

### INTRODUCTION

Monash University is a high-impact research-intensive university, home to many highly cited researchers who excel in national competitive grant schemes through the Australian Research Council, National Health and Medical Research Council and the Medical Research Future Fund. Monash's Responsible Research Culture Framework underpins our approach to excellence, and orients our research to ensure positive outcomes for people and the planet while minimising harm. This duty of care, demonstrating sound judgement and accountability for how the research is conducted, extends to responsible practices in managing and governing data. Commonwealth data is an incredibly important resource for highly cited Monash researchers, who for decades have requested data from various public sector bodies

The introduction of Data Availability and Transparency Act and the DATA scheme, aimed at breaking the legislative barriers for Australian government entities through trusted data sharing mechanisms, was welcomed across the research sector and Monash was one of the first universities to be accredited as Data User under the scheme. The University spent about \$250k over the last 2 years in staff time, including one full time staff for one year to operationalise the scheme. However, almost 18 months after the accreditation, Monash researchers have not succeeded in any of their requests to access commonwealth data through the scheme.

Therefore, Monash welcomes this review of the Data Availability and Transparency Act. Based on our experience, the actions and outcomes to date have not lived up to the intentions. In short:

- Has the operation of the DAT Act advanced its objects?
  - Not yet.
- Does the DAT Act improve information flows between public sector bodies and accredited entities?
  - Not in our experience as an accredited entity. Not one of our requests through the DATA scheme has been successful.
- How does the DAT Act add value in the wider data sharing context?
  - No value added yet. It has great potential to improve researcher experience and efficiency in discovery, access, linkage and use of Commonwealth data; and to enable institutions to better meet risk, compliance and data governance accountabilities
- What changes could be made to the DAT Act or the DATA Scheme to make it more effective in facilitating access to, sharing and use of public sector data?
  - Prioritise improvements to curation and access of high-value datasets, as determined by researchers.
  - Extend the scope of the DATA scheme and create a streamlined and consistent data sharing approach across all public sector bodies.
  - Focus on making the Act and Scheme work for existing accredited participants before staging access to additional entities.
- Should the DAT Act be allowed to sunset?
  - No. If the Act's objects are realised, there will be significant efficiency and quality gains, including a reduction in the time taken for researchers to obtain data, and improved quality of the data. This will improve the capacity of public research to contribute to Australia's economic and societal prosperity.

Our recommendations and experience with the scheme are explained below. We look forward to further engagement as the review continues.

Professor Robyn Ward Deputy Vice-Chancellor (Research & Enterprise)

<sup>&</sup>lt;sup>1</sup> Due to the lack of outcomes and value, Monash reluctantly decided to reduce investment in the DATA scheme. Consequently, the full time staff member joined the ONDC to support the roll out of scheme



#### RECOMMENDATIONS

Public sector data provides longitudinal insights that enable evidence-based policy development and evaluation, targeted public services, and real-world innovation. Our researchers have long struggled to access the valuable data assets within public sector bodies due to time-consuming, costly, inefficient and inconsistent data sharing practices. Hence, Monash strongly supports the successful implementation of Data Availability and Transparency Act and the associated DATA scheme. By unlocking access to this data, researchers can translate knowledge into action, shaping decisions that improve lives, strengthen systems, and deliver greater public value.

- 1. Prioritise curation and access for high value datasets across agencies, as determined by researchers, to progress the scheme objectives and deliver value for the current participants. This is essential to ensure the accredited entities build and retain confidence in the Scheme and accelerate the leveraging of public sector data for research and development, thereby improving the information flow between the public sector bodies and the accredited entities. The National Disability Data Asset (NDDA) that has been recently made available, is a valuable starting point and we can provide information on other high value datasets.
- Create a streamlined and consistent data sharing approach for all public sector bodies, that embeds Dataplace as the
  "one-stop-shop" and "only mechanism" to request data from all public sector bodies. Clarify how other
  Commonwealth legislation and regulatory frameworks interact with the DAT Act (e.g. Census and Statistics Act, ATO
  Legislation and Medicare/ PBS Privacy Rules) for data sharing
  - a. Provide clarity and visibility about the required steps and obligations imposed by agencies for every dataset to make the request processes efficient
  - b. Mandate timeframes for the data custodians to respond to the data requests
  - c. Establish an accredited data users group that ONDC can consult with on regular basis for co-design and to make sure the needs and experiences of accredited entities inform the delivery of the scheme
  - d. Stage introduction of data from state and territory entities

This will also provide Universities with visibility of all Australian government data being used by their researchers to strengthen data governance and assist university compliance responsibilities

- 3. Make expanded participation in the scheme contingent upon a subsequent evaluation of the process that demonstrates success with the current identified entities.
- 4. Continue the Act beyond 2027, incorporating all the above recommendations and with provisions to increase the scope of scheme participants and revise the scope of 'precluded purposes' in the future

#### MONASH EXPERIENCE AND CHALLENGES

Commonwealth data is a valuable resource for Monash researchers, who have regularly sought access to national datasets for their research either individually or for linkage with other research datasets. For decades, Monash researchers have regularly requested data (often for data linkage purposes) from data custodians such as Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS) and Department of Health (via Services Australia). These datasets included the Medicare Benefits and Pharmaceutical Benefits Scheme (MBS, PBS) data, the Australian Cancer Database, the National Death Index (NDI), and the National Aged Care Data Clearinghouse datasets to name a few. In the past, these requests were made by our researchers directly to the relevant agencies and they faced a number of well-known challenges that persist to this day, including ability to locate relevant datasets<sup>2</sup>, length of time to source data, cost, iterations required to receive data of sufficient quality<sup>3</sup>.

