

DPAU DATA ACCESS POLICY

This policy will define the stipulations of access to data hosted on DPAU and the procedure that is to be followed in order to gain access to DPAU data, subject to a successful application that has been bound by the necessary controls.

Who Can Apply:

All bona fide researchers can use DPAU data for health-related research that is in the public interest. Researchers wishing to gain access to data hosted on DPAU must agree to the terms and conditions of the DPAU Data Access Agreement which governs use of data hosted on DPAU.

A bona fide researcher is defined as being a person with professional expertise to conduct bona fide research; and who has a formal affiliation with a bona fide research organisation that requires compliance with appropriate research governance and management systems as described in the Data Access Agreement. PhD and student applications must list their sponsor/supervisor as the lead researcher and themselves as a researcher taking part in the study.

The DPAU Data Access Application Process:

Please see the DPAU Data Access Application Process [here](#).

The DPAU Data Portal website provides detailed Data Access Application [Process](#) and [Guidance](#).

Parties interested in accessing data held within DPAU are required to complete the DPAU Data Access Application [form](#). All applicants are required to agree to the terms & conditions specified in the DPAU Data Access Agreement ([DAA](#)). Review of these applications will go through a two-stage review process: an initial screening by DPAU staff followed by the review and approval by the relevant Contributing Research Studies (CRS) or their nominee.

Applicants must confirm that they have appropriate ethics approval from their organisation to access and use the data held by DPAU and must provide the reference details of this approval in their application. Should an applicant's organisation not require them to obtain ethics approval for their project, then the applicant must explicitly state this in their application to DPAU. However, under no circumstances may an applicant knowingly or intentionally contravene the right to privacy or confidentiality granted to research participants under New South Wales, Australia law nor under the laws of the CRS state or nation.

All applications must include details of the ethics approval for the proposed project. Projects are not covered by the ethics approval of the CRS unless all investigators named on the Data Access Application and who will have access to participant-level data released to this project are named personnel on the CRS.

The policies of DPAU are informed by the policies of the Centre for Healthy Brain Ageing, UNSW Sydney, the advice of UNSW Legal, and the policies and procedures of Dementias Platform UK (PDUK). DPAU acknowledges the in-kind contribution and support received from DPUK, and their trailblazing in making valuable research data widely available to bona fide researchers. **Version:20210702**

The first stage of the review of the application will be conducted by DPAU staff to assess for basic feasibility of the application i.e., is the form complete, are the requested data available, or likely to become available in a reasonable timeframe, is the request sufficiently detailed to allow scientific review. The second stage of the review is conducted by the CRS based on their specific ethics & governance requirements. We aim for the entire review process to be completed within 4 weeks.

Before approving an application, DPAU and/or the relevant CRS may request modifications to the project. Communication may be directly between the applicants and the relevant CRS with DPAU being privy to the negotiations and the final arrangements. Modifications will be made on a case-by-case basis but should adhere to the principles of good research practice. As part of the review and feedback process, DPAU and/or the relevant CRS may also ask the project team to consider the inclusion of additional investigators &/or potential co-authors on the project. Should the applicant not wish to include the requested modifications, additional investigators or potential co-authors, then this will be resolved by negotiation or, if this is not possible, the decision of DPAU will prevail.

If the inclusion of any additional specific conditions is required by the CRS, those specific conditions will be discussed and agreed to by all parties, before the entering of DPAU Data Access Agreement.

Once an application is approved by DPAU and the relevant CRS, DPAU will require the requesting the lead researcher's institution (which is usually the lead institution for their collaboration) and all project team members seeking to access data on DPAU Analysis Environment to sign the Data Access Agreement.

Contact information

If you require further information about the DPAU Access Application Form, the application process, or your application then please contact dpau@unsw.edu.au with subject "DPAU Data Access Application Enquire"