

Summary of the 2023 Privacy Impact Assessment

National Disability Data Asset and Australian National Data Integration Infrastructure

Descriptive Transcript

Introduction

Visual description: On the top right side of the screen, there is a logo with two red, two green and two blue lines connected at a central point. The words 'National Disability Data Asset' are to the right of the logo.

On the left of the screen, text appears against a purple background. The text says 'Introduction'.

An Auslan interpreter dressed in black appears on the screen and starts signing.

The interpreter continues to sign on the centre of the screen and the logo is shown at the top right throughout the entire video.

Audio transcript: The Australian, state and territory governments are working together to develop the National Disability Data Asset.

The National Disability Data Asset will provide a more complete picture of the life experiences of people with a disability.

The Australian National Data Integration Infrastructure is the underlying infrastructure to deliver the National Disability Data Asset. The underlying infrastructure provides the technology solution that allows data to be connected and analysed for the National Disability Data Asset.

The National Disability Data Asset is being developed by the Department of Social Services (DSS), the Australian Bureau of Statistics (ABS) and Australian Institute of Health and Welfare.

These three Australian government agencies are referred to in this document as the Commonwealth Partners.

Privacy experts, Maddocks have undertaken a Privacy Impact Assessment (PIA) for this phase of the National Disability Data Asset and underlying infrastructure (the Project).

The PIA is expected to be updated in 2025.

Maddocks have produced a detailed 2023 PIA Report. This summary provides an outline of the 2023 PIA including the process, and a summary of findings and recommendations.

More information about privacy is available on the National Disability Data Asset website at [Privacy for the National Disability Data Asset](#).

The Privacy Impact Assessment (PIA) process

Visual description: On the left of the screen, text appears against a purple background. The text says 'The Privacy Impact Assessment process'.

The Auslan interpreter re-appears on the screen and restarts signing.

Audio transcript: This PIA has been conducted to ensure the potential privacy impacts have been appropriately considered.

The 2023 PIA:

- considers compliance with the [Privacy Act 1988](#) (Cth) including the [Australian Privacy Principles](#) (APPs);
- highlights privacy risks and areas for improvement in terms of risk mitigation;
- is intended to help the Commonwealth Partners manage identified privacy risks and impacts of the implementation of the National Disability Data Asset and its underlying infrastructure; and
- considers the safeguards that have been, or should be, put in place to secure personal information from misuse, interference or loss, or from unauthorised access, modification or disclosure.

Over 150 individuals participated in stakeholder consultation sessions for this PIA.

The sessions were run by Australian Bureau of Statistics and Department of Social Services.

Two sessions with people with disability were co-facilitated by Deafblind Australia, and the session with people with intellectual disability was facilitated by Inclusion Australia with support from Down Syndrome Australia.

Maddocks produced a Consultation Report, which summarises the feedback.

Summary of findings

Visual description: On the left of the screen, text appears against a purple background. The text says 'Summary of findings'. The Auslan interpreter restarts signing.

Audio transcript: Generally, strong support was given for the development of the National Disability Data Asset during Privacy Impact Assessment (PIA) consultation.

It was highlighted that there can be serious negative impacts for people if their health information (including disability related information) is disclosed without authority.

The Australian community expects that sensitive information under the Privacy Act should be protected above and beyond other personal information.

Maddocks noted that the Commonwealth Partners were taking a comprehensive ‘privacy by design’ approach to implementing the Project.

In particular, the governance arrangements once fully established, will be extensive and robust. These arrangements have been well designed to manage the data and privacy risks of the Project, including to identify future risks.

The Commonwealth Partners will put in place a number of measures to protect people’s personal information. This includes using detailed data sharing agreements and the legal framework of the [Data Availability and Transparency Act 2022](#) when linking data, and set rules on the disclosure of outputs from the linked data.

However, Maddocks acknowledges “there is an inherent privacy risk of re-identification posed by linking of de-identified data from the National Disability Data Asset, which may increase over time as more datasets are included and the asset size is increased”.

The recommendations are designed to address this risk and enhance privacy protections.

Recommendations

Visual description: On the left of the screen, text appears against a purple background. The text says ‘Recommendations’. The Auslan interpreter restarts signing.

