External Research Request Interim Policy

Contents

1 Purpose

To provide information to individuals and organisations requesting assistance from the National Disability Insurance Agency (NDIA) for research purposes.

The National Disability Insurance Scheme (NDIS or Scheme) is currently in transition, progressing towards complete roll-out of full Scheme in 2020, which is unprecedented in its scale and scope. As the NDIA looks beyond transition towards the research requirements of a mature NDIS, policy positions are currently being developed in several areas. In addition, changes to legislation related to data sharing and release are anticipated with the introduction of the *Commonwealth Data Sharing and Release Act* proposed by the Australian Government.

This document is presented as an interim policy to provide requestors with information in a timely manner, while acknowledging that the information contained within is likely to change at full Scheme. A final policy will be released when these details are known.

2 Audience

This policy applies to individuals and organisations requesting assistance from the NDIA for research projects (requestors). Examples include, but are not limited to:

- academic institutions including universities and research institutes
- hospitals and health services

- government bodies (Australian, state, territory or local) within Australia and internationally
- NDIA-funded organisations such as Partners in the Community
- NDIS providers
- non-profit organisations and charities
- participant representative groups such as peak bodies and advocacy groups
- NDIA personnel (employees, contractors and volunteers) studying towards a higher degree or collaborating with an external agency on a research project
- commercial organisations and consultancies.

3 Scope

This policy covers requests for:

- access to the following in accordance with the *National Disability Insurance Scheme Act 2013 (Cth)* (NDIS Act) for research purposes:
  - tailored releases of NDIS data including aggregate (summary level) and unit record (individual level) data
  - administrative data held by the NDIA such as corporate, financial and human resources data
  - NDIA documents
  - information about NDIS participants, their families, carers, guardians, and nominees or NDIA personnel (employees, contractors and volunteers) for participation in research as:
    - o study subjects
    - o members of project teams, expert advisors on steering committees and working parties, or similar activities
- collaboration on research projects
- funding and in-kind support for external research projects conducted independently of the NDIA
- endorsement of projects
- access to NDIS/NDIA resources for commercial or profit-making purposes.

This policy does not cover requests for:

- non-research purposes such as media reports
- activities covered under the *Freedom of Information Act 1982 (Cth)*
- internal purposes, such as NDIS data requests by NDIA personnel
- research and evaluation that the NDIA has funded or contracted
- arrangements specified in any Bilateral Agreements between the Commonwealth and state or territory governments in respect of the NDIS.

4 Policy statement

The NDIA is committed to maximising the benefits that can be derived from publicly funded disability-related information, and recognises the value in supporting high quality research with potential to drive improvements in outcomes for NDIS participants, the Scheme, or that is generally in the public interest.

4.1 Corporate Plan Aspirations

The Research and Evaluation Branch will provide a single point of contact to facilitate requests and will consider research requests that align to the delivery of the aspirations, goals and related outcomes as stated in the NDIA's Corporate Plan 2019-23. The NDIA's aspirations are listed below:

- Aspiration 1: A quality experience and outcomes for participants

- Aspiration 2: A competitive market with innovative supports

- Aspiration 3: A connected and engaged stakeholder sector

- Aspiration 4: A financially sustainable Scheme

- Aspiration 5: A high-performing NDIA

All requests must be made by completion of the External Research Request Form ('the Form') and submitted by email to research@ndis.gov.au.

All requests will be assessed in accordance with applicable legislation and guidelines, in particular the NDIS Act, *Privacy Act 1988 (Cth)* and the NDIA Information Handling Operational Guideline.

4.2 Ethics approval

If required, approval from a National Health and Medical Research Council (NHMRC) registered Human Research Ethics Committee (HREC) should be obtained prior to lodging the Form and a copy of the HREC approval letter included with the request. If HREC approval is not required, a letter of exemption or other form of justification should be provided. Registered HRECs can provide advice on whether a project requires ethics approval. A list of registered HRECs is available from the NHMRC website.

4.3 Access to NDIS data

Requests for access to NDIS data are covered by the NDIS Public Data Sharing Policy; a list of data available for release is provided in Appendix A. Detailed information on available variables (metadata) is available at NDIS Data and Insights – Data Downloads ('data rules'). Publicly available data can be downloaded from the NDIS Data and Insights webpage.

Requestors seeking access to tailored releases of NDIS data must complete the Form and submit requests by email to research@ndis.gov.au.

4.4 Access to NDIA documents

Publically available documents can be downloaded from the NDIS website. Requests for access to other documents held by the NDIA are handled centrally by the Freedom of Information (FOI) team. Requestors are directed to the NDIS FOI webpage for more information.

4.5 Access to NDIS participants

The NDIA does not currently provide direct access to NDIS participants, their families, carers, guardians or nominees for engagement in research as study subjects or expert advisors. Requestors are advised that many of the peak bodies and associations for people with disabilities have processes that enable consideration of requests for access to their members for research purposes.

4.6 Access to NDIA personnel

Requestors seeking access to NDIA personnel for engagement in research as study subjects or expert advisors must complete the Form and submit requests by email to research@ndis.gov.au. Contact should be initiated as early as possible in the project development phase.

4.7 Collaboration

We define collaborative projects as those where all parties are involved in the conception, design and reporting of the research and each party has a clearly defined role in implementation, data collection and/or analysis.

Requestors seeking to collaborate with the NDIA on research projects must submit requests by completion of the Form and email to research@ndis.gov.au. Contact should be initiated as early as possible in the project development phase.

4.8 Funding or in-kind support

The NDIA does not usually provide funding for externally-conducted research in response to unsolicited requests from external organisations (e.g. as 'industry partners').

The NDIA may provide in-kind support such as provision of data, knowledge or skills and access to facilities or services where external projects align with NDIA goals and priorities.

Requestors seeking support of this nature must complete the Form and submit by email to research@ndis.gov.au. Contact should be initiated as early as possible in the project development phase.

The NDIA may invite external organisations to apply for grant funding to undertake targeted research projects. Information regarding future research grant funding rounds will be published on the NDIS website.

4.9 Endorsement

The NDIA does not provide endorsement for external research proposals. In principle, the NDIA supports research that improves outcomes for people with disability, NDIS participants and/or the Scheme, however it is not a function of the NDIA to evaluate the rigour of study proposals and assess the capability of research teams which would be required in order to endorse external projects.

4.10 Access to NDIA/NDIS resources for commercial or profit-making research

The NDIA does not currently provide support or assistance for commercial or proprietary research, such as research done by a private individual or a company for the purpose of making a profit.

The NDIA may provide support or assistance to professional management consulting firms or organisations engaged to perform services on behalf of government bodies or non-profit organisations where the purpose of the research is non-commercial. While it is noted that consultants provide their services on a commercial basis, in this instance, the aim of the research is not profit-making. Consultants seeking support from the NDIA will need to provide evidence of their engagement together with completion of the Form and submission by email to research@ndis.gov.au.

5   Related documents

5.1 Legislation

- *National Disability Insurance Scheme Act 2013 (Cth)*
- *Privacy Act 1988 (Cth)*

5.2 National research policies and guidelines

- Open Access Policy (National Health and Medical Research Council, 2018)
- Principles for accessing and using publicly funded data for health research (National Health and Medical Research Council, 2015)

5.3 NDIA policies and documents

- External Research Request Form

- National Disability Insurance Scheme Corporate Plan 2019-2023
- Research and Evaluation Integrity Policy
- Public Data Sharing Policy
- Information Handling Operational Guideline