POLICY –
DPUK DATA ACCESS

Background

This document explains the Dementias Platform UK (DPUK) policy on data access via the DPUK Data Portal. The Data Portal increases scientific opportunity and rigour by providing access to multiple independent cohort datasets for bona fide researchers, by creating an environment for the testing of emerging hypotheses, and for replication. This is achieved by providing:

- a secure and fully auditable environment in which cohorts can manage access to their data;
- a single point of contact for multiple datasets;
- a streamlined access application procedure;
- standardised curation of datasets to a common data model.

Principles

The policy is based on five principles:

1. DPUK operates solely as a data processor on behalf of the data controller, which remains the cohort host institution, acting on behalf of the cohort research team.

2. DPUK recognises the cohort research teams as collaborators in the enterprise of making their data increasingly available to the scientific community. By default, DPUK recognises the cohort research teams as collaborators with third party researchers wishing to access cohort data via the Data Portal. A third party researcher is an individual who is not party to the data deposit agreement underlying the deposit of data into the Data Portal.

3. DPUK invites data access applications from all bona fide researchers. A bona fide researcher is defined as 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 participating in the research process.

4. All data will remain non-identifiable and that no attempt will be made to identify individuals.

5. Findings will be disseminated in line with the stipulations of the DPUK Publications Policy.

Procedures

Please see the DPUK website for the processes involved in DPUK data access.

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