Audio transcript: This Privacy Impact Assessment makes recommendations on the following topics about the Project:

1. Principles for adding datasets into the disability data asset in the future
2. Collection notices for data providers
3. Addressing re-identification risks – overarching governance measures
4. Addressing re-identification risks – output risks
5. Managing data breaches
6. Develop compliance framework.

For more information on each recommendation, please see Appendix A – Detailed recommendations.

Appendix A – Detailed recommendations

Visual description: On the left of the screen, text appears against a purple background. The text says 'Appendix A – Detailed recommendations'.

The Auslan interpreter re-appears on the screen and restarts signing.

Audio transcript: There are 13 Australian Privacy Principles (APPs). They are the rules in the Privacy Act about managing personal information. After each recommendation is a list of the APPs it relates to. You can find more about APPs on the Office of the Australian Information Commissioner [Australian Privacy Principles](#) webpage.

Recommendation 1: Principles for adding datasets into the disability data asset in the future

Rationale

There are robust governance arrangements for how the National Disability Data Asset can be used for research projects through the Charter.

It is also important to ensure there are clear principles for the inclusion of new datasets into the asset.

Recommendation

As an additional transparency and governance measure, Maddocks recommends that a set of principles is developed to guide government decisions on the inclusion of new datasets.

These principles should be published on the [National Disability Data Asset website](#), together with high level summaries of the data.

At a minimum, Maddocks suggests that the principles should require consideration of:

- the public interest for including new datasets within the National Disability Data Asset;
- guidance could be provided about how the public interest should be assessed (for example, that the potential benefits to the disability community of including the new dataset should be taken into account, and balanced with any competing factors);
- the utility of including the data within the National Disability Data Asset;
- to promote the data minimisation principle, data should only be included in the National Disability Data Asset where they are likely to be used in approved projects; and
- the types of information within the dataset and restrictions on use, including:
 - whether the dataset includes sensitive information (as defined in the Privacy Act), or other information likely to have a particular sensitivity (even if does not meet the Privacy Act definition); and

- whether the dataset includes information about First Nations people or other vulnerable populations (in addition to people with disability).

Recommendation 2: Collection notices for data providers

Rationale

The inclusion of data into the National Disability Data Asset will be done through various legal pathways, depending on how information was initially collected by the relevant data provider. Some of these pathways do not require the consent of individuals for the provision of data into the National Disability Data Asset.

An important privacy principle is ensuring individuals know how personal information collected about them will be used and disclosed.

Recommendation

To promote the privacy principle that individuals should be aware of how information about them is used (even where their name and other identifying information is not included in the data), Maddocks recommends that the Australian National Data Integration Infrastructure Board (with support from the Council) endorse standard wording that can be included in collection notices of data providers, for inclusion in their forms, websites and other publicly facing information.

The Australian National Data Integration Infrastructure Board provides strategic oversight of the delivery of the underlying infrastructure of the National Disability Data Asset and consists of members across Australian, state and territory governments.

Data providers should be required (for example, through relevant data sharing agreements), or at least encouraged, to update their respective collection notices as a best practice privacy measure to include this wording over time.

Recommendation 3: Addressing re-identification risks – overarching governance measures

Rationale:

One of the principles of the draft National Disability Data Asset Charter (Charter) written by the disability community is 'privacy and security of data'.

The National Disability Data Asset will only contain de-identified information. However, some stakeholders have expressed the view that information cannot be truly de-identified and that the risk of re-identification will increase over time for the National Disability Data Asset.

Recommendation

To further promote and operationalise the 'privacy and security' principle in the draft Charter, Maddocks recommends that the Council work plan, or other overarching governance documentation, includes regular processes for review of the strategies used to address re-identification risks. This review process could be, for example, scheduled annually.

In addition, there could be a documented trigger for review (such as if there was an attempted or realised data breach of an Approved Computer System, or Australian Government advice about increased cyber threats).

This aims to ensure that the processes that will be employed to de-identify persons and mitigate re-identification risks for the National Disability Data Asset remain fit-for-purpose in light of technical advances and emerging risks into the future.

Recommendation 4: Addressing re-identification risks – output risks

Rationale

If the risk of re-identification is realised using the data from the National Disability Data Asset, there is a potential risk of greater harm to individuals concerned, given the nature of the data and the potential particular vulnerabilities of the individuals concerned.

