

## **Terms and Conditions for access to Bio-Hermes data in the Biomarker Data Challenge**

In these terms and conditions (T&C) , the parties accessing the data are referred to as ‘the approved researcher’. The University of Glasgow, working in Partnership with University of St Andrews and the Scottish Funding Council Brain Health ARC are referred to as ‘the host organisation’. The data will be stored and accessed on a secure platform provided by Alzheimer’s Disease Data Initiative (ADDI). The original data were collected by Global Alzheimer’s Platform Foundation (GAP) who deposited the data with ADDI under a separate legal agreement. Each party shall comply with their respective obligations under data protection law, including UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018.

The T&C materials are to be agreed between the approved researcher, the host organisation, ADDI and GAP. In these T&C the roles and responsibilities of the approved researcher are described to ensure that the approved researcher is aware of all the associated obligations.

The approved researcher must agree to all the conditions before access to data can begin.

The T&C have been formulated based on the five pillars of good practice in secondary data access of clinical information.

### **Safe People**

Only suitably trained and approved researchers can access the data

### **Safe Projects**

Data are only used for ethically approved research with the potential for public benefit

### **Safe Settings**

Access to data is only possible through the ADDI secure technology systems and the data never leave the secure environment

### **Safe Data**

The data made available will be fully anonymised to protect privacy

### **Safe Outputs**

Research outputs will be in aggregate only, and will be assessed to ensure there is no possibility of participant identification

## **Statements to be agreed by the researcher(s) prior to data access**

Access to the Bio-Hermes dataset is reserved for researchers named on the application form. Access credentials must not be shared with others in the applicant team or in other teams without prior approval.

Access to the Bio-Hermes dataset is only allowed while the named applicant(s) is part of the applicant team. If the named applicant(s) leave the team or change position then this must be notified to the host organisation and approval sought for ongoing access.

Access to the Bio-Hermes dataset is only for the duration of the project as stipulated in the application.

Only researchers appropriately trained and skilled in data protection, confidentiality, governance, and security can access the Bio-Hermes dataset. Proof of suitable training or experience will be requested at time of application.

Researchers must only access data on a device that meets the security requirements of the host organisation (typically not a personal device). The device should not be left unattended while accessing the data portal and the researcher(s) shall protect the screen from onlookers.

Access to the secure environment is only permitted from locations defined in the project application.

Only anonymised aggregate data may be downloaded following quarantine and screening prior to release from the secure environment.

The researcher(s) shall not, and shall not attempt to, link or combine the data with other information or data (including any information relating to an identified or identifiable natural person) available to them.

The researcher(s) shall not, and shall not attempt to, identify individuals from the data; or attempt contact any data subject.

The researcher will not exploit the data for financial or other gain or commercial activity.

The researcher(s) shall be responsible for ensuring that the host organisation is informed without delay, and in any event within 12 hours of the researcher(s) becoming aware of:

- i. any unauthorised access, disclosure, loss, damage, or alteration of the data
- ii. any element within the data that might permit the identification of a data subject,
- iii. anything that may impact or compromise confidentiality, integrity, or availability of data,
- iv. any complaints from an individual or supervisory authority in relation to the data; and
- v. any request from a research participant to exercise their rights in respect of the data.

The researcher(s) shall not:

- i. use the data or any research output for any purpose contrary to the applicable laws or Approved Project purposes.
- ii. download, extract, transmit, transfer, remove, share, copy, or publish any of the data from the secure environment.

Any outputs will be accompanied by an acknowledgement of source/ copyright statement requirements and any other form of words to be agreed with the host organisation and GAP (Data Controller).

Outputs including aggregate source data, derived data, metadata, researcher analyses and other research outputs must be shared with the host organisation, who will in turn share with GAP (Data Controller).

This agreement begins upon all parties signing these materials. The agreement terminates (i) after completion of the assignment or (ii) upon expiration of the specified study duration as described in the application. The agreement can be terminated by either party, provided that a period of notice of 14 days is observed.

NAME (PRINT)	SIGNATURE	DATE
(Researcher – lead )		
(Researcher)		
(Researcher)		
(Host organisation)		
(Global Alz Platform)		