# Summary of the 2023 Privacy Impact Assessment Consultation Report

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 Bureau of Statistics have worked with Maddocks, an independent privacy expert.

A Privacy Impact Assessment (PIA) is an assessment of a project and how it might affect privacy, including any risks.

Both worked on a Privacy Impact Assessment (PIA) for the National Disability Data Asset and its underlying infrastructure, the Australian National Data Integration Infrastructure.

A PIA provides suggestions to manage, minimise or eliminate privacy risks.

The Australian Bureau of Statistics with assistance from project partners the Department of Social Services and Australian Institute of Health and Welfare, and Maddocks undertook consultation for the PIA between March and July 2023.

Over 150 people attended the sessions. Maddocks produced a detailed Consultation Report. This Summary Consultation Report provides an overview of the feedback and concerns raised during the consultations.

Other privacy materials are available on the National Disability Data Asset website at Privacy for the National Disability Data Asset.

## Approach to stakeholder consultation

**Visual description**: On the left of the screen, text appears against a purple background. The text says 'Approach to stakeholder consultation'.

The Auslan interpreter restarts signing.

**Audio transcript**: The aim of the consultation was to learn about stakeholders' views about privacy for the National Disability Data Asset and its underlying infrastructure.

Stakeholders were asked to give feedback and raise any concerns about potential privacy risks and the planned privacy protections for the National Disability Data Asset and its underlying infrastructure.

Maddocks have used the outcomes from the consultation to inform the PIA.

## Who was consulted

**Visual description**: On the left of the screen, text appears against a purple background. The text says 'Who was consulted'. The Auslan interpreter restarts signing.

**Audio transcript**: A range of people were invited to take part in the consultation sessions. Sessions were attended by:

A range of people took part in the consultation sessions. This included:

- members of the disability community, including from different backgrounds
- disability representative organisations
- privacy associations
- academics
- government officials and managers involved in project governance
- the Office of the Australian Information Commissioner and its state and territory regulator counterparts, and
- data providers from Australian, state and territory governments.

## How the consultation worked

**Visual description**: On the left of the screen, text appears against a purple background. The text says 'How the consultation worked.' The Auslan interpreter restarts signing.

**Audio transcript**: A total of 12 two-hour sessions were held online, each with different stakeholder groups.

Deafblind Australia helped run two sessions with people with disability. Also a session for people with intellectual disability was run by Inclusion Australia with help from Down Syndrome Australia.

## Summary of feedback

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

**Audio transcript**: Generally, strong support was given for the development of the National Disability Data Asset. Several stakeholders across the sessions said that the National Disability Data Asset could have a practical and positive effect upon the lives of people with disability, through allowing deeper and better policy insights.

This summary of feedback focuses on the key themes that were raised during the sessions.

Some comments have been assigned to the type of stakeholder who provided the opinion, for example disability representative organisations.

The Australian Bureau of Statistics, Department of Social Services and Australian Institute of Health and Welfare are described in this summary as 'Commonwealth Partners'.

## 1. Data handling

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '1. Data handling'.

**Audio transcript**: Several stakeholders, particularly privacy organisations and regulators, asked about the rules for keeping and destroying information in the National Disability Data Asset.

Several stakeholders questioned how the data quality and accuracy will be maintained. For example, how the National Disability Data Asset would account for information it held that later become inaccurate.

Commonwealth Partners noted that consideration is being given to the level of detail of datasets and accompanying data quality standards, and this information will be publicly shared once decided.

The National Disability Data Asset Charter (the Charter) will include a commitment around data quality.

A retention, archiving and destruction policy is being developed consistent with the *Archives Act 1983* (Cth) and the *Privacy Act 1988* (Cth).

## 2. Use and access

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '2. Use and access'.

**Audio transcript**: Several stakeholders asked about limitations around access to the data. For example, whether non-government organisations (particularly disability representative organisations) would be able to access de-identified unit record data for analysis, or only be able to access the aggregate data.

Data providers raised questions around the proper use and interpretation of data. For example, whether there were plans for researchers to work with experts to quality assure their analysis and conclusions before publication.

Several stakeholders raised concerns about if the data will be able to be used for different purposes over time, and if this means the data could be misused.

Commonwealth Partners noted entities need to be accredited under the *Data Availability and Transparency Act 2022* to be able to access de-identified unit record data in the National Disability Data Asset.

Currently entities that could be accredited are Australian government agencies, state and territory government agencies, and Australian universities.

For-profit organisations and other non-government entities, such as disability representative organisations, are not currently able to be accredited under the Data Availability and Transparency Act 2022.

However, these organisations would be able to make use of aggregate data and could access de-identified unit record information via a contract with an accredited entity.

Prior to access, all projects require approval.

This project-level approval would be informed by data sharing agreements entered into by data providers, and the permissible uses for data as set out in the Charter.

## 3. Transparency and consent

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '3. Transparency and consent'.

**Audio transcript**: Several stakeholders, across multiple organisations and consultation sessions, expressed a concern that data could be included in the National Disability Data Asset without specific consent of individuals.

Commonwealth Partners explained that the National Disability Data Asset will use information already held by different government agencies.

