

**DPAU Data Access Agreement** 

# **DPAU Data Access Agreement**

The University of New South Wales

and

[Insert name of institution]

"the DPAU User"



Version: 20250522





#### **DPAU Data Access Agreement**

#### THIS AGREEMENT is dated

#### **PARTIES**

Version: 20250522

(1) THE UNIVERSITY OF NEW SOUTH WALES ABN 57 195 873 179, a body corporate established pursuant to the University of New South Wales Act 1989 (NSW) of UNSW Sydney NSW 2052, Australia ("UNSW")

and

(2) [Insert full name and address of the contracting Institution] for and in relation to the Project entitled [insert Project ID and the title of Project] ("the DPAU User").

#### **BACKGROUND**

- A. The Centre for Healthy Brain Ageing (CHeBA) at UNSW is leading the establishment of Dementias Platform Australia (DPAU). DPAU will facilitate data sharing between Australian and international dementia researchers. DPAU is an online data sharing platform modelled on the successful Dementias Platform UK (DPUK).
- B. DPAU is supported by a grant from the National Institute of Health (USA) to CHeBA for the *Cohort Studies of Memory in an International Consortium* (COSMIC). DPAU is further supported by a National Collaborative Research Infrastructure Strategy (NCRIS) grant under the Australian Research Data Commons' (ARDC) 2020 Platforms program.
- C. DPAU is designed to deliver a secure, trusted and scalable environment for data sharing, governance, control and management services for researchers.
- D. The aim of DPAU is to develop and manage a new resource to help dementia researchers maximise their use of existing study data from global well-established population or cohort studies.
- E. The DPAU User submitted a Data Access Application to DPAU for access to Contributing Research Studies Data (CRS Data). The DPAU user applied for the CRS Data in order to generate a Third Party Report (TPR) for the purposes of the Project defined in the Application. That Application has been approved under DPAU processes.
- F. In consideration of being afforded access to the CRS Data that is hosted on DPAU relating to the Project, UNSW and the Recipient agree as follows:







### **TERMS AND CONDITIONS**

- 1. The CRS Data that the DPAU User will be able to access will only be the data approved for that purpose under DPAU Approval processes ("the Approved CRS Data"). The Approved CRS Data may be less than the full scope of data requested in the Application.
- 2. The Approved CRS Data may only be used by the DPAU User for the purposes specified in the approved Application.
- 3. Any amendment(s) to the Application proposed by the DPAU User after the date of this Agreement must be submitted to DPAU for approval. If approval is granted for the amendment(s) in whole or in part, all references to the Application in this Agreement will incorporate the Approved Amendments. For the avoidance of doubt, the DPAU User may not use the CRS Data for the amended purposes unless and until DPAU provide written confirmation to the DPAU User that such amendment(s) have been approved.
- 4. DPAU User will inform DPAU and relevant CRS(s) of any changes to the planned output of the Application in a timely manner.
- 5. Only the Applicant(s) named in the Application are permitted to access the Approved CRS Data.
- 6. The created account will only be used by the Applicant(s) and by no other individual. Any unusual activities on the account shall be communicated by the DPAU User and the Applicant(s) immediately to DPAU.
- 7. Any personnel changes shall be communicated immediately to DPAU, relevant accounts access permission shall then be updated accordingly.
- 8. Any changes of Ethical Approval for the Application shall be communicated immediately to DPAU.
- 9. The DPAU User understands that the relevant CRS may require nominated investigators and potential co-authors to be included on the Project. If approval of the Application is subject to such requirements, the DPAU User agrees to comply with those requirements to the best of the Applicant abilities, and to notify DPAU if a collaboration is found not to be feasible.
- 10. The application is adhered to the DPAU application process and is requesting access to the study area and/or study specific DPAU data. The DPAU User will be only provided with access to the Approved CRS Data on the DPAU Analysis Environment for the specified period of the Project. At the end of the period the access to the DPAU Analysis Environment will automatically terminate.
- 11. The DPAU User will follow the publication policy and publication process as specified in Schedule 1.
- 12. The DPAU User agree to:
  - a. never make public the results of analysis that in reasonable opinion might result in an individual, or small groups of individuals, being identified.
  - b. abide by all relevant laws and codes of practice current at the time.
  - c. treat the data as strictly confidential; and use responsibly and take proper precautions regarding the security of the data.
  - d. not to attempt to establish the identity of any individual to which the data relates.
  - e. utilise the results of research exclusively for public benefit and not for commercial gain, unless this was expressly approved as part of our application process by each and all relevant CRS.
  - f. take reasonable steps to ensure that, when accessing DPAU data, the display screen is not being overlooked by unauthorised persons and that the DPAU User has taken all reasonable physical precautions to maintain the security of the data supplied.







