

# DATA AVAILABILITY AND TRANSPARENCY BILL AND ACCREDITATION

Submission to the consultation

November 2020

## ABOUT RESEARCH AUSTRALIA

We are the national peak body representing the whole of the health and medical research pipeline.

**Our vision:** Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

**Our mission:** To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

### Our goals:

Engage	Connect	Influence
Australia in a conversation about the health benefits and economic value of its investment in health and medical research.	researchers, funders and consumers to increase investment in health and medical research from all sources.	government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

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## Summary of recommendations

<b>The Data Availability and Transparency Bill</b>	<p>Guidance should be provided by the Data Commissioner in relation to data outputs as they relate to the requirements of Open Data Policies, and it may also be appropriate to refer to Open Data Policies in the Explanatory Memorandum as a consideration in relation to data outputs.</p>
	<p>The obligation on Data Custodians to consider requests for data sharing does not go far enough. At a minimum, clause 23 of the Bill should be amended to require data custodians to:</p> <ul style="list-style-type: none"> <li>• consider reasonable requests for data sharing;</li> <li>• respond to all data sharing requests in a timely and efficient manner; and</li> <li>• give reasons for their decision when declining a data sharing request.</li> </ul>
	<p>A public register of refused data sharing applications should be created and maintained by the National Data Commissioner, similar to the register of data sharing agreements to be maintained under clause 132 of the Bill.</p>
<b>The Accreditation Framework</b>	<p>Research Australia submits that there is no evident reason to create accreditation eligibility criteria relating to the ownership of the entity.</p>
	<p>The question of the extent to which the National Data Commissioner deals directly with individuals or leaves it to the entity to take the appropriate steps (training, identity checking etc.) should be based on what will be the most effective and efficient approach. Research Australia would welcome the opportunity to get a better understanding of the digital platform to be developed by the National Data Commission and how this could utilise to manage the endorsement and accreditation of individuals and their initial and ongoing training.</p>
	<p>The costs of the accreditation scheme should not be borne by the accredited users and ADSPs as participants in the Scheme but by the community as a whole through payment of taxes, as the benefits for the data sharing scheme are widespread throughout the community.</p>

# DATA AVAILABILITY AND TRANSPARENCY BILL AND ACCREDITATION

## SUBMISSION TO THE CONSULTATION

### Introduction

Research Australia welcomes the opportunity to make a submission in response to the consultation on the Data Availability and Transparency Bill Exposure Draft (the Bill) and the Accreditation Framework Discussion Paper.

Research Australia has been advocating for many years for improved access to public data for research.

We have keenly followed, and contributed to, the Public Sector Data Management project, initiated in 2015. We made submissions to the Productivity Commission's 2016 Inquiry into Data Availability and Use. Strongly supportive of the Commission's recommendations, we have worked with the Department of Prime Minister and Cabinet on the consultations which have culminated in the release of the Data Availability and Transparency Bill exposure draft and the proposed Accreditation Framework.

Research Australia is pleased with the way the Productivity Commission's recommendations have been enacted in the exposure draft. We also wish to thank the Interim National data Commissioner and her team for the way in which the consultation has been conducted over several years.

The exposure draft, when enacted, will mark a major step forward in the use of public data for research purposes, and provides very significant opportunities to advance both Australia's health and prosperity.

The few recommendations we make in respect of the Bill and the Accreditation Framework are designed to further improve its effectiveness.

# The Data Availability and Data Transparency Bill

## Chapter 2- Authorisations to share data

Several provisions in Chapter 2 relate to the outputs from data sharing and how these may be utilised.

‘Output’ is defined by clause 10, with reference to subclause 13(1). The outputs principle is specified in section 16, section 18 deals with the content of the Data Sharing Agreement (including how outputs are to be treated), and section 23 deals with how outputs exit the data sharing scheme.

