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Data Services for Cohort Studies: Increasing the impact of existing research studies and epidemiological readiness

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Introduction

The Dementias Platform UK (DPUK) Data Portal is a secure, accessible environment facilitating provision of rich data towards the largest Dementia, cognition and ageing community of cohort studies in the world. DPUK is also providing services for cohort studies and researchers to maximise the research potential of the programme's community.

Objectives and Approach

As part of the engagement of DPUK cohorts with the Data Portal, cohorts will upload data onto the DPUK instance of UK Secure eResearch Platform infrastructure. The Data Portal allows access to a collaborative working space that allows cohorts to enrich their own data, perform their own analysis, and enhance the research potential of their data whilst making use of expertise at various DPUK sites, such as data linking, curation and multi-modal specialism. Cohort data divided into ontologies allows researchers to access data specific to their study needs and can be requested from multiple cohorts simultaneously.

Results

By utilising the Data Portal researchers have access to cohort data that has been prepared for dementia epidemiology using the agreed ontologies, providing more rapid access to cohort data that otherwise may be large and complex. The knowledge and experience of DPUK staff and collaborators can also help to guide nascent cohorts and feasibility studies into producing research-ready datasets, enabling them to achieve greater impact with their data. A range of analytical tools are provided on the Data Portal making analysis of a cohort's own data or multiple independent datasets more accessible. Alongside data curation, DPUK also facilitates data linkage to routine sources, beginning with a Wales-wide use case that will expand to the UK over the course of the project.

Conclusion/Implications

Data from international sources accessible using a central platform permits international collaboration, with ontologies allowing previously disparate data to be combined and analysed to build knowledge and research impact. DPUK projects create policy leading results and operational research standards, enhancing cohort impact and discovery of benefits for Dementia patients.

