POLICY – DPUK DATA MANAGEMENT

Background

This document explains the end-to-end process of data management within Dementias Platform UK (DPUK). The policy describes the obligations on the involved parties. DPUK uses the UK Secure eResearch Platform (UKSeRP) informatics architecture, and references to DPUK data management are made in the context of UKSeRP policies and practices. This policy, along with those for data access and cost recovery, support a wider aim of DPUK which is to reduce the transaction costs of accessing and analysing cohort data.

Principles

The policy is based on four principles:

- Non-identification of individuals is paramount: all data will remain non-identifiable and no attempt will be made to identify individuals;
- DPUK data management is fully aligned with the obligations described in the DPUK Data Deposit Agreement;
- DPUK data management is fully aligned with the obligations described in the DPUK Data Access Terms of Use document
- DPUK data management practice does not change the legal status of the data, which remains the property of the cohort research teams or their legal representatives

.

Process

Please see the DPUK website for the accompanying process and procedures involved in DPUK data management.

Release date of document: 26 October 2020