**Statutory Review of the Data Availability and Transparency (DAT) Act 2022**

**Australian Institute of Health and Welfare submission**

## Introduction

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to provide a submission into the Statutory Review of the *Data Availability and Transparency (DAT) Act 2022* (the Review). We appreciate the intent of the legislation and the role the Office of the National Data Commissioner is playing in guiding and supporting its implementation

The AIHW is a Data Custodian, an Accredited User and Accredited Data Service Provider (ADSP) under the DATA Scheme.

*Broad role and functions relevant to data sharing*

The AIHW is a national agency established under the *Australian Institute of Health and Welfare Act 1987* (AIHW Act) as an independent statutory body to collect and produce information and statistics on Australia's health and welfare.

The AIHW Act establishes a Board as our governing body. The Board is accountable to the Parliament of Australia through the Minister for Health and Aged Care.

The AIHW Act requires the AIHW Board to appoint an AIHW Ethics Committee. The main functions of the Committee are to consider ethical matters relating to Institute activities or Institute-assisted activities and to advise any body or person on ethical matters concerning the collection and production of health- and welfare-related information and statistics.

Section 29 of the AIHW Act imposes strict confidentiality requirements that prohibit the release of documents and/or 'information concerning a person' held by the AIHW unless one of the following apply:

- express written permission has been provided by the relevant data supplier(s);
- release has been approved by the AIHW Ethics Committee;
- the data are in the form of publications containing de-identified statistics, information and conclusions.

In the absence of express approval of the data supplier(s) or the AIHW Ethics Committee, only de-identified data can be shared or released. A breach of section 29 of the AIHW Act comprises an offence punishable by fines and/or imprisonment.

In addition to our enabling legislation, Ethics Committee functions, and the *Privacy Act 1998,* the AIHW operates within a Data Governance Framework which comprises the elements of the AIHW approach to data governance and describes in detail how they work together to support the legal, ethical and safe management of our data holdings. It recognises that a combination of supporting legislation, roles, policies, practices, standards, tools and technologies is required to deliver effective data governance arrangements at AIHW. The AIHW has embedded the five safes framework into our approach in making decisions about sharing and releasing data.

We hold valuable data on a wide range of health and welfare topics, including expenditure, hospitals, disease, injury, mental health, ageing, homelessness, housing, disability, child protection and the needs of Aboriginal and Torres Strait Islander (First Nations) people. Our health and welfare data holdings are substantial, including more than 150 datasets. The vast majority of our data holdings are supplied by state and territory government agencies.

The AIHW has a long-standing data linkage program, including a commonwealth-state and territory data system which supports health and welfare research and government reporting (National Health Data Hub). This linkage system underpins the AIHW's contribution to the national data linkage system in Australia.

The AIHW publishes more than 400 reports and data releases annually and, in addition, requests for access to other data holdings can be made via the AIHW website.

The AIHW has a number of mechanisms to manage the sharing and release of data.

a. Open access - Data are made publicly available with few or no restrictions on who may access the data and what they may do with it. For example, publishing data to a publicly accessible website—sometimes referred to as open access or open data.
b. Delivered access - Data are made available by direct delivery to the user's custody. For example, the user agrees to specific conditions associated with management and use of the data before we agree to deliver it to them.
c. Secure access - Data are made available to users via remote access that has a high level of security infrastructure control and where the users' activities can be remotely supervised to ensure conditions of access are met.

*AIHW role in relation to the National Disability Data Asset*

The National Disability Data Asset (NDDA) is an enduring national asset that comprises de-identified data from the Australian Government and state and territory sources. The NDDA aims to improve inclusion and opportunity for people living with disability by linking data to better understand their life experiences.

The NDDA project is led by the Department of Social Services (DSS), with the support of technical partners the AIHW and the Australian Bureau of Statistics (ABS), and in co-design with states and territories and people with disability. A tripartite Memorandum of Understanding between DSS, ABS and AIHW was executed in June 2022 to establish funding and working arrangements to deliver the project.

The AIHW is jointly responsible with the ABS, as the Technical Team, for working with Commonwealth and state and territory governments on the technical aspects of the project. The AIHW has played a key role in developing the underlying infrastructure – the Australian National Data Integration Infrastructure (ANDII). The ANDII includes an ICT system for data asset creation, commonwealth, state and territory co-governance new data sharing arrangements to enable data asset creation, as well as workflow management, including data access, use and release processes.

With this context in mind, this submission provides advice consistent with the key consultation points included in the Review Issues paper, and more broadly within the Terms of Reference of the Review.

## 1. Has the operation of the DAT Act advanced its objects?

*The DAT Act has not reduced barriers or enabled streamlined data sharing*

One of the original intentions of the DAT Act was to enable data sharing between:

- Commonwealth to Commonwealth Agencies, and
- Commonwealth to state and territory agencies (and vice versa).

The DAT Act only applies to the sharing of data by a Commonwealth entity, and only if the entity is a custodian of the data as defined by the DAT Act.

The complexity of the DAT Act, and how it has been interpreted, has meant that this original intention has not been achieved.

