link collections such as quality clinical registries, is Cancer Council's vision for cancer data in Australia.

Cancer Council's review of the Bill draws extensively on this vision, and we expect to publish the work later in the year. Cancer Council supports the proposed Data Sharing Principles and the Bill as progress to improving the utilisation of public data in Australia.

Strong community, stakeholder and political trust in and support for routine health data collection for research and ongoing monitoring and quality improvement of the health system is fundamental to the development of a mature cancer data system in Australia. To facilitate safe, streamlined and timely access to linked unit-level record data for the purpose of informing health improvements, the elements required in Australia are:

- a data culture whereby complete transparency is maintained around what data are held, how data security is maintained and how data are being used;
- nationally uniform legislation that governs cancer and other health data;
- single independent custodianship of a national health data repository, where access is acquired through one streamlined application process; and
- nationally uniform security protocols to protect privacy and enable the safe sharing and transfer of health data.

An example of a more mature data system than Australia's is the Institute for Clinical Evaluative Sciences (ICES) in Ontario, Canada. It is a research organisation that uses population-based health and social data to produce knowledge on a broad range of health care issues. ICES is a central linkage agency in the province with streamlined linkage processes, and rapid access for accredited researchers. The agency holds unit-level records and data custodians grant authority to ICES for the use of their datasets in linkage requests, bypassing the need for individual access requests. The streamlined access process and richness of the repository enables the data held by ICES to be used in hundreds of research projects per year and is accessible via a secure portal that can be accessed internationally.

## Culture

The risk aversion approach to data sharing in Australia has been attributed to limited community engagement or understanding of the benefits that data provides. This could be improved by promoting transparency and consultation between stakeholders and custodians, building trust with the community about the appropriate use, and demonstrating the impact that using data can provide.

The safeguards within the Bill, to build trust in the data sharing schemes and its operation, are consistent with enablers identified in Cancer Council's vision for cancer data, including:

- focus on safe and simplified data sharing;
- broad community and stakeholder engagement with data collection and use for ongoing monitoring and quality improvement of the health system; and

- transparency for the public in how data is used to improve health outcomes.

The role of the National Data Commissioner and the Office of the National Data Commissioner also present opportunities to promote the use of data to enable, rather than restrict the use of data to inform improvements in health and healthcare.

### Access

Access to data in Australia requires approval from each data custodian and a request submitted to a linkage agency. This often results in laborious and lengthy waiting times to access the requested data. Accrediting users and data service providers to access public data, as outlined in the Bill, goes some way to reducing these potentially unnecessarily restrictive and burdensome processes, thereby improving the timeliness of data access in Australia. However, access to datasets not held by government, for example radiotherapy treatment data from private providers, clinical quality registries and research datasets including the 45 & Up dataset held by the Sax Institute sit outside this Bill and require a continuation of existing data access arrangements of submitting individual data requests to each custodian.

The Bill provides for two types of accreditation, accredited user and accredited data service provider, and suggests organisations have accredited data service providers so that complex data can be integrated or shared on behalf of a data custodian. Entering into Data Sharing Arrangements will guide the appropriate use of data and demonstrate a commitment to building trust in its use.

Cancer Council supports the two types of accreditation proposed as it will allow entities to only have to seek accreditation once and use that accreditation to support multiple data requests. Over time however, data arrangements should expand to include non-government datasets. Cancer Council supports the reforms aim to encourage both academics and the research community to innovate and find new insights from public sector data without having to go through complex and unclear bureaucratic processes.

The Bill provides a pathway to ensuring security is maintained to an appropriate standard when data is shared. To ensure data will be used in an appropriately safe and secure environment, such as one that minimises the likelihood of unauthorised use, access or loss of data, controls, in both physical and digital environments that can be put in place to control how data is stored, transferred and accessed should be integrated into data sharing guidances. The use of secure cloud platforms, potential for “real-time” linkage in some settings and high-speed, high capacity, secure data portal for data transfer would enable rapid, safe and convenient access to requested datasets. This is another area of improvement for Australia’s data system.

Cancer Council supports the introduction of reforms to enable safe, and consistent data sharing practices and simplified pathways to share data, recognising that data has greater value when it is shared and used by others, and linked to other datasets enabling more in depth analysis and generating information.