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Dementias Platform UK (DPUK) Portal

Thompson, Simon¹

¹Swansea University

Background

Established by the Medical Research Council (MRC) in June 2014, it is a £53 million collaboration between universities and drug companies to transform the best dementia research into the best treatments as quickly as possible.

DPUK will bring together 33 different dementia cohorts as well as imaging, brain bank, genomics and NLP.

Method

To achieve this DPUK has a large number of work packages developing knowledge, capability and science. Work package 2 - DPUK Data portal has many cross cutting themes but its main aim is to provide a central access mechanism for the researchers to access the diverse datasets in a secure research platform which is delivered using the UK Secure e-Research Platform (UKSeRP).

The Portal supports the work of WP1 Cohort Profiling by providing information capture systems as well as automated publicly accessible summaries and more detailed reporting for DPUK members.

There are obvious sensitivities around the sharing of the cohort datasets, especially given the many years of investment and commitment by the cohorts PI. However, many of these cohorts are no longer funded and risk of becoming obsolete and possibly being lost unless they become adopted by a programme such as DPUK. UKSeRP will provide a technical platform far more advanced than is often available to the cohorts and therefore the cohorts will benefit from these additional capabilities. The system leaves data ownership with the cohort PI and the governance structure puts them in the centre of the process and ensures that the cohort data is only used in projects that the cohorts are comfortable with.

The Portal supports the project application and approval process, and supports the governance structure and cohort engagement process. The application process is common regardless of the type of dataset required (phenotypic, genomic, imaging, physical samples)

Conclusion

DPUK has extended UKSeRP to add the technical capabilities developed jointly with other work packages, most notably the addition of a fully federated image retrieval and analysis system and the genomics analysis system.

The platform will be fully operational by the end of the year.

*Corresponding Author:

Email Address: simon@chi.swan.ac.uk (S. Thompson)

