

29 May 2025

Dr Stephen King

Via email: DATActReview@finance.gov.au

CC: Mr Taylor Black

Dear Dr King,

## Response to the Statutory Review of the Data Availability and Transparency Act 2022

Thank you for the opportunity to provide a response to the Statutory Review of the Data Availability and Transparency Act 2022.

Research Australia is the peak body for the Australian health and medical research and innovation sector. Our membership is drawn from the whole pipeline of health and medical research and innovation, from universities and medical research institutes to charities and patient groups, and health care providers and companies commercialising new health technologies. We wanted to take the opportunity to respond to the Statutory Review with a letter, rather than individual responses to each of the terms of reference as our feedback is at a higher level that cuts across most questions posed in Terms of Reference.

Research Australia has been an active contributor to the development of the Data Availability and Transparency Act and have participated in previous consultations and inquiries since the Productivity Commission Inquiry into Data Availability and Use in 2016 and 2017. Effective health research relies on access to linked, high-quality data and collaboration across institutions. Without nationally consistent data-sharing legislation and frameworks, Australia is at risk of lagging behind in areas like AI in healthcare, precision medicine, and real-world evidence generation. Research Australia commend the Act for enabling structured access to Commonwealth-held data under a safe framework and recommend that the review considers further measures to expand its scope.

In summary, Research Australia recommends the following:

- Increase accessibility of the DAT legislation;
- Consider outreach and training programs to ensure researchers are aware of the requirements and opportunities of the DAT Act;
- Reduce ongoing administrative and governance burdens on accredited users;
- Expand eligible accredited users to include not-for-profit research institutes;
- Harmonise the governance system in the States and Territories to create a pathway for data custodianship

## **Further Information**

As noted in the Issues Paper, as of 20 March 2025, 34 entities are accredited to participate in the DATA scheme (17 Commonwealth entities, 10 State & Territory entities, and 7 Universities) <sup>1</sup>. In



<sup>&</sup>lt;sup>1</sup> Statutory Review of the Data Availability and Transparency Act 2022 – Issues Paper (April 2025) https://www.finance.gov.au/sites/default/files/2025-04/statutory-review-of-the-dat-act-issues-paper.pdf

addition, 8 data sharing agreements have commenced under the DATA Scheme, which represents a small fraction of the over 11,000 data sharing agreements operating outside of the Scheme. Whilst acknowledging the Act is still in its relative infancy, there appears to be a slow uptake of accreditation specifically from universities and a low number of new data sharing agreements which could be inhibiting the Act from realising its full potential. Research Australia recommends the Review considers the extent to which the Act is accessible, and to consider outreach and training programs within the existing remits of the Act to ensure researchers are aware of the requirements and opportunities of the DAT Act. This is likely to increase understanding and application of the legislation and accreditation process as well as reduce the administrative burden on researchers where possible.

Furthermore, Research Australia encourage the Review to consider expanding the type of accredited users to include not-for-profit research institutes to stimulate further health and medical innovation in the interest of public health and prosperity. Across the health and medical research ecosystem, researchers adhere to high data governance standards and ethics and are therefore well-placed to enter into data-sharing agreements with trusted partners. Safeguards and privacy controls in place at universities and research institutes allow researchers to engage sensibly with data, maximising health benefits to consumers and minimising privacy risk. As per Research Australia's previous submission to the Senate Finance and Public Administration Legislation Committee, we recognise that there are risks associated with greater use of data held by the Australian Government but acknowledge that by engaging with trusted users the benefits of doing so in a controlled way outweigh the risks. This position is set within the context of strong public support for the use of deidentified medical records for research in the public interest, which Research Australia's previous opinion polls have consistently highlighted <sup>2</sup>.

In the Act's current format, State and Territory bodies are either intermediaries (ADSPs), accredited users, or both and are not eligible to become data custodians. Access to health data is key to the work of Australia's health and medical researchers and improving access to datasets and information has the potential to lead to research breakthroughs which would otherwise not be possible. Research Australia would therefore encourage the Review to explore furthering the role of the States and Territories to data custodians under a harmonised governance system, thereby opening pathways for researchers to utilise State-based datasets such as hospital and pathology data, where it is safe and appropriate to do so.

Thank you again for the opportunity to comment on the Statutory Review of the Data Availability and Transparency Act 2022. We look forward to continuing to work closely with the DAT Act Review Secretariat to ensure that we collaboratively continue to transform health and medical research and innovation to improve lives, build the economy and contribute to health system sustainability.

Yours sincerely,



Dr Talia Avrahamzon Head of Policy and Advocacy Research Australia

<sup>&</sup>lt;sup>2</sup> Research Australia Submission to the Senate Finance and Public Administration Legislation Committee (March 2021) https://researchaustralia.org/wp-content/uploads/2021/03/RA-Sub-DAT-Bill-Senate-Committee-FINAL.pdf