Department of Health, Disability and Ageing's submission to the statutory review of the *Data Availability and Transparency Act 2022*

The Department of Health, Disability and Ageing (the department) welcomes the statutory review of the *Data Availability and Transparency Act 2022* (DAT Act) and appreciates the opportunity to provide a submission.

The department is committed to the safe sharing and release of data and insights to support better health and wellbeing for all Australians, now and for future generations. This includes managing access to sensitive health, disability and aged care information, such as data from the Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), Australian Immunisation Register (AIR), and supporting national initiatives such as the National Disability Data Asset (NDDA).

As custodians of Commonwealth health, disability and aged care information, the department receives requests through multiple pathways. Regardless of the pathway, the department must apply a risk-based approach to complex assessments of any release of sensitive data. The legislative authorisation is one key element in the assessment. The assessment also includes consideration of the social license, ethics, data proliferation and commercial sensitivities.

There is increasing demand for use of integrated data assets such as the Australian Bureau of Statistics (ABS) Person Level Integrated Data Asset (PLIDA) and the Australian Institute of Health and Welfare (AIHW) National Health Data Hub (NHDH). The department contributes significant and valuable data to both of these assets.

The department has been assessed as an accredited user of the Data Availability and Transparency Act Scheme (the Scheme) and receives requests from other accredited users for access to health data. This submission reflects these experiences in responses to questions in the published Issues Paper.

Has the operation of the DAT Act advanced its objects?

The value of public sector data to good policy, services and research is well documented (Productivity Commission's 2017 Inquiry into Data Availability and Use). The DAT Act was established as an alternative legislative pathway to safely share data with accredited users where existing legislation prevents or limits sharing. The DAT Act has incorporated international best practice safeguards in its institutional arrangements including data sharing principles, participant accreditation, and mandatory data sharing agreements.

There continues to be challenges with operationalising the Scheme. It has introduced additional layers of legislative complexity where, for the majority of cases, there is an existing legislative pathway.

The limited number of Data Sharing Agreements (DSA) established since 2022 indicates ongoing challenges in operationalising key elements of the legislation. Particular challenges include:

- narrow or unclear definitions on which the DAT Act relies
- overly prescriptive DSAs making it difficult to consider the risk profile of varying projects, and
- lack of clarity on how the DAT Act interacts with other legislation such as the *Privacy Act 1988*.

As accredited users of the Scheme, the department has discussed using the DAT Act to obtain sensitive data from other Commonwealth agencies. Legislation does not appear to be a significant barrier to accessing data: instead, agencies are preferencing existing data sharing arrangements such as integrated data assets like the ABS PLIDA. This is to minimise data proliferation and reflects stretched resourcing availability to navigate alternate arrangements.

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

There are existing pathways for accessing health, disability and aged care data. The demand for data through existing pathways has increased by 50% from 2023 to 2024.

The improved foundational safeguards under the Scheme, such as the data sharing principles and accreditation, provide confidence that participants meet required standards to handle sensitive health data safely and securely. The accreditation of jurisdictional data linkage centres as Data Service Providers under the Scheme has provided assurance for the sharing of the Commonwealth's Medicare Consumer Directory data with five States to enable the creation of national data linkage infrastructure, which facilitates interoperability between Commonwealth and State data systems.

Conversely, the exclusion of private sector and community sector entities from applying for accreditation under the DAT Act creates a barrier to data access under the Scheme and has impacted the department's ability to use the DAT Act to share data with other players in the health sector. Access remains limited to data from other Commonwealth entities who are not active participants of the Scheme.

In some cases, accredited users have expressed an expectation that their accreditation fulfills all criteria for being approved to access data. This is contrary to the intended operation of the Scheme, with decision-making authority retained by the department to ensure decisions are informed by expert knowledge of the data, privacy concerns, and awareness of public expectations of how sensitive information should be managed. Accreditation is only the entry point to the Scheme, it is not approval to access certain datasets without any further consideration of the project's merits, risks involved, and appropriate controls.

Within our department, assessment by qualified stewards of health data is required to enable data sharing. Where data is assessed as suitable to share in the public interest, the department has found it is more efficiently managed under existing legislation and through established processes outside the Scheme. Annually, the department manages more than 200 requests from other Commonwealth agencies, state and territory governments, academics and researchers. Requests are received through multiple pathways, of which the Scheme is a small component. Assessing requests for sharing sensitive health data is complex and time-consuming. Decisions must balance the release of data in the public interest with risks such as social license, ethics, data proliferation, and commercial sensitivities, all of which can be done more efficiently using existing approaches.

A significant limitation with the DAT Act is that it does not address the differing legislative barriers faced by state and territory public sector departments for a consistent data sharing pathway across governments. Differing legislative requirement across governments as well as portfolios adds complexity to national data sharing. This has limited the DAT Act's utility where data sharing between state and territory governments and the Commonwealth is necessary, such as for the NDDA. The DAT Act has been used in part for the NDDA. However, as state and territory data is not defined as public sector data under the Scheme (i.e. it is not Commonwealth data) there have been complex workarounds put in place to facilitate the sharing.