In the context of research, outputs will include publications which arise from research utilising the data covered by the data sharing agreement. Under Open Data Access policies there are efforts to ensure that not only research findings in the form of journal publications are made available but also data relating to the publication. These efforts are supported by the Australian Government. The National Health and Medical Research Council has published an Open Data Access Policy for health and medical researchers.<sup>1</sup>

NHMRC supports the sharing of outputs from NHMRC funded research including publications and data. The aims of the NHMRC Open Access Policy are to mandate the open access sharing of publications and encourage innovative open access to research data....

The NHMRC Open Access Policy is consistent with the Australian Government’s commitment to open access, open data and intellectual property (IP) management.

There is a clear tension between sharing data and protecting the privacy of individuals, and this tension is addressed in the NHMRC’s Open Data Access Policy.

NHMRC acknowledges the importance of making research data publicly accessible and therefore strongly encourages researchers to consider the reuse value of their data and to take reasonable steps to share research data and associated metadata arising from NHMRC supported research.

When sharing data, researchers should ensure that appropriate metadata accompany the datasets. This will allow users of the data to fully understand the data, the curation strategies, assumptions, experimental conditions and any other details relevant to the interpretation of the data. When sharing research data, researchers must also consider the appropriate level of access that they would like to provide to users. The level of access may range from highly restricted (e.g. commercial in confidence, patient level, culturally sensitive, national security) to fully open access.

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<sup>1</sup> National Health and Medical Research Council, 2018 *Open Access Policy*, most recently amended April 2020

While it is clear that ‘outputs’ include highly aggregated data, (paragraph 188 of the Explanatory Memorandum refers to facilitating ‘*release of outputs from the scheme, such as highly aggregated research outputs.*’) it is not clear that the full range of data and circumstances considered under the Open Access Data Policy, including metadata, is countenanced by the Bill, either in relation to exit from the Data Sharing Scheme or as being able to be covered under the terms of the Data Sharing Agreement.

These are issues that will need to be considered and agreed by the researcher and the Data Custodian and addressed in the Data Sharing Agreement. For example, a Data Sharing Agreement might need to consider access to the data by peer reviewers, or future requests from other researchers for access to the data. If the researcher does not hold the data at a sufficient level of specificity or no longer has access to the data, the Data Sharing agreement may need to address situations in which the Data Custodian will provide access to the dataset to third parties for specific purposes. This may require consideration of when the data sharing agreement ceases.

It is important that access to data for these purposes can be addressed as part of a Data Sharing Agreement. **Research Australia submits that this does not require amendment of the Bill; these issues may be effectively addressed in rules and guidance provided by the National Data Commissioner around Data Sharing Agreements. It may also be appropriate to refer to this in the Explanatory Memorandum; for example, it could refer explicitly to the NHMRC’s Open Data Access Policy as a consideration in relation to data outputs.**

## Requests to share data

Clause 23 of the Bill makes it clear that data custodians are not obliged to share public sector data: ‘However, data custodians should consider reasonable requests for sharing.’

Research Australia accepts that there is no obligation to share data and agrees there should be an obligation on data custodians to receive and consider requests for sharing. While the Bill requires data custodians to consider applications, it does not require them to make a decision or impose a time period for doing so. There is anecdotal evidence that some applications for data sharing under existing arrangements are frustrated by long delays in addressing applications. Evidence of delays was provided to the Productivity Commission’s 2016 Inquiry into Data Availability<sup>2</sup>.

Furthermore, the lengthy approval process for researchers requesting access to personal data limits their ability to make potentially life-saving discoveries:

- Nearly five years after requesting the data, researchers at the University of Melbourne received de-identified information about CT scans and cancer notifications. Their work showed there was an increased cancer risk for young people undergoing CT scans, and led to changes in medical guidelines for the use of scans. “Had [the] study been approved sooner, and been able to proceed at an earlier date..., we would have had results sooner, with potential benefits in terms of improved guidelines for CT usage, lesser exposures and fewer cancers” (John D Mathews, sub. 36, p. 13).
- Since 2008, government agencies have been providing funding to the Vaccine Assessment Using Linked Data Safety Study. Among other objectives, this study examines whether there is a relationship between vaccination and admission to hospital or death. The study requires data from both the Australian and State Governments. Obtaining data from the Australian Government has taken six and a half years; State data has not yet been linked (Research Australia, sub. 117). The researchers have been waiting for the linked data for more than eight years.

