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Australian Data Strategy  
Data and Digital Branch,  
Policy, Innovation and Projects  
Department of the Prime Minister and Cabinet  
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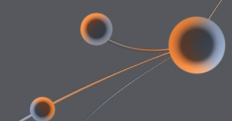
## Response to the Australian Data Strategy Discussion Paper

Research Australia appreciates the invitation to make this submission the Australian Data Strategy Discussion paper. We are the national peak body for Australian health and medical research, representing the entire health and medical research pipeline, from the laboratory to patient and the marketplace. Research Australia works to position Australian health and medical research as a significant driver of a healthy population and a healthy economy, and data is a critical input to our members' work.

Our response to each of the questions posed in the Discussion paper is provided below.

### **1. To what extent do you agree that the outline of the Australian Data Strategy covers the right issues?**

Research Australia broadly agrees that the outline of the data strategy covers the right issues. It is important that we continue to demonstrate to the Australian population the public benefit of sharing data held by governments.



## 2. What key areas or issues are missing? Why are they key issues?

Building the capacity of the APS and Government agencies to share data securely and safely is not addressed as part of the strategy.

This should be a critical component; not only to ensure the greatest benefit can be derived from data sharing and the strategy but also to minimise the errors, breaches and failures which can be very damaging to public confidence. A January 2021 report of Federal Government data breaches identified human error as the cause of 88% of the data breaches reported.<sup>1</sup> This suggests that there is still significant work to be done to improve the capacity of the APS and Government to safely and securely share data.

## 3. Are the issues below considered important to your organisation; and if so why?

- a. Ethical and transparent use of data
- b. Data security
- c. Data privacy
- d. Data innovation
- e. Accessible data/open data
- f. Data sharing for improved services

All of the listed issues are important, and all reflect key elements of any data strategy, both to guide data sharing and use and engender public confidence.

Research Australia suggests that '*f. Data sharing for improved services*' is framed too narrowly. For example, the Data Sharing and Availability Bill currently before Parliament identifies three purposes for sharing data:

- (a) delivery of government services;
- (b) informing government policy and programs;
- (c) research and development.<sup>2</sup>

Research Australia proposes that item f. be framed as '*Data sharing for improved services and public benefit*', or simply as '*Data Sharing for public benefit*'. This will better capture the rationale, and therefore, the mindset for sharing data rather than reasons to the contrary.

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<sup>1</sup> Office of the Australian Information Commissioner, 2021, Notifiable Data Breaches Report, July to December 2020

<sup>2</sup> Data Availability and Transparency Bill 2020, clause 15

#### 4. What are the top three outcomes from the Australian Data Strategy you would like to see by 2025?

1. Social licence for data sharing: more Australians understand the importance and value of sharing Government data about them (deidentified and aggregated) and are more supportive of the Government doing so.
2. Faster, more complete and secure access to data for research purposes in the public interest.
3. There is a cost to collecting, analysing and making data available. By 2025 we are better able to calculate these costs and can assess whether the way we collect and use data adds value. This includes finding additional ways of using data we already collect to add greater value and identifying data we don't currently collect which would add value to the economy and society. For example, the ABS do not currently collect sufficient data on R&D or economic activity to enable an assessment of whether the investments the Government is making to promote R&D are successful.

#### 5. Do you have any other comments on the Australian Data Strategy?

One of the dot points under the Chapter heading 'Data Now' is

- *'Data is used to respond to priority issues'*

Consideration should be given to how priority issues are identified and by whom, and the role that exists for engaging the public in this process of identifying priority issues. This may be an appropriate topic for the Data Strategy to address directly, or it might be a separate process outside the Strategy.

Identifying the priority issues to be addressed through the better use of Government data would be a good way of engaging with the Australian public and gaining their support for the use of data. It would also help prioritise where and how resources are allocated. The successful application of Government data in high profile areas that are valued by the Australian community would help win public support for the greater use of data more generally and support the Data Strategy's objectives.

The introduction to the Australian Data Strategy Discussion paper notes the progress being made in a range of areas, including the recently signed Intergovernmental Agreement on Data Sharing between the Commonwealth, State and Territory governments. The sharing and linking of Commonwealth, State and Territory datasets is an area of critical importance and value to health and medical research, as it is to many other areas of our economy. Further development of the Strategy should specifically consider how it can support sharing and linking of data with and by state and territory governments, including creation of an intergovernmental agency or facility to support this activity.

