



**Dementias**  
Platform<sup>UK</sup>  
Medical Research Council

# **DATA ACCESS AGREEMENT**

**THIS IS A SAMPLE DOCUMENT FOR  
YOU INFORMATION ONLY**

**VERSION 4, APRIL 2018**

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**THIS AGREEMENT is dated**

**BETWEEN**

- (1) **SWANSEA UNIVERSITY** an academic institution set up by royal charter having a registered address at Singleton Park, Swansea, SA2 8PP ("**Swansea**")
- (2) **[INSERT NAME]** of [address]

**BACKGROUND**

Dementias Platform UK (DPUK) brings together a number of universities and others in a common effort to build on existing national capabilities in order to implement a world-leading programme of research activity that will address the major burden of dementias associated with age-related neuro-degeneration.

The DPUK Data Portal is a data storage, analysis and linkage platform that is envisaged to be used as part of the DPUK project in order to integrate multiple cohorts for a comprehensive epidemiological research platform. The Portal will also aid the development of bio-informatics methods to support a large-scale experimental medicine platform and increase data linkage facilities. The DPUK Data Portal is hosted on an instance of UK Secure eResearch Platform at Swansea. Swansea manages the maintenance of and administration of access to the DPUK Data Portal on behalf of DPUK.

As a result of a successful Study application, Swansea is willing to grant access to certain data held within the DPUK Data Portal to the User[s] and User Institution[s] and this agreement governs the terms under which access will be granted.

In signing this agreement, You (defined below) are agreeing to be bound by the terms and conditions of access set out in this agreement.

For the sake of clarity, the terms of access set out in this agreement apply both to the User and the User's Institution (as defined below). User Institution and User are referred to within the agreement as "**You**" and "**Your**" and shall be construed accordingly.

## DEFINITIONS:

<b>Anonymised</b>	refers to the state of Data within the DPUK UKSeRP. Data provided will go through split-file anonymisation in order that Data is both robustly anonymised (double encryption between NHS Wales Informatics Service and Swansea) and standard in format.
<b>Application</b>	means the application made by the User attached at Appendix 2.
<b>Bona Fide Research</b>	means research that can be considered to be as follows: <ol style="list-style-type: none"><li>1. An intention to generate new knowledge and understanding using rigorous scientific methods. (This includes discovery research, development and validation of methodology and technology, validating and challenging previous findings, and pilot research).</li><li>2. An intention to publish the research findings and share the derived data in the scientific community, without restrictions and with minimal delay, for wider scientific and eventual public benefit. (Recognised constraints include a short prepublication delay to ensure proper management of intellectual property).</li><li>3. The intended activities are not inconsistent with legal and ethical requirements or widely recognised good research practice.</li></ol>
<b>Bona Fide Researcher</b>	means any one researcher who should have the professional expertise to conduct bona fide research; and who has a formal relationship with a bona fide research organisation that requires compliance with appropriate research governance and management systems (MRC definition).
<b>Cohort</b>	means a group of Participants who share a common characteristic.
<b>Data</b>	means Anonymised data derived from a Cohort being used as part of a Study (defined below) including Interrogated Information.
<b>Data Provider</b>	means the organisation(s) that has/have agreed to share with DPUK its/their Data that is routinely collected within the organisation.

<b>DPUK</b>	means the Dementias Platform UK Consortium – the overarching project with the aim of building a platform for experimental medicine that is used by scientists and industry by providing an environment that is optimal for translational research.
<b>DPUK Data Portal</b>	means the database that contains all the data obtained for use as part of the DPUK project, containing data linkage infrastructure and governance system provided by the UK Secure eResearch Platform; this also pertains to the virtual desktop infrastructure used to access DPUK Data.
<b>Interrogated Information</b>	means all reports which have been generated as a result of a User being afforded access to Data (via the SAP approval process).
<b>Publication Process</b>	means the process attached at Appendix 1.
<b>Study</b>	means the description of the research set out in the Application.
<b>SAP</b>	means the Study Approvals Panel, responsible for the governance review of DPUK projects, publications and outputs. The SAP will comprise Principal Investigators Representatives from each DPUK member whose Data has been approved for use in a Study, and representatives from any other Data Provider involved in a Study.
<b>Study Period</b>	[as set out in the DPUK study approval.]
<b>User</b>	means a researcher whose User Institution who is aware of and accepts the terms of this Data Access Agreement, and are party to this Data Access Agreement under the terms of signature.
<b>User Institution</b>	means the organisation at which the User is employed, affiliated or enrolled.

# TERMS AND CONDITIONS

Following your successful Study request to DPUK and in consideration of being afforded access to the Data relating to the Study defined within the Application, You agree as follows:

1. The Data that you have been afforded access to will be only the Data listed within the said Application, to include any amendments, whether this pertains to the addition or removal of Data from the Application. Updated versions including such amendments shall be appended at Appendix 2.

2. You are part of a DPUK Study that has adhered to the DPUK study application process and are requesting access to the study area and/or study specific DPUK data.

3. You agree to use the Data only for the purpose of performing the Study. You will not use the Data for any other purpose.

4. You agree that any amendments to the Study must be approved by SAP before You may use the Data for such amended purposes.

5. You agree to follow the Publication Process attached at Appendix 1 and the DPUK Publication Policy

6. This agreement shall be construed, interpreted and governed by the laws of England and Wales and shall be subject to the exclusive jurisdiction of the English courts.

