

Summary of 2023 Privacy Impact Assessment Consultation Report

National Disability Data Asset and the Australian National Data Integration Infrastructure



This document is in Easy Read.

Background

The National Disability Data Asset is being made by the:



- Department of Social Services (DSS)
- Australian Bureau of Statistics (ABS)
- Australian Institute of Health and Welfare (AIHW).



These Australian government agencies are called 'Commonwealth Partners'. Partners means that they work together.

When you see the word 'we' or 'us' it means the Commonwealth Partners.

The National Disability Data Asset is a new way to bring together information about all Australians.

In this document we call it the data asset.

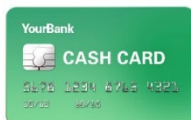


Data is:

- facts
- information
- records.



The information in the data asset will not have private information. This means the data asset will not have a person's:



- name
- where they live
- their phone number
- email address
- bank details.



We worked with a company called Maddocks to do a Privacy Impact Assessment (PIA). Maddocks are not part of the government. They are a business that is very good at helping to make or keep data private.

Maddocks did a report on the PIA.

A report is a written document to say what was learned.



You can get a summary of the PIA report on the webpage: [Privacy for the National Disability Data Asset](http://www.ndda.gov.au/privacy-policy) (www.ndda.gov.au/privacy-policy).

What is this summary about?

This document is a summary of the 2023 PIA Consultation Report. It has some of the ideas from focus groups we ran with Maddocks.



The PIA and the ideas from the focus groups will help make the data asset better.

About the focus groups

The focus groups were done with more than 150 people. A focus group is a way for people to have a say about what they think.



The focus groups were done to learn what people think about privacy for the data asset and the computer system that supports it.

We asked people to talk about:



- things that might go wrong when we use and share data
- what needs to be done to keep data safe and private.

Who we spoke to in the focus groups

Many people were asked to join the focus groups, like:



- people from the disability community and different backgrounds



- disability organisations that work with people with disability



- privacy organisations
- academics – people who do research and work for universities
- people from the government and some people who work on the data asset

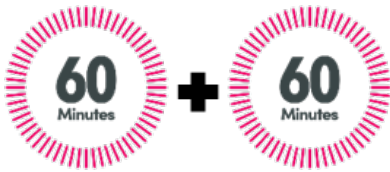


- people from the Office of the Australian Information Commissioner and state and territory groups that work on privacy and information rights



- data providers from Australian, state and territory governments. Data providers work for government and share data.

How the focus groups worked



There were 12 focus groups that went for 2 hours each.



People from different places were part of the focus groups.



Deafblind Australia helped with 2 of the focus groups. Inclusion Australia with help from Down Syndrome Australia did a focus group with people who have intellectual disability.

Summary of the feedback

This feedback is from what people said in the focus groups:



- most people said they support the data asset



- some people said that the data asset could help people with disability have better lives.



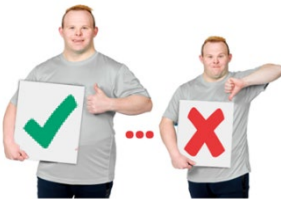
The feedback summary has important ideas that were talked about in the focus groups.

1. Data handling

Focus group feedback



- Some people, including people from privacy organisations, asked about the rules for keeping and not keeping data in the data asset.



- Some people asked how we will make sure data is correct, and what will be done if things change and it is not correct anymore.

Commonwealth Partner comments



We said that we will carefully think about the rules for:

- data we keep or do not keep in line with the *Archives Act 1983*



- the quality of the data
- how much information will be in the datasets.



A dataset is a way to put data together so that it can be looked at in groups, to see what the data says.



The National Disability Data Asset Charter (the Charter) has rules about what people can and cannot use the data asset for.

2. Use and access

Focus group feedback



- Some people asked who will be able to access the different data.
 - for example, what data will disability organisations be able to access.



- Data providers asked how we will make sure researchers use the data in the right way.
- Some people asked if the data could be used in the wrong way or a way that is not planned.

Commonwealth Partner comments



We said researchers will need to be part of an accredited group to use the data asset. Accredited means that they have been approved to follow the rules in the *Data Availability and Transparency Act 2022*.



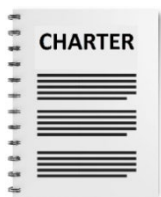
Australian, state and territory government agencies and Australian universities are the only groups that can be accredited.



For-profit and other organisations that are not part of government currently cannot be accredited. They can use some of the data if a group or a person that has been accredited says it is okay.



This must be written in a paper called a contract.



Before researchers can use data, all research projects must be approved and checked that they follow the Charter.

3. Consent to use the data

Focus group feedback



Some people were worried that data could be used in the data asset without their consent.