**Research Australia submits that the obligation to consider requests does not go far enough; data custodians should be obliged to respond to the data sharing requests, and to give reasons where a request is declined.**

**Research Australia proposes that at a minimum, clause 23 should be amended to require data custodians to:**

- **consider reasonable requests for data sharing;**
- **respond to all data sharing requests in a timely and efficient manner; and**
- **give reasons for their decision when declining a data sharing request.**

Such an amendment to the Bill would provide a clearer obligation on data custodians, and provide a basis for the National Data Commissioner to provide guidelines to data custodians about the process and what is considered to be a ‘timely and efficient manner’. Such an approach would be consistent with recommendation 6.7 of the Productivity Commission’s final report.

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<sup>2</sup> Australian Government, Productivity Commission 2017, *Data Availability and Use*, Report No. 82, Canberra, p.6



## Reporting of data sharing requests

Research Australia notes that the National Data Custodian is obliged by clause 124 to provide an annual report which, among other things, reports on the number of data sharing applications received by data custodians, and ‘information about the reasons for requests being agreed to or refused’.

Research Australia believes reporting of information about data sharing applications that are refused and the reasons for refusal are especially important. **Research Australia proposes that a public register of refused data sharing applications should be created and maintained by the National Data Commissioner, similar to the register of data sharing agreements to be maintained under clause 132.**

This register will be valuable to any person considering making a data sharing application. Identifying similar applications in the two registers which have been refused as well as those that have been approved will assist applicants to prepare applications that are likely to be successful. A register of refused applications could also assist data custodians by discouraging applicants from lodging applications that are likely to be rejected.

While there is additional work in creating this register, the requirement to report on refused applications in the Annual report already creates a requirement to collect the information. Providing this information in a register rather than just as part of the Annual Report will make it far more useful, as outlined above.

Research Australia submits that the creation of a public register of refused data sharing applications is consistent with the object of the Bill outlined at clause 3 related to promoting integrity and transparency. The creation of the register is also consistent with the National Data Commissioner’s functions under clause 41, particularly as they relate to promoting understanding and acceptance of best practice in data sharing.

## The Accreditation Framework

The Accreditation Framework outlined in the Discussion Paper is broadly suitable, although there are some opportunities to streamline the process.

Research Australia's focus is on accreditation for the purpose of research and development, and our response to the questions is from this perspective. We have not responded to all the questions posed in the Discussion; only those that are relevant to our submissions.

### What is considered to be an appropriate level of Australian ownership for an organisation to be eligible for accreditation?

It is not clear from the Discussion Paper why the level of Australian ownership of an organisation is a consideration in relation to accreditation.

The Bill provides that for the purpose of research and development, an accredited user must be a constitutional corporation. The definition of constitutional corporation includes foreign corporations.

Eligibility criteria considered in Chapter 3 of the Discussion paper relate to:

- appropriate governance and administrative arrangements to protect, manage and use data
- arrangements for security and privacy of data to ensure appropriate handling, and
- technical skills and capabilities to protect, manage and use data.

In relation to the second criterion, security and privacy of data, the Bill requires that the entity is: an APP entity (i.e. subject to the Privacy Act 1988); is subject to the Privacy Act as if it were an APP entity; or is subject to a State or Territory Act that imposes some similar requirements (Clause 27).

In addition to these, there is the requirement that any Data Sharing Agreement be in the public interest. (We note that the National Data Commissioner will provide guidance in relation to this.)

If the question of the level of Australian ownership is about control over how the data is used, this concern would appear to be addressed by these requirements.

**Research Australia submits that there is no evident reason to create accreditation eligibility criteria relating to the ownership of the entity.**

## Should individuals acting on behalf of an Accredited Data Service Provider be accredited individually? If so, what might be appropriate arrangements?

The Discussion paper refers to accredited individuals. While this specific question in the Discussion paper relates specifically to individuals acting on behalf of Accredited Data Service Providers, it appears that the Discussion Papers also considers ‘accrediting’ individuals acting on behalf of accredited users.