The final Data Governance Framework (dated 31 August 2023) provides for a de-identification policy to be developed.

Recommendation

Maddocks recommends that any de-identification policy should:

- clearly articulate to persons subject to the policy the potential for real and serious harm to flow if an individual is identified through the use of data in the National Disability Data Asset, and the need to carefully consider and control this risk; and
- in light of the above, particularly set out the controls to be placed on outputs of approved research projects. In this context, consideration should be given to whether any additional controls that are employed in other integrated assets, such as the person-level integrated data asset (formerly known as the Multi-Agency Data Integrated Project), should be put in place, such as a process for all outputs to be 'vetted' as appropriately de-identified before they can be removed from the underlying infrastructure environment.

Recommendation 5: Managing data breaches

Rationale

There is a shared governance and risk ecosystem for the National Disability Data Asset and underlying infrastructure, which means that there is potentially an increased risk of data breaches, and an increased risk that they will not be handled expeditiously (given the number of structures and entities involved).

Recommendation

The final Data Governance Framework (dated 31 August 2023) provides that Data and Privacy Breach and Incident register will be created and maintained as part of a Data Breach Response Plan which will be reviewed annually.

Maddocks recommends that the Data Breach Response Plan which is developed treats data across the 'hub and spoke' model equally; that is, that a single model for data breaches be developed which clearly articulates the responsibilities of the various governance bodies and entities involved, including when data is held by the Australian Bureau of Statistics as opposed to the entity responsible for an Approved Computer System.

The Plan should specify which body or bodies would be responsible for determining the wording to be included in any notifications to the Office of the Australian Information Commissioner, Office of the National Data Commissioner, and any affected individuals (if required).

Recommendation 6: Develop compliance framework

Rationale

The National Disability Data Asset and the underlying infrastructure will be subject to a range of governance measures, including data sharing agreements. The final Data Governance Framework (dated 31 August 2023) envisage audits being undertaken in respect of the underlying infrastructure.

Recommendation

Maddocks recommends that the Australian National Data Integration Infrastructure Board develop a compliance framework to monitor compliance against the requirements set out in data sharing agreements, covering the National Disability Data Asset and the underlying infrastructure.

This could include annual self-reporting to the Australian National Data Integration Infrastructure Guardian or National Disability Data Asset Guardian.

This reporting could include matters covered in Recommendations 2, 3 and 5 regarding collection notices and security incidents and other measures such as undertaking independent audits of systems and processes.

Appendix B - Glossary

Visual description: On the left of the screen, text appears against a purple background. The text says 'Appendix B – Glossary'. The Auslan interpreter re-appears on the screen and restarts signing.

Audio transcript:

Australian National Data Integration Infrastructure Guardian: Australian National Data Integration Infrastructure Guardian is the role fulfilled by the Australian Bureau of Statistics (ABS) as the body accountable of the safe, legal and ethical management of the underlying infrastructure for the National Disability Data Asset. Enabled by an ABS authorised officer who has the delegation to enter into data sharing agreements to create, maintain and update the underlying infrastructure, and authorise access and use.

Charter: The National Disability Data Asset Charter is a document which has been drafted by the disability community and will be endorsed by the Council and Disability Ministers. It provides guiding principles and acceptable and unacceptable uses of the National Disability Data Asset.

Council: The National Disability Data Asset Council is a co-governance body which will provide strategic oversight over the uses of the National Disability Data Asset. The Council involves shared decision-making between government and the disability community.

National Disability Data Asset Guardian: National Disability Data Asset Guardian is the body that is accountable for the safe, legal and ethical management of the National Disability Data Asset.

The National Disability Data Asset Guardian is a role fulfilled by the ABS, enabled by an ABS authorised officer who has the delegation to enter into data sharing agreements to create, maintain and update the National Disability Data Asset, and authorise access and use.

Sensitive information: Sensitive information might include information or an opinion about your:

- racial or ethnic origin
- religious beliefs or affiliations
- membership of associations or unions.

This has been adapted from the Privacy Act 1988 (Cth).

More information on the meaning of sensitive information can be found in section 6 of the Privacy Act and at Office of the [Australian Information Commissioner – What is personal information?](#)