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

The DAT Act has provided limited value to the wider data sharing context beyond providing the accreditation safeguards that provide confidence to the department that accredited users are safe entities with whom to share sensitive data. The cultural shift towards greater openness and willingness to share data where it can be done safely and securely benefits begun prior to the DAT Act implementation.

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?

The department is unsure whether refining the DAT Act or the DATA Scheme is a valuable investment and whether this will be able to make it an efficient and effective mechanism.

A more pragmatic implementation of the DAT Act may make it effective. The review provides an opportunity to:

- reduce the legislative complexity and recognising existing legislative pathways for the most efficient approach to sharing data.
- consider inclusion of state and territory governments, private and non-government sector entities to bolster the value proposition of the DAT Act and Scheme.
- consider the extent to which the Scheme's accreditation framework balances ease of access to the Scheme, confidence in accredited users and Accredited Data Service Providers (ADSPs), including the standards to which accredited entities are held, and regulatory burden.
- consider he current operationalisation of the Scheme, including the ease with which participants can navigate it and the extent to which it supports flexibility and consistency in data sharing.

The department considers that exclusions of current precluded purposes and the inclusion of data safeguards in the DAT Act are appropriate.

Establishment of the DAT Act has focused on embedding the Scheme as a main mechanism for nationwide data sharing, which is not how the department uses this Scheme. The department asserts that existing data sharing mechanisms, that have been developed over decades, remain more efficient to the new complex Scheme.

There is a conflict in using the Scheme as a primary mechanism for data sharing when the same request could be met under existing legislation and governance controls, and within existing resources. This complexity is at the heart of implementation challenges as data custodians are working to navigate sharig under the DAT Act and the establishment of new data sharing agreements in comparison with more established policy and processes under existing health and aged care legislation such as the use of Public Interest Certificates.

There is a need to standardise workflows and infrastructure for both the Scheme and existing legislative mechanisms to provide transparency to requesters on how to access data.

The guidance and processes established on the Scheme's digital platform, Dataplace, are still maturing and require enhancements to improve functionality. Dataplace's processes do not reflect the work required to assess data sharing requests undertaken by the department. This increases the

governance burden on agency custodians, who must balance the demand for data and associated risks with limited resourcing and capacity.

The Scheme and Dataplace, would benefit from better integration with well-established mechanisms to streamline and simplify data sharing processes. Additional guidance and support for Scheme implementation should include:

- Clarity on how custodianship is defined and guidance for data custodians. In some cases, more than one custodian is responsible for health data, due to the way the data is collected, stored and managed.
- Additional guidance to data requesters on details required to properly assess requests for health data. The department generally receives requests for data projects through Commonwealth data brokers such as the ABS, AIHW, and Services Australia, whose data request forms are comprehensive and clear. These brokers also guide and handle requests.
- Expanding information in the public domain for the Scheme as an alternative pathway to data sharing, rather than the sole pathway.
- Increasing flexibility to allow custodians capacity to tailor DSAs to be fit-for-purpose (i.e. the contents should be recommended practices, not legal requirements).
- Reducing requirements for custodians to report to the Office of the National Data Commissioner (ONDC).
- Revising guidance on response times from data custodians to manage data requester expectations. Our experience shows that responding to requests for sensitive health data exceeds the ONDC recommended timeframe of 28 days.
- Empowering the ONDC to play a more active role in providing guidance and support to participants who are new to Commonwealth data sharing processes and building templates and guidance to support them. The ONDC should be supportive of, and seek to improve participants understanding of, the legitimate reasons why data may not be shared, or not shared in some forms (e.g. privacy, public expectations, social licence).

As digital technology and national data sharing infrastructure evolve, it is vital that the DAT Act and Scheme are flexible enough to keep pace with the changing environment and remain fit-for-purpose.

Consultation Question 5: Should the DAT Act be allowed to sunset?

For the DAT Act to be effective, it requires a clear articulation of its place within the broader legislative and data sharing context. Its scope could be constrained as a legislative option to be used to support data sharing in the public interest where there is no existing legal pathway.

A stronger implementation focus is warranted to address challenges in operationalising the DAT Act and consider measures to include all governments as participants. This would necessitate greater resourcing at Commonwealth and state level.

The department would not support further scope expansion to the DAT Act, such as sharing for compliance or regulatory functions, without strong use cases, a clear social license, and further work to first address the existing implementation issues.

If the DAT Act was to sunset, the department recommends using non-legislative means to retain valuable parts of the DATA Scheme that support effective data sharing practices, including:

- Accreditation – to ensure continued efficiencies in establishing an organisation's capacity to handle and use Commonwealth data; custodians would not have to re-vet organisations or people for each data sharing transaction.
- Visibility of data sharing transactions and data sharing requests denied – for transparency within governments and with the Australian public.
- Incentives for agencies to share data – alternate mechanisms could be considered to incentivise agencies to share data to support broader Government data and digital priorities.