

# Data access policy

## Background

Dementias Platform UK (DPUK) aims 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 neurodegeneration.

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 housed on an instance of UK Secure eResearch Platform (UKSeRP) at Swansea. Swansea manages the maintenance and administration of access to the DPUK Data Portal on behalf of DPUK.

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

## Data Access Policy

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

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.