

## Research Data Enquiry

### Introduction:

This document details the procedure followed when a researcher wants to use ANDA data for research.

### General procedure

All correspondence should be via email. Where communication has been initiated via telephone, a follow-up email summarising the conversation with ANDA staff member should be sent by the researcher. A copy should be sent to [anda@nadc.net.au](mailto:anda@nadc.net.au)

If a request for use of data for commercial purposes is made, an appropriate fee commensurate to the request will be charged.

### STEP 1: Initial enquiry

The researcher contacts ANDA via email ([anda@nadc.net.au](mailto:anda@nadc.net.au)) to express an interest in using ANDA data. An ANDA staff member will contact the researcher to acknowledge receipt of the enquiry and forwards the researcher:

- A Guide for access to ANDA data analysis
- Case Record Forms and Data Definitions Forms to indicate available data fields.
- ANDA Analysis Proposal Form (for completion).
- ANDA Data Extract Request Form (for completion).
- ANDA Data Access Agreement (for completion).

Evidence of ethics approval for the research proposal should be provided by the researcher (if not available at this time, it must be provided prior to STEP 3 (data extraction)).

#### **STEP 1**

#### **ANDA staff will log the enquiry including:**

- Name of the researcher making the enquiry.
- Centre involved.
- Date of enquiry.
- Name of ANDA staff member responding to the enquiry.
- The description of the enquiry provided by the researcher.
- Date that necessary paper-work was sent to researcher.
- Date that necessary completed paper-work was received by ANDA.
  - o Date of ethics approval.
- Any additional information requested by ANDA staff (if applicable):
  - o What was requested.
  - o Date information was requested from researcher.
  - o Date information was received by ANDA.

**STEP 2: Proposal review (ANDA)**

The ANDA Data Custodian will consider the research proposal in the context of the quality of available ANDA data and the information provided by the researcher. If feasible, the proposal will be forwarded to the ANDA Scientific Advisory Committee in the form of a summary. Failure to be approved may relate to:

## Feasibility and acceptability:

- If there is a similar study already underway
- If the data are known to be insufficient to address the study question
- The timelines requested by the researcher are unacceptable
- The proposal is scientifically unacceptable
- No ethics approval (if applicable)

## Data acceptability:

- Too many outstanding data queries
- Data completeness is too low
- Data does not exist in the format required to address the study question

**STEP 2*****ANDA staff will up-date the enquiry log including:***

- Decision regarding feasibility and acceptability (with reasons).
  - Date decision is made.
- Decision regarding data acceptability (with reasons).
  - Date decision is made.

***If approved:***

- Period for which approval remains valid.
- Date the researcher is notified of above points.
- Request for documentation of ethics approval (ethics committee and number).

***If rejected:***

- Date the researcher is notified.
- Any follow-up information requested by the ANDA Scientific Advisory Committee.
  - What was requested.
  - Date requested.
  - Date researcher returns requested information.

**STEP 3: Extract data and liaise with researcher**

If approved by the ANDA Scientific Advisory Committee, an ANDA staff member will extract the data following quality procedures to ensure that the data is correct, accurate and complete.

Data together with a data explanation sheet will be forwarded to the researcher using secure data sharing protocols. Questions regarding the data may be directed to the ANDA staff member providing the explanation sheet.

Any proposed presentation or publication of ANDA data must be presented to the ANDA Scientific Advisory Committee for final approval prior to any presentation or submission (at least 2 weeks for an abstract or presentation and at least 4 weeks for a full publication). The approval or rejection for presentation or publication of any and all works relating to ANDA data is at the sole discretion of the ANDA Scientific Advisory Committee.

**STEP 3*****ANDA staff will up-date the enquiry log including:***

- Date data was extracted.
- Date data extract was sent to researcher.

***If the researcher does not wish to proceed:***

- Reasons researcher is not proceeding with study.
- Date that ANDA is notified of study cessation.

***If the researcher intends to submit works relating to ANDA data:***

- Date that intended presentation / submission is sent to the ANDA Scientific Advisory Committee.
- Date reviewed by the ANDA Scientific Advisory Committee.
- Final outcome of the ANDA Scientific Advisory Committee (approval or rejection):
  - o Any follow-up requested by ANDA Scientific Advisory Committee.
  - o Date the researcher is notified.
  - o Date the researcher provides follow-up information.
- Date of completion (i.e. date of publication or rejection).

### Analysis Proposal Form

Please refer to the ‘Australian National Diabetes Audit (ANDA): A guide for access to ANDA data analysis’ when completing this form (Appendix A).

Completed forms and any supporting documentation to be forwarded to the ANDA Secretariat.

Name, title, email address and institution of Project Leader (lead person) and supervisor (if applicable)	
Other collaborators (title, email address and institution)	
Brief title of potential project	
Is a student involved in the project (will the project contribute to their award?)	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, please provide students name, course, institution, course start date and expected completion date Please list supervisors	
Does this application supersede a current or previous application?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Please provide a lay synopsis of your proposed project (75-100 words) that can be published on the ANDA website if the project is approved.	
Please provide a detailed outline of what you are interested in. Include: - Background and rationale - Hypothesis/research questions - Variables - predictor and outcome - Main method of analysis	
Please provide a list of fields required for your study and the format of the data extract ie csv file etc	xls <input type="checkbox"/> csv <input type="checkbox"/> other <input type="checkbox"/> specify _____
Expected outcomes and likely target audience	
Time frame of project (start/finish dates; expected paper submission dates)	
Who will provide substantive expertise and input?	
Who will provide statistical expertise and input?	
Has/Will Ethics Committee Approval be sought?	Yes <input type="checkbox"/> Date..... No <input type="checkbox"/>