- g. notify DPAU immediately if the DPAU User suspects that the availability, integrity or security of the DPAU is compromised in any way.
- 13. The DPAU User understands and acknowledges that use of the data should not be construed as conferring ownership of the data, which are protected by copyright and other intellectual property rights.
- 14. The DPAU User understands and acknowledges that the data accessed from the DPAU may not be copied or distributed in any form.
- 15. UNSW through the DPAU, each CRS, depositors or copyright holders, or the funders of the collection of the data shall not be liable for the use of the data under this agreement.
- 16. UNSW through DPAU, shall a) bear no legal responsibility for the accuracy or comprehensiveness of the data; and b) accept no liability for indirect, consequential, or incidental, damages or losses arising from the unavailability of, or break in access to, the data for whatever reason.
- 17. If the DPAU User decides to upload any content onto the DPAU Analysis Environment, then the DPAU User will ensure that this is done from a secure location and from a computer with an up-to-date operating system with the latest security patches and the DPAU User will run reliable, effective and up to date antivirus software to ensure the security of the DPAU User systems.
- 18. The DPAU User will share all code, statistical scripts or otherwise with DPAU for the benefit of other users of the DPAU.
- 19. The DPAU User's activity whilst using the DPAU may be subject to audit, and the DPAU User shall cooperate with Monash University and UNSW through DPAU in facilitating such audit.
- 20. Data on the DPAU is classified as sensitive/highly sensitive and confidential and the DPAU User agrees to maintain keep all data confidential.
- 21. The DPAU User will be liable for any breach of confidentiality or applicable law where the DPAU User has acted outside the scope of the approved Application and/or this Agreement.
- 22. The DPAU User acknowledges that the CRS provide DPAU with de-identified data and that DPAU undertakes further checks to confirm appropriate data de-identification has occurred. The DPAU User must ensure that any Personal Information it obtains or holds as a result of accessing data pursuant to this Agreement is collected, stored, used and disclosed by the DPAU User in accordance with the Relevant Privacy Laws. The DPAU User will immediately notify UNSW through DPAU if it becomes aware that the Approved CRS Data contains any Personal Information.
  - **Relevant Privacy Laws** means the Privacy Act 1988 (Cth) and any other legislation, code or guideline which applies in the jurisdictions in which the DPAU and the DPAU User are located and which relate to the protection of Personal Information;
  - **Personal Information** means information or an opinion about an identified individual, or an individual who is reasonably identifiable (a) whether the information or opinion is true or not, and (b) whether the information or opinion is recorded in a material form or not.
- 23. UNSW through the DPAU, may revoke the approval of the Application and terminate the access to the DPAU services if the DPAU User is found to be not comply with these terms of use, the Application or the Publication Policy, or if any changes to the Application are deemed to be inconsistent with the compliance requirements of UNSW through the DPAU.
- 24. The DPAU User acknowledges that the DPAU is hosted on the Monash SeRP, which is the Secure eResearch Platform developed by Swansea University (UK) and managed by Monash University including its ancillary computer codes, algorithms, statistical scripts, tools, techniques, methods, and similar materials which will receive and store the date for the DPAU. The DPAU User must use the Monash SeRP in accordance with the SeRP end-user terms that are attached as Schedule 3.
- 25. Any dispute resolution required around general research practices and ethics will in the first instance be guided by the following UNSW & NHMRC documents:







A. National Statement on Ethical Conduct in Human Research (NHMRC) <a href="https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018">https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018</a>

- B. Australian Code for the Responsible Conduct of Research (NHMRC) <a href="https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018">https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018</a>
- C. Research Code of Conduct (UNSW) https://www.gs.unsw.edu.au/policy/researchcode.html
- D. Intellectual Property Policy (UNSW) https://www.gs.unsw.edu.au/policy/ippolicy.html
- E. Research Authorship and Resolving Disputes Between Authors Procedure (UNSW) https://www.gs.unsw.edu.au/policy/researchauthorproc.html
- F. Research Handling Research Material & Data Procedure (UNSW) https://www.gs.unsw.edu.au/policy/researchdataproc.html

These documents provide the principles and foundations for the research conduct and practice adopted by DPAU. Any policies and legislative requirements of the relevant CRS institution(s) and country of origin and the country in which researchers performing the data analysis, and/or their host institutions, are situated, will be considered as appropriate. Where any legislative requirements are conflicting, the strictest criteria apply.

