

Research and data request policy for the NDSS

Reviewed and revised September 2022

Purpose

This policy outlines the management of requests for access to [National Diabetes Services Scheme](#) (NDSS) data for statistical analysis and research, research policy development, service planning and delivery, to assist with recruitment of people with diabetes into research projects, or for other purposes. This policy should be read in conjunction with the [NDSS Privacy Policy](#).

This policy applies to requests by researchers, health services and planning agencies, NDSS Agents and other parties requesting assistance for research projects.

Diabetes Australia also provides NDSS data to the Australian Institute of Health and Welfare, Bio Grid Australia, and the Department of Health and Aged Care while administering the NDSS, as described in the NDSS Privacy Policy. Requests for access to data can also be made to the Australian Institute of Health and Welfare. Those disclosures are not subject to this policy.

Scope

This policy covers requests for:

- recruitment of people registered with the NDSS into research projects
- access to identified unit record NDSS data such as for NDSS data linkage purposes
- access to specific NDSS data sets consistent with the NDSS data request form ndss.com.au/access-to-ndss-data.

Background

The Commonwealth of Australia through the Department of Health and Aged Care has contracted Diabetes Australia to administer the NDSS. In fulfilling its NDSS responsibilities, Diabetes Australia collects and stores the personal information of people registered with the NDSS in accordance with the [NDSS Privacy Policy](#).

Many people registered with the NDSS are supportive of diabetes related research and are happy to be informed about research projects, and to consider participation in research projects where they have provided their explicit informed consent. Data suppression is applied to the release of Scheme data where values in any data class are less than a value of 10 units and only data that is relevant to the research will be provided. Some individuals may have opted out of being contacted for research opportunities in which case they will be removed from any data provided for this purpose.

Policy statement

Diabetes Australia supports the NDSS database as a national asset that may be used for research, policy development, or service planning and delivery to provide improved health outcomes for people with diabetes and wide-ranging benefits for the community.

Access to NDSS data supports Goal 7 in the [Australian National Diabetes Strategy](#) to strengthen prevention and care through research, evidence and data.

Population data about people in Australia who are diagnosed with diabetes and registered with the NDSS, including prevalence rates, is available at the [Australian Diabetes Map](#).

Diabetes Australia aims to uphold the NHMRC [Principles for Accessing and Using Publicly Funded Data for Health Research](#).

Data request process

All requests for NDSS data to conduct research must be made by completing and submitting the [Research and Data Request Form](#) by email to ndssdata@ndss.com.au.

Please allow a minimum of 15 business days for the request to be considered. Complex requests such as for a **data linkage** may take longer to process and may require approval from the Department of Health and Aged Care to proceed.

No changes will be accepted once the request form has been submitted. Where changes are necessary, a new request form will be required noting additional processing time.

Data request assessment

As the administrator of the NDSS, Diabetes Australia is subject to the *Privacy Act 1988* ('the Privacy Act') and the Australian Privacy Principles (APPs) contained in the Privacy Act. The APPs set out the way organisations can collect, use, disclose and provide access to personal and sensitive information. Diabetes Australia will assess each request on a case-by-case basis and will consult where necessary with the Department of Health and Aged Care.

Diabetes Australia's assessment will include, but not be limited to the following considerations:

- the significance of the proposed research/activity to the management of diabetes, improved health outcomes or the more efficient delivery of health services
- ethics approvals for research projects, including whether applications align with the [Guidelines under Section 95 of the Privacy Act 1988](#)
- whether it is feasible to gain access to the requested data for the research/activity through another means e.g., the Australian Institute of Health and Welfare

- whether the request is for identified or de-identified Scheme data. Any request for identified data will require Department of Health and Aged Care approval. The provision of de-identified data, if approved, will be suppressed where data values in any data class are less than a value of 10 units.

Confidentiality and privacy

To ensure the confidentiality and privacy of people registered with the NDSS, Diabetes Australia does not allow researchers or other parties to contact people with diabetes registered with the NDSS to request permission for research.

All contact with people registered with the NDSS as prospective participants in research or other activities is made by Diabetes Australia on behalf of the researcher/party making the request. Diabetes Australia will provide a covering note to accompany the proposed research/activity information and include details provided by the party making the request. Diabetes Australia will advise in this covering note that they are not obligated to participate in research or other activities.

People with diabetes registered with the NDSS who have opted-out of directly participating in research activities will not be contacted.

Any organisation requesting access to NDSS data, whether identified or de-identified, must sign a confidentiality undertaking in the form required by Diabetes Australia before any data will be provided.

Costs

The full cost of any activities undertaken by Diabetes Australia relating to research or data requests will be charged to the researcher/party on a cost recovery basis. A 50% deposit will be required prior to the request being completed.

A cost estimate will be provided at the time the request is made and will include an administration fee and costs associated with data preparation and extraction, printing, and distribution of communications. A firm quote will be provided when the request has been approved and Diabetes Australia has been provided with quotations from relevant suppliers.

There is no charge to NDSS Agents.

Provision of reports

The researcher/party *must* provide Diabetes Australia with reports including research project status updates and a copy of the final research report. A final draft report is to be provided to Diabetes Australia for approval of the acknowledgement text *prior* to publication.

Acknowledgements

The researcher/party *must* acknowledge the use of the NDSS database in all reports, publications and presentations with the following text:

***This data was sourced from the National Diabetes Services Scheme (NDSS).
The NDSS is an initiative of the Australian Government administered by Diabetes
Australia.***

or

***Participants in the study were recruited as people with diabetes registered with the
National Diabetes Services Scheme (NDSS.) The NDSS is an initiative of the
Australian Government administered by Diabetes Australia.***

Data breaches

The researcher/party *must* abide by the *Australian Privacy Principles* as set out in the *Privacy Act 1988*, the *NHMCR Principles for access and using publicly funded data for health research* and any relevant local legislation.

Any breaches in relation to NDSS data must be advised to Diabetes Australia immediately.

Enquiries

Please email ndssdata@ndss.com.au.

Related documents

Legislation

- [*Privacy Act 1988 \(Cth\)*](#)

National policies and guidelines

- [*Principles for accessing and using publicly funded data for health research*](#)
(National Health and Medical Research Council, 2015)
- [*Australian National Diabetes Strategy 2021-2030*](#)
(Australian Government Department of Health, 2021)
- [*Guidelines under Section 95 of the Privacy Act 1988*](#)
(National Health and Medical Research Council)

Diabetes Australia NDSS documents

- [*External Research and Data Request Form*](#)
- [*NDSS Privacy Policy*](#)
- [*Australian Diabetes Map*](#)

Document Management

Document approval

Date	Version	Position
12/09/2022	8.0	Executive General Manager, National Diabetes Services Scheme