

National Disability Data Asset Expression of Interest for Planned Panels Information Pack



The Department of Social Services (DSS) is seeking expressions of interest for joining panels for the National Disability Data Asset. If agreed to by the National Disability Data Asset Council (Council), these panels would form in 2024 and provide support to the Council. DSS is looking for people that are passionate about making life better for people with disability, and interested in helping make invisible needs visible through data. This information pack has been developed to support people to apply for panels.

The National Disability Data Asset

The National Disability Data Asset will connect existing de-identified information from different government agencies about people with disability and all Australians.

Currently governments do not have a complete picture of how people with disability are supported by different government services. People with disability are supported by all levels of government and agencies including through things like Medicare, public hospitals, schools, employment, housing, NDIS and income support. Information on all these services and supports is not currently in one place so we are not able to understand the needs of people with disability and how to make their lives better.

The disability data asset will initially link over 200 government datasets. When the disability data asset is finished, it will be used to provide a complete picture of the programs and services used by people with disability. This will mean governments will have better quality information to improve these programs and services.

The disability data asset will be used to share information about how we can improve life for people with disability. It will also improve how we report on changes for people with disability under *Australia's Disability Strategy 2021 – 2031*.

More information can be found on the [National Disability Data Asset website](#).

Co-governance of the National Disability Data Asset

The National Disability Data Asset will be co-governed by governments and the disability community. This means that the disability community will be involved in decisions about the disability data asset.

One way the disability data asset will be co-governed is through the Council. The Council includes 6 government representatives, 3 disability community members and 3 disability data experts. The Council will provide recommendations on the strategic direction of the disability data asset to disability ministers. The role of the Council is to make sure the disability data asset is used correctly and only for purposes that align with community expectations.

The Council will guide the use of the disability data asset according to the Charter. The Charter was written by members of the disability community and lists principles to guide use of the data and acceptable and unacceptable uses.

Another way the disability data asset will be co-governed is through panels that guide the Council on specific topics. The panels would consist of individuals with specialist knowledge and provide support on priority areas for the disability data asset such as:

- consulting with the disability community
- intersectionality
- data improvement
- areas for future development.

Planned panels

DSS have been working with [Disability Representative Organisations](#) and state and territory officials to seek the Council's agreement to set up panels that would provide support to the Council. Three panels are being proposed to the Council. These include a:

- Disability Indicators Panel
- Disability-informed Ethical Oversight Panel
- Disability Data Development Scoping Panel.

The Disability Indicators Panel is planned to start in February 2024. Expressions of interest for this panel were collected over November and December 2023.

DSS is now looking for panel members for the Disability-informed Ethical Oversight Panel and Disability Data Development Scoping Panel. Priority will be given to people with disability.

The Disability-informed Ethical Oversight Panel will start when the first project application is received in 2024 and members will be appointed until mid-2025. More information on the Disability--informed Ethical Oversight Panel is available in [Attachment A](#).

The Disability Data Development Scoping Panel will be operational from June to October 2024. More information on the Disability Data Development Scoping Panel is available in [Attachment B](#).

Attachment A: Disability-informed Ethical Oversight Panel

The purpose of the panel

The purpose of the Disability-informed Ethical Oversight Panel is to consider ethical uses of disability data. The panel will review proposed projects that intend to use disability asset data and develop a framework to guide consistent assessments of project proposals. It will review project proposals from a 'do no harm' perspective.

The Disability-informed Ethical Oversight Panel members will be people from the disability community with knowledge in human rights and ethical use of data for research.

Key responsibilities

The Disability-informed Ethical Oversight Panels' roles and responsibilities may include:

- Applying a disability perspective when reviewing project proposals to ensure projects are aligned with the disability community's expectations
- Providing guidance on the expected benefits of the project to the disability community
- Developing a framework that will guide a consistent disability-informed ethical oversight approach to future proposed National Disability Data Asset research projects.

Information about the role

If the Council approves the creation of a Disability-informed Ethical Oversight Panel, it will start when the first project application is received in 2024. When appointed, the panel members will meet virtually and spend about 8 to 10 days per year preparing for, attending meetings and working on the framework. Panel members will be appointed until mid-2025.

Non-government members will be remunerated for their time as guided by the [Remuneration Tribunal \(Remuneration and Allowances for Holders of Part-time Public Office\) Determination \(No. 2\) 2023](#).

Skills, experience and characteristics

The panel will consist of 5 members with knowledge in human rights, ethical use of data for research and members with connection to the disability community. [Disability Representative Organisations](#) recommended that priority be given to people with disability and that skills in human rights and data analysis and management would be valuable to this panel. This advice is reflected in the Characteristics Matrix at Table 1, which details the proposed characteristics of panel members.

How to apply

To find out more about this opportunity and to express an interest in joining the panels, please visit DSS Engage at <https://engage.dss.gov.au/national-disability-data-asset-planned-panels-expressions-of-interest>.

[Disability Representative Organisations](#) are also helping us to find people to join the panels and share information about this opportunity.

Table 1: Disability-informed Ethical Oversight Panel Characteristics Matrix Table

Characteristic	Disability community representatives	Disability research representatives
Human rights background	Preferred	Required
Understanding ethical use of data for research	Preferred	Required
Lived experience of disability	Required	Preferred
Experience with data and research and/or skills in data analysis and management	Required	Data expert
Communicating to different parts of the community	Required	Required
Established connections with the disability community	Required	Preferred

Attachment B: Disability Data Development Scoping Panel

The purpose of the panel

The purpose of the Disability Data Development Scoping Panel (Scoping Panel) is to provide the Council with recommendations on priority data and knowledge gaps that future time-limited disability data development panels could focus on until the end of 2025.

Key responsibilities

The Scoping Panels' roles and responsibilities may include:

- Developing a report for the Council, that will identify 6 potential disability data development panels
- Providing recommendations to the Council on other possible data development panels
- Providing recommendations on the strategic direction of the disability data asset.

Information about the role

If the Council approves the creation of a Scoping Panel, it will be operational from June to October 2024. When appointed, the panel members will meet virtually and spend a total of 8 to 10 days working on a paper and attending meetings.

Non-government members will be remunerated for their time as guided by [Remuneration Tribunal \(Remuneration and Allowances for Holders of Parttime Public Office\) Determination \(No. 2\) 2023](#).

Skills, experience and characteristics

If approved by the Council, the Scoping Panel will have 10 members. DROs recommended the majority of members should be from the disability community. The plan is for the panel to include:

- 4 members who are experts in disability research
- 6 members of the disability community or their representatives with proven links to the disability community
- 2 observers from government with expertise in disability research and/or policy.

[Disability Representative Organisations](#) recommended that priority be given to people with disability and that skills in human rights and ethical use of data would be valuable to this panel. This advice is reflected in the Characteristics Matrix at Table 2, which details the proposed characteristics of panel members.

How to apply

To find out more about this opportunity and to express an interest in joining the panels, please visit DSS Engage at <https://engage.dss.gov.au/national-disability-data-asset-planned-panels-expressions-of-interest>.

[Disability Representative Organisations](#) are also helping us to find people to join the panels.

Table 2: Disability Data Development Scoping Panel Characteristics Matrix Table

Characteristic	Disability community representatives	Disability research representatives
Human rights background	Commitment to upholding human rights	Preferred, at least needs to be committed to upholding human rights
Understanding of ethical use of data for research	Preferred	Required
Lived experience of disability	Required	Preferred
Experience with data and research	Interest in data and research	Data expert
Communicating to different parts of the community	Required	Required
Established connections with the disability community	Required	Preferred