7. You agree to:

- use the Cohort Data entrusted to You for the public good and only as approved by the DPUK. -
- acknowledge in any resulting publications the origins of the Cohort Data and the use of the DPUK Data Portal for access and analysis.
- never make public the results of Your analysis that in Your reasonable option might result in an individual, or small groups of individuals, being identified.
- abide by all relevant laws and codes of practice current at the time.
- treat the Data You may view as strictly confidential; and use responsibly and take proper precautions with regard to the security of the Data.

8. You agree that if You suspect that the availability, integrity or security of the DPUK Data Portal is compromised in any way You will immediately notify Swansea.

9. You will not attempt to establish the identity of any individual to which the Data relates.

10. You understand and acknowledge that use of the Data granted under this Agreement should not be construed as conferring ownership of the Data, which are protected by copyright and other intellectual property rights.

11. You understand that no Data may be copied or electronically distributed, by any means and for any purposes, from the DPUK Data Portal; also that it may not be accessed for any purpose other than for the performance of a study that has been approved by the SAP and then only used as approved by the SAP

12. Swansea, the institutions comprising DPUK, the Data Provider(s) or guardians, 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. For the purposes of clause 20 the benefit conferred

by this clause 12 is intended to be enforceable by the persons referred to in it.

13. Swansea 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.

14. You agree that You will submit a report to the SAP, if requested, on completion of the [Study] and shall mark the report as “confidential information of [name of User Institution] communicated by Swansea University within the framework of the DPUK Programme” so that the members of DPUK are notified to treat the report and all information, data, results, and conclusions contained within such report as confidential information belonging to the User Institution.

15. You accept that the user account created for You will be used by Yourself only and no other individual.

16. You agree that any Data printed out for internal meetings shall be disposed of securely, for example by shredding, once it is no longer required. You will ensure that the person who printed Data ensures that all copies are disposed of. All printed Data must be kept for the minimum possible time and stored securely while not in use.

17. You agree to ensure that Your computer operating system, used to access the DPUK Data Portal, is, as far as possible, updated with the latest security patches, and that You will run reliable, effective and up-to-date anti-virus software. Failure to do this will result in Your (User) access privileges being revoked.

18. This agreement expires at the end of the Study Period. This agreement may be terminated by either party for any material or persistent breach of the obligations set out in this agreement, by giving thirty (30) days’ written notice to the other of its intention to terminate. The notice shall include a detailed statement describing the nature of the breach. If the breach is capable of being remedied and is remedied within the thirty-day notice period, then the termination shall not take effect. If the breach is of a nature such that it can be fully remedied but not within the thirty day notice period, then termination shall also not be effective if the party involved begins to remedy the breach within that period, and then continues diligently to remedy the breach until it is remedied fully. If the breach is incapable of remedy, then the termination shall take effect at the end of the thirty day notice period in any event. Confidentiality obligations shall continue to apply after termination and continue for 5 years beginning on the date of the termination or expiry.

19. These terms may only be varied by written agreement of the parties to this Agreement.

20. No one except a party to this agreement has any right to prevent the amendment of this agreement or its termination, and no one except a party to this agreement may enforce any benefit conferred by this agreement, unless this agreement expressly provides otherwise.

This Agreement and any dispute or claim arising out of or in connection with it or its subject matter or formation (including non-contractual disputes or claims) shall be governed by and construed in accordance with the law of England and Wales. Each party irrevocably agrees that the courts of England and Wales shall have exclusive jurisdiction to settle any dispute or claim arising out of or in connection with this agreement or its subject matter or formation (including non-contractual disputes or claims), except that an application for interim relief may be made to any court of competent jurisdiction.

# APPENDIX 1 (DATA ACCESS AGREEMENT)

## PUBLICATION PROCESS

Users wishing to publish results, Data (which may include Interrogated Information) and/or other information acquired/generated from their use of the DPUK Data Portal will inform the Swansea with prior written notice (including a reasonable summary of the proposed publication) at least thirty (30) days prior to submission of any such publication. Swansea will notify all the relevant Data Provider(s) in writing of the planned publication and information will be marked by You in accordance with clause 14.

The Data Provider will also be notified that they may object to or request a delay to a proposed publication for accuracy/patent reasons and/or require deletion of that Data Providers Confidential Information, provided such objection/request is submitted in writing to DPUK within twenty (20) days of receipt of the notification from DPUK. If this objection is upheld by DPUK the User will: (a) modify or delay the publication as reasonably requested; and/or (b) delete such Confidential Information from the intended Publication.

The Data Provider will also be notified that if they do request a delay on the submission of a publication, such delay shall not last longer than is absolutely necessary to seek the required approvals; and therefore shall not exceed there (3) months from the date of receipt of the proposed publication.

All approved publications arising from the use of the DPUK Data Portal shall give due credit to the Parties involved and shall also acknowledge the participation of the Data Provider, unless requested to the contrary by the Data Provider.

# APPENDIX 2 (DATA ACCESS AGREEMENT)

## APPLICATION

# DATA ACCESS AGREEMENT

I have read the terms and conditions set out in the Dementias Platform UK Data Access Agreement version 1.4 and agree to be bound by them. I declare that I am not currently being investigated under data protection legislation applicable in the UK or in the past been found to be in breach of such legislation.

## Researcher

Name: \_\_\_\_\_

Job Title: \_\_\_\_\_

Organisation: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Institution Authorised Signatory

I confirm for and on behalf of my Organisation that the Organisation is liable also for any breach of these terms and conditions.

Name: \_\_\_\_\_

Job Title: \_\_\_\_\_

Organisation: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_





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