26. Any dispute or difference arises in connection with this Agreement, then the Parties shall negotiate in good faith using their best endeavours to resolve the dispute or difference. If the dispute or difference cannot be resolved in the first instance, the Parties agree to refer the dispute to, as applicable, the Deputy Vice-Chancellors (Research) or Chief Executive Officers, or equivalent, or their nominees. Notwithstanding a dispute or difference, the Parties will continue to perform their obligations under this Agreement which are not affected by the dispute or difference.

This agreement has been entered into on the date stated at the beginning of it.







The Main Applicant named Schedule 2 of the Application acknowledges this Agreement and agrees to comply with its terms (insofar as they are applicable to the Applicant).

THE MAIN APPLICANT		
Signed		
Print		
Position		
Date		

The Co-Applicants named in Schedule 2 of the Application acknowledge this Agreement and each agrees to comply with its terms (insofar as they are applicable to that person):

THE CO-APPLICANT	
Signed	
Print	
Position	
Date	

[repeat this block for each Co-Applicant if there is more than one Co-Applicant].







# Version: 20250522 DPAU Data Access Agreement SCHEDULE 1 - DPAU PUBLICATION PROCESS AND POLICY

## **Background**

This document explains the expectations of DPAU and its funders with regards to authorship and the acknowledgment of DPAU funding associated with scientific and other outputs. It aims to promote awareness of the scientific opportunities provided by DPAU and to facilitate access to scientific findings that have been obtained through DPAU funding.

The policy is structured around DPAU projects using DPAU for data access and analysis.

## **Principles**

The policy is based on four principles:

- 1. Maximising awareness of and access to findings established by DPAU activity.
- 2. Promoting awareness of the scientific opportunities provided by DPAU.
- 3. Establishing the provenance of datasets and analyses conducted within DPAU.
- 4. Acknowledging the broad range of contributions that establish data provenance.

## **Publications and Authorship Guiding Principles**

The key guiding principles for publications and authorship are as below:

- The author line should recognise responsibility for the scientific integrity of any publications.
- Criteria for authorship should broadly follow the International Committee of Medical Journal Editors criteria. These criteria include data acquisition, and it is anticipated that Contributing Research Studies (CRS) providing the data for projects will have the option of being represented by a named individual in the author's list.
- Authorship roles should be identified using the categories of academic contribution proposed by the digital taxonomies project and available on the CRediT website (see https://casrai.org/credit/).
- The contributors' line should recognise the role of supporting scientists including individuals involved in data acquisition, infrastructure build and maintenance and methods development.
- Contributorship roles should be identified using the categories of academic contribution proposed by the digital taxonomies project. (CRediT website: see <a href="https://casrai.org/credit/">https://casrai.org/credit/</a>).
- The principles discussed in the following report should be considered: IWCA Report
  (2012). Report on the International Workshop on Contributorship and Scholarly attribution.
  2012 Harvard University and the Wellcome Trust:
  <a href="http://projects.ig.harvard.edu/attribution">http://projects.ig.harvard.edu/attribution</a> workshop.







#### **DPAU Data Access Agreement**

**Procedures** 

Version: 20250522

# For published manuscripts

The following must be included:

- Author line recognition: this must recognise the responsibility for the scientific integrity of the manuscript
- Contributors line: this must recognise the role of supporting scientists including those
  involved in data acquisition, infrastructure build and maintenance, and methods
  development.
- Acknowledgement section (to include one of the following, as appropriate):

  This research was facilitated through access to Dementias Platform Australia (DPAU:

  https://dementiasplatform.com.au), a secure data sharing resource hosted by the Centre for Healthy

  Brain Ageing at the University of New South Wales Sydney, Australia. The establishment of DPAU

  is supported by grants [2R01AG057531-02A1, 3RF1AG057531-01S1] from the National Institute of

  Health (NIH) to the Cohort Studies of Memory in an International Consortium (COSMIC) and a

  National Collaborative Research Infrastructure Strategy (NCRIS) investment [P20E-058] from

  Australian Research Data Commons' (ARDC) 2020 Platforms program.

This research was facilitated through access to Dementias Platform Australia (DPAU) hosted by the University of New South Wales Sydney, Australia. The National Institute of Health (NIH) supports DPAU through grants [2R01AG057531-02A1, 3RF1AG057531-01S1], the Australian Research Data Commons (ARDC) supports DPAU through grant [P20E-058].

• Other acknowledgements: data providers should be acknowledged as participants in the research unless there has been a specific statement to the contrary that this is not necessary given by the data provider. It is the lead applicant's responsibility that all relevant CRS are consulted on the appropriate acknowledgement of their studies, and that these are included in publications. It is anticipated that CRS providing the data for projects will have the option of being represented by a named individual in the author's list, otherwise, this would be recorded in the acknowledgements section as opposed to a formal authorship.