We participated in both the Productivity Commission's Public Inquiry into Data Availability and Use (2016-17) and the subsequent Data Sharing and Release legislative reform discussion paper (2019), welcoming and supporting the government's intention to streamline and enhance access to public sector data for supporting world leading research and development.

<sup>&</sup>lt;sup>2</sup> In a 2023 inhouse survey, 75 percent of Monash researchers reported difficulty in locating relevant datasets available in government agencies, with several responses indicating that agency contacts were a factor in success: "knowing what data is available is dependent on who you know at the agencies"

<sup>&</sup>lt;sup>3</sup> 2024 inhouse poll of Monash data linkage community of practice (more than 100 members)



#### ACCREDITATION APPROACH

In February 2023 Monash formed a DATA Scheme Accreditation Working Group, with academic and professional leaders to evaluate the expected benefit of the Scheme, advise on the accreditation approach, and provide ongoing oversight for the DATA Scheme operations at Monash. In preparation for accreditation, the University undertook a research data governance uplift program to ensure that all the criteria for accreditation assessment were (and continue to be) met. Monash University was accredited under the Data Scheme in late December 2023. One full time staff was appointed to operationalise the Scheme, and this included

- Onboarding administrators and users to Dataplace and the development of processes and procedures for Scheme operations, ensuring they were embedded into the existing University research processes
- Setting up compliance and risk management systems to incorporate DATA Scheme operations and any mandatory reporting requirements
- Promoting the Scheme within the University through roadshows, FAQs and training materials

#### **OUTCOME**

Despite all our efforts in the last two years to secure accreditation, and to promote and operationalise the Scheme internally, each one of Monash's eight data requests to Dataplace (as of 15 May 2025) have been refused, or data custodians have requested researchers to withdraw the request and reapply via their existing access mechanism<sup>4</sup>.

We believe this is not just an issue for Monash. The register of data sharing agreements published by ONDC lists only eight data sharing agreements in the time since the Act came into effect. All are between Commonwealth agencies, and none are for the eight accredited universities.

#### Monash University engagement with the Scheme and the ONDC

- Beta testing the Australian Government Data Catalogue and Dataplace portal
- Assessing processes associated with data requests including:
  - o those that need permission through ASIO; and
  - o acceptability of using approved platforms of universities with government agencies who are data custodians
- Providing a list of public sector datasets that would be of interest to researchers to help ONDC identify high value datasets
- Inviting ONDC to present at our event co-hosted by ARDC and PHRN "Navigating Linked Data Access in a Changing State and National Landscape" in December 2024, attended by over 100 researchers where we raised and discussed current challenges in the data sharing landscape
- Co-presenting with ONDC about the current state of DATA scheme at eResearch Australasia 2024 where all
  universities participated and channelled their challenges to ONDC
- Advocating to Commonwealth agencies about the metadata quality and other challenges that the researchers face in requesting and using Commonwealth data

#### Challenges

In the last year, Monash has identified and shared with the ONDC a range of the challenges:

- Burden on researchers to determine the right pathway for requesting a dataset when there are conflicting messages from agencies. Researchers must determine whether their request can be made under a custodians' existing legislation and processes (e.g. see advice on ATO and ABS website re data sharing at Figure 1 and Figure 2 over page) rather than going to Dataplace, searching the catalogue and managing the process there.
- Persistent redirection away from the Scheme by the agencies. After three months of waiting time on a few
  requests via the Scheme, the researchers have been asked to reapply with the agency, that is, start over again
  adding an additional three month delay to an already lengthy process.
- Lack of case studies/successful data sharing with researchers through the Scheme that demonstrate the value
  of the Scheme for University researchers. Without successful case studies researchers will be less inclined to use
  the Scheme in the future.
- Australian Government Data Catalogue is yet to mature. Datasets are limited for the major agencies and key data
  assets do not provide clear guidance in how to obtain (e.g. Pharmaceutical Benefits Scheme is listed under three
  data custodians with unclear pathways to access the data).

<sup>&</sup>lt;sup>4</sup> Requests were made by Monash health and business researchers to the Australian Bureau of Statistics, Australian Institute of Health and Wellbeing, Australian Taxation Office, Department of Health and Aged Care, Services Australia and the National Disability Insurance Agency.
MONASH RESPONSE TO STATUTORY REVIEW OF DAT ACT 2022 | 3



# When we will consider sharing data under the DATA Scheme

When we receive a request, we'll first determine if the data can be shared using an existing process or product, for example:

- data already available in <u>ATO's research and statistics</u>
- Business Longitudinal Analysis Data Environment (BLADE) ☐
- Person Level Integrated Data Asset (PLIDA) ☐

If possible, we'll use the existing process or product. If not, we'll then consider if the DATA Scheme applies.

