Version 12: February 2025

Swansea University
Prifysgol Abertawe

DATA ACCESS AGREEMENT (DAA)

RELATING TO DPUK DATA PORTAL AND AFFILIATED HUBS

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) ("User Institution" (add your institutions name))

BACKGROUND

A. Dementias Platform UK (DPUK) and AFFILIATED HUBS 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.

B. The DPUK Data Portal (defined below) and AFFILIATED HUBS (defined below) is a data storage, analysis and linkage platform that is envisaged to be used as part of the DPUK/AFFILIATED HUBS project in order to integrate multiple cohorts for a comprehensive epidemiological research platform. The DPUK Data Portal and AFFILIATED HUBS are 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 and AFFILIATED HUBS on behalf of DPUK.

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

D. In signing this agreement, the User Institution is agreeing to be bound by the terms and conditions of access set out in this agreement. For the avoidance of doubt, while the terms of access set out within this agreement apply to both the User and User Institution, the User Institution remains liable for the action of the User in

relation to the User's use of the DPUK Data Portal and AFFILIATED HUBS. The User Institution and User are referred to within the agreement as "**You**" and "**Your**" and shall be construed accordingly.

E. Swansea shall also provide additional resources to the user as further detailed in this Agreement.

DEFINITIONS:

Additional resources	**means the additional support that Swansea will provide to the user as set out in schedule 1 of this Agreement**
AFFILIATED HUBS:	means hubs created and/or generated with the use of Data Provider Data contained within DPUK's secure environment.
Anonymised	refers to the state of Data within the DPUK Data Portal. Data provided will go through split-file anonymisation in order that Data is both robustly anonymised (double encryption between Digital Health and Care Wales (DHCW) and Swansea) and standard in format.
Application	means the application made by the User attached at Appendix 1.
Bona Fide Research	means research that can be considered to be as follows: **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).

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).
3. The intended activities are not inconsistent with legal and ethical requirements or widely recognised good research practice.

Bona Fide Researcher 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).

Cohort means a group of Participants who share a common characteristic.

Data: means anonymised data being used as part of a Study (defined below in appendix) including Interrogated Information.

Data Provider means the organisation(s) that has/have agreed to share with DPUK and/or its AFFILIATED HUBS, its/their Data that is routinely collected within the organisation.

DPUK	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.
DPUK Data Portal	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.
Interrogated Information	means all reports which have been generated as a result of a User being afforded access to Data (via the SAP approval process).
Publication Process	means the process available at https://www.dementiasplatform.uk/dpuk-policies.
Study	means the description of the research set out in the Application at Appendix 1.
Study Folder	means the folder on the DPUK Data Portal and/or affiliated hub into which the Cohort Data and metadata for analysis, approved by the Data Provider, will be uploaded to the researchers who have signed the Data Access Agreement for the Study specified in Appendix 1.

SAP	means the Study Approvals Panel, responsible for the governance review of projects, publications and outputs. The SAP will comprise Principal Investigators/Representatives from each DPUK member whose Cohort Data has been approved for use in a Study and/or representatives from any other Data Provider involved in a Study.
Study Period	as confirmed by DPUK as part of providing approval for the Study. As outlined in the project date field of the application found in Appendix, or thereafter if an extension to this date is sought by the Application and approved by the data provider.
User	means a researcher whose User Institution 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.
User Institution	means the organisation at which the User is employed, affiliated or enrolled.

TERMS AND CONDITIONS:

Following your successful Study request to Swansea (DPUK and AFFILIATED HUBS) and in consideration of being afforded access to the Data held within the DPUK Data Portal and AFFILIATED HUBS you are required to undertake the study defined within the Application, You agree as follows:

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

2. You accept that the User account created for You will be used by yourself only and no other individual. You agree to report any unusual activity on your account without delay to administrators on helpdesk@chi.swan.ac.uk.

3. You are part of a Study that has adhered to the DPUK/affiliated hub study application process, has been approved by the SAP and are requesting access to the study area and/or study specific Data and you will be provided with access to the Data on the DPUK Data Portal and/or affiliated hub for the Study Period. At the end of the Study Period your access to the DPUK Data Portal and/or affiliated hub will automatically terminate.

4. You agree to only use the Data only for the purpose of performing the Study specified in your approved application. You will ensure that the Data remains in the specific Study Folder at all times. If you have access to multiple Study Folders, copying of the Data to other Study Folder locations is strictly prohibited and will be considered a breach of this Agreement. You will not use the Data for any other purpose.

5. You agree that any amendments to the Study must be approved by SAP and/or the Data Provider before You may use any Data for such amended purposes.

6. You agree to follow the policies applicable to your Study and use of the DPUK Data Portal and AFFILIATED HUBS which are available at https://www.dementiasplatform.uk/dpuk-policies.

7. You agree to follow the Publication Process detailed within the publication policy available on the link above in clause 6 and by informing Swansea of any publications at least 30 days prior to submission. Swansea will notify the Data Providers and give them opportunity to review the planned publication. The Data Providers may either approve the planned publication, request their Cohort Data is removed from the publication, or request a delay to publication for amendments provided that this notification is received within 20 days of Swansea notifying them. Delays of planned publications are limited to a maximum of 3 months from Swansea providing the Data Providers with the planned publication. All approved publications shall credit the Data Providers and Swansea (DPUK and AFFILIATED HUBS), unless expressly requested to the contrary by the Data Provider or Swansea.

