



Privacy Assessment Summary

Survey of Disability, Ageing and Carers data for the National Disability Data Asset September 2024

The <u>National Disability Data Asset</u> will bring together de-identified government information about all Australians. This helps us better understand and improve the experiences of people with disability. The Australian National Data Integration Infrastructure is the underlying system that supports the National Disability Data Asset. It allows us to connect and analyse data.

In 2024, the Australian Bureau of Statistics (ABS) conducted a privacy assessment to consider the use of ABS Survey of Disability, Ageing and Carers (SDAC) data for the National Disability Data Asset. The ABS runs the SDAC collection. SDAC includes information about people with disability, older people (aged 65 years or more) and people who care for people with disability or older people.

What will SDAC data be used for in this project?

De-identified analytical data from SDAC and associated linkage information will be used in the underlying system for the National Disability Data Asset. The data in scope has already been de-identified and transformed for the <u>Person Level Integrated Data Asset</u> (PLIDA).

Expanded information would be available in the National Disability Data Asset to enable analysis by approved researchers. This will support improvements to policies and services for people with disability, their families and carers.

How will SDAC data be accessed?

The ABS and the Australian Institute of Health and Welfare (AIHW) will prepare the National Disability Data Asset modules for research projects.

The ABS and AIHW are both <u>accredited</u> by the Office of the National Data Commissioner who checks they have appropriate data management policies and practices and the necessary skills and capability to ensure the privacy, protection and appropriate use of data.

The modules will only be transferred to a secure analytical environment hosted by the ABS for approved projects and approved researchers from accredited organisations. The ABS will conduct additional privacy work and approvals if there are future proposals to use the modules with SDAC data in other approved systems.

Under the *Data Availability and Transparency Act 2022* (also called the DATA Scheme), researchers must belong to an Australian, state or territory government agency or Australian university.



What is the Privacy Assessment about?

This project involves changing the ABS data handling to share SDAC data under a new legal framework. This privacy assessment considered possible impacts on the privacy of individuals. It looked at privacy risks and how they are managed.

This builds on the Privacy Impact Assessment (PIA) for the National Disability Data Asset and underlying system undertaken by privacy experts at Maddocks in 2023.

The PIA:

- checked whether the National Disability Data Asset and underlying system are in line with the <u>Privacy Act 1988</u>, including the Australian Privacy Principles – these are the laws about how to manage personal information
- noted any privacy risks and ways to reduce these risks
- helped us to manage any privacy risks
- checked how the National Disability Data Asset protects personal information. This includes from misuse, loss or unauthorised people accessing, changing or sharing information.

The ABS and Maddocks consulted with over 150 stakeholders for the 2023 PIA. An update to the PIA is planned for 2025. More information on the 2023 PIA is available on the <u>Privacy for the</u> <u>National Disability Data Asset webpage</u> and <u>ABS PIA register</u>.

What are the laws that apply?

Data is shared for the National Disability Data Asset using the Data Availability and Transparency Act and relevant laws. This includes state and territory laws. We only share data when it is safe, legal, ethical and secure.

A small number of government agencies provide services for the National Disability Data Asset. For example, doing the work of linking data together. These agencies must be <u>accredited</u> under the DATA Scheme. They must follow the Privacy Act, including the <u>Australian Privacy Principles</u>. They must also follow other privacy laws that apply.

Under the DATA Scheme, a data sharing agreement is set up between the data provider and accredited organisations. This agreement must be registered by the National Data Commissioner prior to data being shared. Information about registered agreements are put on the Office of National Data Commissioner's <u>Data Sharing Agreement Register</u>.

If a person or organisation doesn't follow the agreed uses in a data sharing agreement, they might get a sanction or penalty. A sanction might include a warning or no longer being able to access the National Disability Data Asset.



How will we keep data safe?

There are many processes and controls working together to maintain privacy and safety of the National Disability Data Asset. The National Disability Data Asset poses no additional risks regarding how data will be used compared to current projects the ABS supports, particularly PLIDA.

The ABS and AIHW are making sure that there are strong privacy and data protections in place. They will make sure the National Disability Data Asset:

- protects privacy
- keeps data secure in accordance with the <u>Australian Government Data Sharing</u> <u>Principles</u> (based on the <u>Five Safes Framework</u>)
- meets legal requirements
- can only be accessed by authorised people.

More information is available on the <u>Privacy for the National Disability Data Asset webpage</u>.

Key findings from the Privacy Assessment

The ABS privacy assessment found that this project does not present high privacy risks. The ABS considers the National Disability Data Asset governance and procedures have sufficient protections in place for the SDAC data to be safely included in the National Disability Data Asset.