Figure 1: Screen shot (26 May 2025 of ATO website)

## When we will consider sharing ABS data under the DATA Scheme

If there is no existing option or product, we will consider if the DATA Scheme applies.

We will consider sharing with Accredited Users and Accredited Data Service Providers if:

- ABS can legally share the data
- the proposed project is for a permitted purpose
- the sharing is consistent with our purpose and role
- the sharing is consistent with the commitments we give to our respondents and providers.

Where we hold data from other data custodians we will only share the data with their approval.

Figure 2: Screen shot (26 May 2025 of ABS website)



**DAT Act Review Team**Digital ID and Data Policy Division
Department of Finance

16 June 2025

#### Dear Review Team

Following the productive roundtable last week, we wish to follow up with this supplementary submission.

As we discussed, the Act and scheme's potential are far from being realised, evidenced by the lack of successful data sharing agreements made via the scheme to accredited non-agency participants. The most common outcome of applications made by Monash researchers through the scheme is a request from the agency to withdraw the application and redirect it through their own well-established proprietary data provision channels.

Nonetheless, we support the Act and believe that a constructive way to make it effective would be for existing accredited participants and data custodians to come together in a forum to understand the issues, challenges and barriers to sharing datasets via the scheme. Ideally, this would also result in an agreement on Trusted Research Environments to minimise the time and costs associated with researchers having to operate within multiple environments.

The Act itself is prescriptive in enabling access to datasets on a project basis and we recommend some changes to improve safe access and reduce overheads for custodians and accredited users.

We appreciate the conduct of this review and remain available for further discussion in the interests of enhanced, effective and safe data sharing.

Professor Jacek Jasieniak Pro Vice-Chancellor, Research Infrastructure Office of the Deputy Vice-Chancellor Research and Enterprise



Recommendation: Extend the Australian government data forum and/or establish other similar mechanisms to bring researchers and the data teams within the commonwealth agencies together to build empathy in data sharing decisions and embed access to data via the Scheme into current data custodian workflows.

The accreditation itself hasn't generated any different behaviours with respect to Monash's dealings with the commonwealth agencies about data. The persistent redirection of requests away from the scheme by agencies and the lack of successful data sharing agreements with any accredited data users suggests there is a barrier within the Commonwealth that must be understood if it is to be overcome. Dimensions could include data custodian concerns about data safety, lack of knowledge and/or trust in the process and/or the accredited institutions, or insufficient value proposition to change existing systems and practices.

Dialogue should aim to build mutual understanding and trust as a basis for co-design of practices and systems that meet the needs of researchers while enabling agencies to acquit their obligations to data safety.

For example, Monash's data user accreditation includes a secure environment that operates within the five safe principles and is capable of handling highly sensitive data. However, the secure environment in which the requested data will be made available, both within and outside the scheme, is at the discretion of the data custodian. There are multiple Commonwealth hosted Trusted Research Environments (TREs) including SEED and SURE with use dictated by each of the data custodians. Requiring researchers to use multiple TREs is costly.

Like agencies, Monash, and most other universities have invested significantly in establishing equivalent secure environments, but the agencies don't recognise these environments for sharing their data.

Monash understands that the agencies would need to validate any file transfers in and out of such environments as part of their data governance and would be open to adapting our secure environments, if it would allow agencies to provide data in them.

Recommendation: Amend the DAT Act to allow multi-use or time-based access to particular high-value or common-use datasets

In addition to using commonwealth data and other secondary data sources, researchers also collect a lot of primary data. Therefore they are custodians themselves of datasets that contain sensitive, personally identifiable information, for which they must meet data custodian responsibilities and obligations in data reuse. All research projects undertaken within universities that involve humans must be approved by a Human Research Ethics Committee and researchers must comply with their ethical standards. They understand the risks and know how to be a custodian of very sensitive data.

The DAT act stipulates that a data sharing agreement can only be at a project level. This increases the number of transactions and associated costs for the agency and the institution, as multiple researchers within the one university might require the same dataset (like NDDA) for different research projects. Each project requires approval and contractual support both internally and for the Commonwealth agencies, leading to inefficiencies and unnecessary costs.

The Act should allow for dataset-based data sharing where appropriate. This could be undertaken on a subscription basis and with a dedicated institutional dataset custodian approving subsequent requests to the dataset from other researchers within the university.

Recommendation: Amend the DAT Act to distinguish between types of requests and allocate settings proportionate to risk

Often data requests are made for discovery purposes, for inclusion in a grant application. In these cases, the dataset itself is not required for immediate use, but to ensure availability and cost to inform research design and budgeting.

The Act and scheme should be amended to allow agencies to distinguish between requests made to validate the availability of the dataset and requests for immediate access. It is critical for researchers to know certainly that the dataset will be available when they are successful with their grant application, especially given the strict timeframes and funding rules of commonwealth-funded project-based grants.