For example, the sharing of ABS Census data to other Commonwealth agencies for linkage projects (such as to the AIHW for the COVID-19 Register for important analysis of the effects of long COVID on CALD populations) has not been enabled. This may be possible for future (2026) Census data, as per the Privacy Impact Assessment.

In the case of the NDDA, using the DAT Act is a major challenge, with 183 (of the total 208) planned datasets to be added provided by state and territory data custodians. The governance and Data Custodian requirements of the DAT Act have contributed to the substantial delays in project timeframes.

The inability of the DAT Act to operate alongside other authorising pathways has been a challenge for the NDDA and impacted abilities to repurpose existing approaches for national data sharing.

*Access to linked data has become more restrictive*

The requirement of needing to be an Accredited Data Service Provider has meant that some information providers won't be able to access their own data in linkage systems built under the DAT Act, negating the intention of the DAT Act to enable data sharing and access.

Similarly to the above point, the requirement to be an Accredited User has meant that some researchers won't be able to access linkage systems built under the DAT Act, negating the intention of the DAT Act to enable data sharing and access.

Complexity and prescriptiveness of authorisations, roles and functions under the DAT Act has made use of the DATA Scheme for delivery of integrated assets difficult in the context of the NDDA. Delivery of linked data assets requires a degree of flexibility on behalf of integrating agencies delivering these services but within clear guardrails and governance frameworks. A high degree of prescriptiveness in authorising legislation is at odds with this requirement.

*Producing policy insights using data shared under the DAT Act is complex and restrictive*

The complexity of the DAT Act, and how it has been interpreted, has meant that there is not a viable pathway for releasing approved aggregated outputs from linkage systems built under the DAT Act, negating the intention of the DAT Act to support information flows and inform policy development, monitoring, evaluation and planning for the government and research sector.

**2. Does the DAT Act improve information flows between public sector bodies and accredited entities?**

The AIHW and our state and territory partners have struggled to use the DAT Act to share data into the ANDII ICT for the NDDA. This is partly due to the legislation being new, combined with limited access to legal resources with expertise in data sharing.

The DATA Scheme also establishes rigorous responsibilities, which consume significant resources to understand and implement within and between agencies.

As referenced above, the AIHW's enabling legislation has been used for many years to facilitate safe data sharing.

The *AIHW Act* permits data sharing with third parties in accordance with requirements imposed by information providers. This provides reassurance to our information providers and information subjects.

**3. How does the DAT Act add value in the wider data sharing context?**

It has provided governance structure to the data integration landscape, however the complexity of the governance imposed by the DAT Act is not scalable or implementable given its current settings.

It provides assurance to data providers that those accessing and using their data are doing so under rigorous conditions imposed under the DAT Act. This provides a standardised approach and assurance in the case of requirements to become an Accredited Data Service Provider. However, accreditation of users has limited the utility of the data for those who cannot meet these conditions due to a range of circumstances (for example, non-citizens, or researchers and PHD students who are not/cannot be 'engaged' by the accredited entity, or entities that don't have the resources to undertake the accreditation process).

In addition, given that accreditation of users under the DAT Act is undertaken at the organisation level, requirements to assess the safety of individual users/researchers for accessing linked data is still required (and undertaken). This brings into question the added value of user accreditation over and above existing mechanisms.

The DATA Scheme has provided an accreditation framework as a key safeguard underpinning the DAT Act. Entities applying for accreditation are assessed against expected capabilities and characteristics as set out by the DAT Act. The accreditation framework provides several benefits:

- Stakeholders across various levels of government have assurances that entities have high standards of data handling, security and privacy via an impartial assessment
- Enhanced staff competence and awareness of developments across the public data landscape and capability standards
- Providing entities with a snapshot of their competency across the five broad categories, providing a base for future developments and improvements.

**4. 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?**

- Include conditions that enable the sharing of Commonwealth data with other agencies. For example, with appropriate conditions the revised DAT Act should enable the ABS to share Census data with other agencies.
- Revisit the need for researchers to be Accredited Users. This can be addressed by the 5 Safes Framework.
- Include conditions to support easy to implement mechanisms that enable approved aggregate data to be released from linkage systems built under the DAT Act, i.e. exit pathways for approved aggregate data to leave the DAT Act.
- Create the ability for state and territory entities to act as Data Custodians under the Scheme
- Create the ability for DAT Act to operate alongside, and not to the exclusion of, other authorising frameworks

**5. Should the DAT Act be allowed to sunset?**

Yes, unless there are significant changes made to make the DAT Act more usable. Because the AIHW already has enabling legislation and a well-established approach to receiving and sharing data, established over many years, we had limited need for the Act to facilitate our functions.

**6. Other – Engagement with Dataplace**

In terms of systems set up to support the Act and the DATA Scheme, Dataplace, established to facilitate requests for access, largely duplicates functionality already in place at AIHW. It also causes some confusion for requestors due to the nature of our holdings (largely not commonwealth data) and additional administrative burden (on us and requestors).

As mentioned in the introduction, the majority of the AIHW's data holdings are sourced from states and territories, and we are required to comply with any conditions they impose. This presents challenges in meeting general expectations about responsiveness and data delivery timeframes on Dataplace and state and territory and Commonwealth collaboration is difficult on the platform, as states and territories are not Data Custodians.

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