The use of the term ‘accredited individual’ is somewhat confusing because the Bill refers to accredited entities, and the term ‘accredited individual’ is used in the Discussion paper to refer to individuals acting for or on behalf of an accredited entity.

Any regulation of individuals employed by or acting on behalf of accredited entities will be through the conditions imposed on the accreditation of entities, so in a sense, there does not appear to be an ability to accredit them individually.

**Research Australia submits the question of the extent to which the National Data Commissioner deals directly with individuals or leaves it to the entity to take the appropriate steps (training, identity checking etc.) should be based on what will be the most effective and efficient approach.** If, for example, an entity has already undertaken appropriate identity checks as part of the employment process, it would appear that the National Data Commissioner also undertaking identity checks would be a duplication of effort. However, if the National Data Commissioner is to undertake more extensive identity, background and/or security checks, then it may be more appropriate for the National Data Commissioner to deal directly with individuals.

Similarly, if the training required to be undertaken by an individual as a condition of an entity’s accreditation is to be delivered by solely by the entity, then it would appear to more efficient to leave it to the entity to ensure that the training has been completed.

If, on the other hand, training and testing of individuals is to be undertaken through a digital platform provided by the National Data Commissioner then it may be more efficient and effective for the Commissioner to deal directly with the individuals and for the record of their accreditation and endorsement by an accredited entity to also be held on this platform. This has particular appeal where an individual is endorsed by more than one accredited user.

Presumably the accredited entity would still be responsible for delivering site specific training relevant to the specific work environment in which the individual is operating, but training and accreditation related to broader aspects of the data sharing scheme and the individuals’ legal obligations etc could be delivered through the Commission’s digital platform. It could even make sense for site specific endorsement related to the use of ADSPs to be delivered via this digital platform.

**Research Australia would welcome the opportunity to get a better understanding of the digital platform to be developed by the National Data Commission and how this could utilise to manage the endorsement and accreditation of individuals and their initial and ongoing training.**

## Is charging a fee for accreditation, such as a renewal fee, reasonable?

The Data Availability and Transparency Bill's origins lie in the Public Sector Data Management Project. The rationale for the Project is the widespread benefits to the Commonwealth and the Australian public that could be achieved by making better use of public data. These include improved service delivery, more effective government and driving the digital economy. There is a clear expectation that the benefits will be widespread throughout the economy and the community.

<sup>3</sup>

**Where the benefits are to be so widespread, Research Australia submits that the costs of the Scheme should not be borne by the accredited users and ADSPs as participants in the Scheme but by the community as a whole through payment of taxes.**

Furthermore, in the case of Accredited Users, the vast majority are likely to be universities and research organisations, and most of the research they undertake using the data will be publicly funded research, either through government grants, philanthropic funding or their own revenue generated from teaching activities etc. as not for profit organisations. Only a small proportion of research income is derived from private sources and only a small proportion of research generates profits for the research organisation or the researchers involved. In most cases the benefits are received by the general public. In such an environment, charging a fee for accreditation will simply redirect public funds from other research activities and may simply increase the demand on governments to fund the increased cost associated with research. The transaction costs of imposing charges will likely outweigh any benefit.

It also seems unlikely that a fee for accreditation will act as an effective price signal in such an environment. An accreditation fee, could however, in some circumstances be a barrier to research being undertaken, and thus contrary to the purpose of the Bill.

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<sup>3</sup> Commonwealth of Australia 2015, Department of the Prime Minister and Cabinet, Public Sector Data Management

## Conclusion

Research Australia is pleased to have this opportunity to comment on the Data Availability and Transparency Act and the proposed Accreditation Framework.

Research Australia is very supportive of the objects of the Bill and believes it provides an enormous opportunity to make much greater and more effective use of data held by the Australian Government in a safe and secure manner that will benefit all Australians.

The few comments we have provided in this submission relate to specific measures that could improve the effectiveness of the Scheme. We would be very pleased to assist the National Data Commissioner in any way we can with the implementation of the Scheme and the further development of the Accreditation Framework.

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