Government agencies will not be collecting any new information specifically for inclusion in the National Disability Data Asset.

Information will only be shared for the National Disability Data Asset and its underlying infrastructure where it is legal to do so.

Various mechanisms are available, including under the Data Availability and Transparency Act 2022, where strict requirements must be met to allow data sharing without an individual's consent.

The lists of datasets included will be published on the National Disability Data Asset website.

## 4. Re-identification risk

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '4. Re-identification risk'.

**Audio transcript**: One of the key concerns raised during consultations was the risk of re-identification of individuals whose data was included in the National Disability Data Asset.

Concerns were raised that even once de-identified, the data may still be linked back to an individual.

Stakeholders asked whether any consideration had been given to artificial intelligence and machine-learning in terms of the future risk of re-identification.

Commonwealth Partners commented that re-identification for any purpose was an unacceptable use under the Charter.

There are many ways that the risk of re-identification will be managed. For example, the separation principle will be followed to ensure information that can easily identify an individual, like names and addresses, will be kept completely separate from the analytical data about that person, such as their income or services they have received.

The concerns about the greater risk of re-identification into the future was noted, agreeing that there needs to be consideration of re-identification as things change over time and to review practices in line with advancements in technology.

## 5. Disability indicators

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '5. Disability indicators'.

**Audio transcript**: Several stakeholders asked about what disability indicators the National Disability Data Asset might use to determine whether someone had a disability.

Commonwealth Partners explained that they are working with a broad range of stakeholders (including members of the disability community and research experts) to ensure the approach to developing disability indicators is fit for purpose.

Commonwealth Partners also confirmed that the disability indicator would build on learnings of the Pilot phase of the project.

It was agreed that it is important to not take a 'one size fits all' approach, and that the National Disability Data Asset would continue to consider how disability is identified and data is curated.

## 6. Consultation with the disability community

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '6. Consultation with the disability community'.

**Audio transcript**: Several stakeholders questioned the degree of consultation that had been undertaken with the disability community, and the extent of co-design arrangements in place.

A stakeholder also questioned whether information, particularly around complex concepts and privacy, would be in plain language, and translated into other languages for culturally diverse members of the disability community.

Commonwealth Partners noted there have been a series of workshops with disability representative organisations to ensure the design of the National Disability Data Asset is aligned with the disability community's expectations.

The National Disability Data Asset will also be overseen by a co-governed Council comprising of government members, researchers and members from the disability community.

Information about the Project will be available in accessible formats including Easy Read, Auslan and plain language. There is a range of accessible information available on the National Disability Data Asset website and the website will continue to be updated as more information is available.

## 7. Governance

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '7. Governance'.

**Audio transcript**: Stakeholders, particularly data providers, were keen to understand the legal authorisation framework that will support data coming into the National Disability Data Asset.

Stakeholders asked whether there would be a consistent approach taken nationally given the differences in state or territory legislation. Also whether data providers would have flexibility to approve data use and authorise projects themselves, or if all approvals had to be delegated to the Australian Bureau of Statistics.

Stakeholders asked how oversight of data usage would be managed after an organisation or body had been granted access to the National Disability Data Asset data.

Another stakeholder asked about whether any individual enforcement mechanism would be possible if a particular individual in the Australian community felt their personal information had been mishandled as part of the National Disability Data Asset.

Commonwealth Partners noted that the legal authorisation framework was under development but would use the data sharing scheme under the Data Availability and Transparency Act 2022 and other key legislation as its basis.

The legal authorisation framework does not examine state or territory legislation that applies to or regulates the handling of data.

States and territories are determining their own legal pathways to share data into the National Disability Data Asset.

Whilst there is now agreement across governments to the legal authorisation framework, at the time of the consultation sessions this framework was not yet finalised.

Some government stakeholders raised that it was difficult to comment on the privacy elements of the National Disability Data Asset until all governance arrangements were confirmed.

The National Disability Data Asset Council has oversight of the use of the National Disability Data Asset and consists of government and disability community members.

A Disability-informed Ethical Oversight Panel will be established by the Council. It will be made up of members from the disability community or their representatives and will be responsible for applying a 'do no harm' lens to project applications using the data asset.

## 8. Ethics

**Visual description**: On the left of the screen, above the Auslan interpreter, text appears against a purple background. The text says '8. Ethics'.

**Audio transcript**: Stakeholders highlighted the need for a focus on privacy and being culturally aware when handling data, particularly for information about First Nations members of the disability community.

Stakeholders provided a number of recommendations, including:

- Implementing an accreditation process that requires institutions and governments to consider the data sovereignty of First Nations members of the disability community, and to have data sovereignty skills.

- Requiring governance arrangements to not only meet legal and privacy standards, but also ethical standards, for example by implementing First Nations research methodologies and data sovereignty expectations in project considerations.
- Cultural competency training to be given to users of disability data asset data to ensure that all findings and outcomes are filtered through a strengths-based, culturally aware lens.
- Training users to ensure they are familiar with the social model of disability and the appropriate language to use to ensure outcomes are beneficial rather than harmful.

Commonwealth Partners noted this feedback and agreed it would be taken to the National Disability Data Asset Council for consideration, once formed.