## 6. How should the Government keep talking about data issues?

It is important that people understand:

- how data about them that is held by Government will be used,
- what the outcomes of using data will be, and
- how these outcomes benefit them and the broader community.

Research Australia has been engaging with the public in relation to the use of health data for research for many years. The following is an extract from our 2019 Opinion Poll which illustrates why this understanding is important.

‘Unlike many fields of science such as physics, geology or botany, health and medical research studies humans. This means that not only are we the beneficiaries of health and medical research, but we are also the subjects. More than any other field, health and medical research relies on our co-operation and participation; providing information about where and when we are sick and healthy, and even samples of our blood, organs and tumours. We asked a series of questions to better understand how much the public appreciate the vital role health and medical research plays in our lives, but also the role we play in advances in this research.

While people overwhelmingly agreed that their own healthcare had benefited from research, with 87% agreeing, far fewer people understood that this research relied on individuals’ personal health information. Nearly one third (31%) didn’t know if they had benefited from research that used individuals’ personal health information. These results are almost identical to when we first asked this question in 2016.

This is a significant information gap, particularly at a time when more health information is being digitised. Our increasing capacity to work with large volumes of data, whether it be individual genomes or population wide health records, is providing enormous opportunities to use health and medical research to improve health outcomes.

People can only reasonably be expected to consent to their information being used if they understand why it is needed in the first place. At the moment a large proportion of people don’t understand the link between their personal health information, research and better health in the future.’<sup>3</sup>

While Research Australia’s Opinion Poll focuses on data for health and medical research, the same principle holds for other types of data and other uses: people do not understand the connection between the use of their data by the Government and other organisations, and the services and outcomes they rely on and value.

This message should be a key element of how the Government talks about data issues. Discussion of the risks of sharing data and safeguards should always occur within the

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<sup>3</sup> Research Australia, Australia Speaks! 2019 Public Opinion Polling for health and medical research, page 4. Available at [https://issuu.com/researchaustralia/docs/2019\\_poll\\_report\\_issu](https://issuu.com/researchaustralia/docs/2019_poll_report_issu)

context of why the sharing of data is valuable, the outcomes and benefits it leads to, and the opportunities that are lost if/when data is not shared.

A dynamic approach to the public discourse rather than a 'set and forget' is encouraged as technology and thus digital applications mature and use becomes more widely embedded in delivery of services by governments. The value attached to data, both perceived and actual, should remain a key part of active conversations and sharing of valuable advances and outcomes of such as a case study or evidence-based approach to how data advances us as a society and contributes to our quality of life.

## **7. How do you see your organisation interacting with the Australian Data Strategy? What guidance is important to you to help you achieve the actions set out in the Strategy?**

One of Research Australia's three Strategic Objectives is *Harnessing the Power of Data to Accelerate Advances in Health*. Under this strategic objective we have identified three actions, which are all relevant to the Government's Data Strategy:

1. Promoting the importance of data about us and the world we live in as a resource enabling research to improve our health
2. Encouraging the policy settings and infrastructure for efficiently shared, linked and secured data for research
3. Demonstrating the contribution of participants to research to highlight the importance of sharing our health experiences and information

We will continue to engage with the public, governments, the health industry and researchers in these actions. For example, when we showcase specific health and medical research, we will emphasise the contribution made by research participants who have provided their data and health information. This will be in addition to describing the research, its outcomes, and the researchers involved. This is part of driving the culture change from within the sector and placing an onus on the research community to take consumers along in the development of their research and even more importantly, to share the outcomes and value derived from said research.

Research Australia would be keen to partner with the Australian Government in supporting these efforts and developing a framework for doing so. This includes identifying and telling these stories and providing case studies that emphasise the important role of health-related Government-held data in advancing research to provide outcomes people care about, such as new treatments and better quality care. Equally, there is as previously mentioned, a discourse to be had within the research community as to the why and importance of data in our lives.

We note that the second part of question 7 may be for a later version/submission given there are as yet, no actions set out in the strategy.

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