Consent is when you say yes or agree to something.

Commonwealth Partner comments



The data asset will use data that has already been collected by different parts of the government.

Government will not be collecting new data that is just for the data asset.



Data will only be shared for the data asset if the law says it is okay.



There are ways to share the data, like following the rules in the Data Availability and Transparency Act. This Act has rules that must be followed when data about a person is shared without their consent.



A list of the datasets in the data asset will be put on the [National Disability Data Asset website](http://www.ndda.gov.au) (www.ndda.gov.au).

4. Re-identification risk

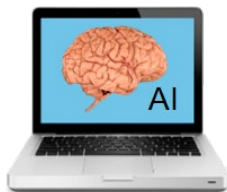


Focus group feedback

Some things people were worried about:



- information like their name, could become known from the data



- if computers could put data together to find out who people are. When computers use their memory to do this it is called Artificial Intelligence (AI).

Commonwealth Partner comments



No one will be able to use the data to work out who people are.



There are lots of ways to make sure private information is not known, like the 'separation principle'.



The 'separation principle' is a way to make sure personal information, like names and addresses, are kept apart from information that is looked at like data about whether a person is working or studying.



No one can see or use both kinds of information at the same time.

The separation principle must be used by people approved to work on the data.



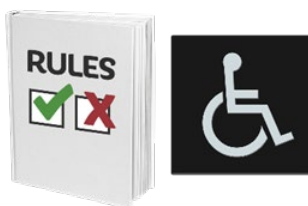
The partners agreed to look at ways we check that we keep data safe into the future.

5. Disability indicators

Focus group feedback



- Some people asked how we will record information about a person's disability across the data asset.



- People also asked what rules will be followed when information about disability is used.

Commonwealth Partner comments



We said we are working on a set of rules with lots of people and groups, like people from the disability community and researchers.



We said things we have learned while making the data asset will help to change and make things better, like how we record if a person has a disability.



It was agreed that things cannot always be done one way, and we will keep thinking about ways to look at how we record if someone has a disability.

6. The disability community

Focus group feedback

Some questions asked were:



- how the disability community was included in the focus groups for the data asset



- how did the disability community have a say about how the data asset was made
- if information would be in plain language or other languages.

Commonwealth Partner comments



People from disability organisations were at the focus groups to make sure the data asset works well for the disability community.



The National Disability Data Asset Council (the Council) includes people from the government and the disability community. They will look at how the data asset is used to make sure it is used in the right way.

The information will be in ways that are accessible, like:



- Easy Read
- Plain language
- Auslan.



Accessible information about the project is on the [National Disability Data Asset website](http://www.ndda.gov.au) (www.ndda.gov.au).

7. Governance – rules to follow

Focus group feedback



People and data providers wanted to know about the rules, they asked:

- what are the rules when data is shared for the data asset
- do all the states and territories across Australia have to follow the same rules
- will data providers be able to approve data being used for projects
- who makes sure the rules are followed when organisations use data from the data asset
- will there be a way for people in the community to do anything if data is not used in the right way.



Commonwealth Partner comments



We said we know that:

- a legal framework is being made for the data asset
- the Data Availability and Transparency Act will be used
- states and territory governments will decide on their own laws.



Governments have now agreed on the legal framework, but at the time when the focus groups were done the framework was not agreed to.



Some people from government at the focus groups said it was hard to give feedback about privacy in the data asset, until they knew how things would be done.



It is planned the Council will make a group called the Disability-Informed Ethical Oversight Panel. This group will include people with disability.

They will look at:



- how people plan to use the data
- if what they plan to do is the right thing and will not cause harm to people with disability
- if research will be helpful to people with disability.

8. Ethics or rules to know what is right and wrong

Focus group feedback

People gave feedback about:



- keeping data private
- people who use data need to know about other cultures, like First Nations people with disability.

Ideas for making things better were:



- sharing information with organisations and governments so they know the best way to use data about First Nations people and people with disability



- to make rules about what is right and wrong, these are called ethical standards, like making sure that data about First Nations people is used in the right way when research projects are done



- people who use the data asset are trained on:
 - how to use data about different groups, like people from other backgrounds or cultures
 - how to work with data about people with disability
 - using the right words when writing papers about the results of the project, this is to make sure that what we learn is used for good and there is no harm done.



Commonwealth Partner comments



When the Council is set up, we will tell them about this feedback.

Learn more



If you want to find out more on the [National Disability Data Asset website](http://www.ndda.gov.au) (www.ndda.gov.au).

This includes [Privacy for the National Disability Data Asset](http://www.ndda.gov.au/privacy-policy) (www.ndda.gov.au/privacy-policy).

You can send us a question about privacy by email to ndda@abs.gov.au

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