#### For conference poster presentations or grant applications

For conference poster presentations, or grant applications utilising data obtained from the DPAU, the following must be used:

This research was facilitated through access to Dementias Platform Australia (DPAU) hosted by the University of New South Wales Sydney, Australia. The National Institute of Health (NIH) supports DPAU through grants [2R01AG057531-02A1, 3RF1AG057531-01S1], the Australian Research Data Commons (ARDC) supports DPAU through grant [P20E-058].







Please add a copy of the DPAU logo to your poster. A high-quality logo can be obtained by

contacting <a href="mailto:dpau@unsw.edu.au">dpau@unsw.edu.au</a>.

## For published abstracts

Reference to DPAU should be made in the text body.

### **Publication Process**

For all Approved DPAU Applications, the following requirements must be observed by the DPAU User:

- DPAU User shall provide a list of expected project output within the DPAU Data Access Application.
- DPAU User will inform DPAU and Relevant CRS(s) of any changes to the planned output of this Application in a timely manner.
- DPAU User wishing to publish results, Data and/or other information acquired/generated
  from their use of the Approved CRS Data will inform DPAU and relevant CRS(s) with prior
  written notice (including a reasonable summary of the proposed publication), together with
  a copy of such publication(s) at least thirty (30) working days prior to submission of any
  such publication(s).
- DPAU will liaise with the relevant CRS(s) who have **thirty (30)** working days to object to, or request a delay to, the publication for accuracy or patent reasons, and/or request deletion of CRS confidential information.
- If DPAU considers that the intended publication does not comply with the process and
  procedure set out in this Schedule 1, and/or if a CRS raises an objection to the intended
  publication, DPAU will work with the objecting CRS and the publishing team to facilitate
  discussions, with the aim of resolving any outstanding issues.
- If the non-compliance with this Schedule 1 and/or the objection raised by a CRS is upheld by DPAU, the DPAU User will:
  - (a) modify or delay the publication as reasonably requested; and/or
  - (b) delete confidential information from the intended Publication.
- The CRS(s) will be notified by DPAU that if a CRS requests a delay on the submission of a
  publication, such requested delay shall not be longer than is reasonably necessary; the
  expectation is that any delay shall not exceed (3) months from the date of receipt by the
  CRS of the proposed publication.
- All intended publications arising from the use of the DPAU shall include an acknowledgement of DPAU and the other acknowledgments set out in the "Procedures" section of this Schedule 1.







DPAU users should update DPAU as soon as the paper is submitted, accepted and
published so DPAU is aware of all results entering the public domain and there is sufficient
notice to arrange any publicity of the findings.

## Open access requirements

The Open Access requirements of DPAU are based on the requirements of its funder (National Institute of Health, NIH).

The NIH Public Access Policy requires that research papers describing research funded by the National Institutes of Health must be available to the public free through PubMed Central within 12 months of publication. PubMed Central is the self-archiving repository in which authors or their publishers deposit their publications.

Once a paper has been published, the lead author will receive an email from PubMed Central about the paper being made open access. It is the lead author's responsibility to ensure the paper is submitted to PubMed Central in compliance with the NIH Public Access Policy.

## **COSMIC Project Publication Process**

In addition to the above DPAU Publication Process, all COSMIC projects applied through DPAU must be compliant with the following terms and conditions:

#### Authors:

- 1. Project workgroup investigators should be the first and last authors.
- 2. Co-authors from each contributing research study (CRS) must be included (up to 3 per study), grouped in alphabetical order of the contributing study names.
- 3. The head of COSMIC (Perminder Sachdev) and COSMIC study co-ordinator (Darren Lipnicki) must be included as co-authors.
- 4. Changes to the order of authors because of direct contributions like analyses or writing can be recommended by the first/last authors, and must be approved by all co-authors prior to submission.
- 5. The line "for Cohort Studies of Memory in an International Consortium (COSMIC)" should be included after the last author.
- 6. All authors must be invited to review the manuscript and give their approval prior to submission.







Version: 20250522 **DPAU Data Access Agreement** Manuscript review process prior to submission to journal:

- 1. The manuscript draft must be emailed to <a href="mailto:COSMIC@unsw.edu.au">COSMIC@unsw.edu.au</a> and <a href="mailto:dpau@unsw.edu.au">dpau@unsw.edu.au</a> for initial review and ascertain list of authors.
- 2. Draft is returned to the lead authors with list of authors.
- 3. Lead authors must invite all authors to review the manuscripts within two weeks and authors must give their approval prior to submission. Each author must check their details, funding and acknowledgement statements.
- 4. During manuscript submission to a journal, it is the lead authors responsibility to include all funding information in the online submission form.
- 5. Once a paper has been published, the lead author will receive an email from PubMed Central about the article being made open access (because of NIH funding requirements); as part of the process they wil be asked to check and approve proofs for the PubMed Central open access version of the paper.