8. In addition to the requirements of the publication policy, you agree to:
    - use the Data entrusted to You for the public good and only as approved by the SAP
    - acknowledge in any results publications the origins of the Data and the use of the DPUK Data Portal and/or AFFILIATED HUBS for access and analysis
    - never make public the results of your analysis that in your reasonable opinion 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
    - not to attempt to establish the identity of any individual to which the Data relates
    - utilise the results of your research exclusively for public benefit and not for commercial gain
    - take reasonable steps to ensure that, when accessing the Data, your display screen is not being overlooked by unauthorised persons and that you have taken all reasonable physical precautions to maintain the security of the data supplied.
9. Taking screenshots or otherwise recording information direct from DPUK Data Portal and/or sharing to another location is strictly prohibited. The only exception to this rule is sharing an 'error message' for the purpose of seeking user support. A screenshot of an 'error message' may be taken and shared under the following conditions:
   The screenshot is tightly cropped to only include information within the error message. You must ensure that no information is captured in the background. The error message must not contain any research data values.
   The screenshot must only be shared with the DPUK Portal technical team via the Helpdesk ticket.

10. You agree that if You suspect that the availability, integrity or security of the DPUK Data Portal and/or AFFILIATED HUBS is compromised in any way you will immediately notify administrators at Swansea at helpdesk@chi.swan.ac.uk.

11. 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.

12. You understand that Data accessed from the DPUK Data Portal and/or AFFILIATED HUBS may not be copied or electronically distributed.

Swansea, the institutions comprising DPUK and AFFILIATED HUBS, 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. Notwithstanding clause 22, 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. As part of the Study if you decide to upload any content onto the DPUK Data Portal and/or AFFILIATED HUBS 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 your systems. You must not upload, distribute or transmit any virus, or any material through the System 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.

15. You are able to bring data into the DPUK Data Portal and/or AFFILIATED HUBS for use in the Study provided that either You are the data owner or You have written consent and approval from the Data owner for such use and prior to the upload. You shall remain responsible for all data You bring in to the DPUK Data Portal and/or AFFILIATED HUBS and, at any time, Swansea may request evidence from You of Your ownership and/or permission. If permission to access the Data is revoked by the Data owner at any point during the Study's duration, it is Your responsibility as the User to ensure that all data You introduce under this clause is removed from the DPUK Data Portal and/or AFFILIATED HUBS and that you provide Swansea with confirmation that this has occurred. Any data introduced into our environment, irrespective of ownership, shall be subject to the same protocols, procedures, and security measures as the data already residing within our environment. This data will not be retrievable or returned during or after the completion of the work, and it shall be subject to the outputs approval process. For further details, please refer to our website https://portal.dementiasplatform.uk.

16. Unless explicitly agreed in advance, You agree to share all computer code, statistical scripts and similar material developed whilst undertaking the Study with the DPUK and AFFILIATED HUBS User community, through the channels DPUK/AFFILIATED HUBS make available for this purpose.

17. You agree to a cap on generating data from analysis resulting in no more than 2.5 x the data originally provided to you in order to limit the storage requirements of your Study to a reasonable amount. This cap will be automatically placed on a Study. DPUK and AFFILIATED HUBS cannot be responsible for monitoring when this cap is nearly reached.

18. Your activity within the DPUK Data Portal and/or AFFILIATED HUBS may be subject to audit and you shall at all times cooperate with Swansea in facilitating such audit.

19. Data on the DPUK Data Portal and/or AFFILIATED HUBS is classified as confidential This excludes approved outputs via the DPUK File out standards and practises, as highlighted via documentation noted on the website: https://portal.dementiasplatform.uk.

20. This agreement expires at the end of the Study Period. This agreement may be terminated earlier 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.

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

22. Subject to clause 12, 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.

23. 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.

24. During the term of the approved project detailed in Appendix 1 Swansea shall supply the services and additional resources to the user

PAYMENT

25. In consideration for Swansea providing the Additional Resources to the User, the User shall pay Swansea the amounts specified in Schedule 1 which shall be exclusive of VAT (if applicable). I

For and on behalf of [add institute]

Name: _____

Job Title: _____

Signature: _____

Date: _____

Read and Acknowledged:

Researcher

Name: _____

Job Title: _____

Signature: _____

Date: _____

APPENDIX 1 (APPLICATION)

[insert a copy of the application]

Schedule 1 – Additional resources to be provided by Swansea to the User

Additional capabilities requested	Amount	Cost p/y	Total costs
Standard desktops	0	£0	£0
Large desktops	0	£0	£0
Extra large desktops	0	£0	£0
HPC cluster access	0	£0	£0
Data Storage	0	£0	£0
Analyst support (Bids formatting and Imaging setup)	0	£0	£0
Developer support	0	£0	£0
Administrative support	0	£0	£0
Total Cost		£0	£0

If applicable, invoices to be sent to [Add relevant email address].

Invoices shall be payable within 30 days of receipt