Version: 20250522 DPAU Data Access Agreement SCHEDULE 2 - DPAU DATA ACCESS APPLICATION

[attached]







# Version: 20250522 DPAU Data Access Agreement SCHEDULE 3 - Monash SeRP End User Terms

#### **End User Terms**

#### 1 PARTIES

- 1.1 This User Agreement is between:
  - 1.1.1 the individual user of the Software (the "you" or "you"); and
  - 1.1.2 University of New South Wales (ABN: 57 195 873 179) of UNSW Sydney NSW 2052, Australia, being the organisation responsible for you (the "Organisation").

#### 2 **DEFINITIONS**

2.1 The following definitions shall apply in these Terms:

Permitted Purpose a research project, the scope of which is agreed between the

Parties, where a scientific endeavor is being used to validate a research

query;

**Project** a research project, the scope of which is agreed between the Parties,

where a scientific endeavor is being used to validate a research query;

**Datasets** a dataset is a collection of data that can be used to validate 1 or more

Projects and which is uploaded to the Software by You or on Your

instruction by the Organisation;

**Software** the Secure eResearch Platform (**"SeRP"**) system software developed by

the University and licenced to the Organisation;

**Terms** means these terms and conditions;

**University** Swansea University, an educational institution with its administrative

office at Singleton Park, Swansea SA2 8PP.





#### 3 RIGHT TO USE THE SOFTWARE

- 3.1 By using the Software you agree to these Terms. If you do not agree to these terms you should not use the Software.
- 3.2 The Organisation authorises you and gives you a non-exclusive, non-transferable right to use the Software for the Permitted Purpose and in accordance with these Terms.
- 3.3 You acknowledge and agree that You are responsible for ensuring that You have full legal rights to be responsible for the Datasets. You further agree that You either;
  - (a) own the Datasets; or
  - (b) have obtained all consent and approval required prior to the upload and use of the Datasets on the Software.
- 3.4 You shall not store, distribute or transmit any virus, or any material through the Software that is unlawful, harmful, threatening, defamatory, obscene, infringing, harassing, racially or ethnically offensive; facilitates illegal activity; depicts sexually explicit images; or promotes unlawful violence, discrimination based on race, gender, colour, religious belief, sexual orientation, disability, or any other illegal activities.
- 3.5 You shall not attempt to reverse compile, disassemble, reverse engineer or otherwise reduce to human-perceivable form all or any part of the Software, except as may be allowed by any applicable law which is incapable of exclusion by agreement between the parties.
- You shall use reasonable endeavours to prevent any unauthorised access to, or use of, the Software and shall notify the Organisation promptly of any such unauthorised access or use.
- 3.7 You agree that if you suspect that the availability, integrity or security of the Software is compromised in any way you will immediately notify the Organisation.
- 3.8 You must treat any username, user identification code, password or any other piece of information provided to you as confidential. You must not disclose such information to any third party nor allow anyone else to use your username and/or password to access the Software.
- 3.9 If we have reason to believe there is likely to be a breach of security or misuse of the Software through your account or the use of your password, we may notify you and require you to change your password, or we may suspend or terminate your account.
- 3.10 The Organisation shall have the right to terminate or disable your right to use the Software if in their reasonable opinion you have failed to comply with any of the provisions of these Terms.





#### 4 DATA

- 4.1 If you decide to upload any content onto the Software then you must ensure that this is done from a secure location and from a computer with an up-to-date operating system with the latest security patches and you will run reliable, effective and up to date antivirus software to ensure the security of the Software.
- 4.2 You must ensure that any data or content uploaded on to the Software does not infringe the intellectual property rights of any third party and complies with relevant data protection and privacy legislation.

#### 5 PRIVACY

5.1 As per the DPAU Data Access Agreement terms.

#### 6 INTELLECTUAL PROPERTY RIGHTS

- 6.1 All intellectual property rights in the Software in any part of the world belong to the University and the rights in the Software are licensed to the Organisation and you.
- You shall have no intellectual property rights in, or to, the Software other than the right to use them in accordance with these terms.
- 6.3 All Intellectual Property Rights in the data or content uploaded on to the Software shall be unaffected by this End-User agreement.

#### 7 TERMINATION

7.1 The Organisation may terminate your right to use the Software at any time by giving written notice to you.



