

## New data resource for dementia research

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An Oxford University-led research programme has launched a new system to help dementia researchers make the most of existing study data. The Dementias Platform UK's new <u>Data Portal</u> is a secure online research environment that will provide researchers with high quality information and tools to help them work together better. It will enable scientists to exploit and share a wealth of data, as well as enabling remote access to, and analysis of, large and complex datasets.

This is the first such portal to have a specific focus on dementia so it will play a part in achieving the Prime Minister's Challenge on Dementia 2020, by providing a platform which <u>researchers</u> from around the world can use to accelerate dementias research.

Oxford University's Professor John Gallacher, Director of the Dementias Platform UK said: 'Our aim is to make dementias research easier and faster for scientists so that we can progress research and ultimately find a way to treat this disease.'

A key tool is the Cohort Finder, which allows cohort descriptions to be easily searched in order to identify and confirm topics for dementia research from over 30 well-established UK population, or cohort studies. A cohort study is a study which works with a specific group of people to understand how health and wellbeing change over time. In the UK, cohort studies play a critical role in research and have broken new ground in understanding the factors which affect human health, informing public health policy and practice and contributing to international health studies. More than half of UK cohort studies have



been running for over twenty years, representing a unique resource for understanding health.

Previously, researchers looking for data to analyse to support their studies could apply to various places to get routine clinical data. However, as that data was originally collected for other purposes (e.g. as part of a GP appointment or hospital visit) the data quality might not be as valuable as cohort data collected for the specific purpose of dementia research. However, scientists would have had to physically read through details of each individual cohort to see whether the data would be of benefit to them. If they wanted to use data from more than one cohort, that would have to be done manually and each cohort contacted separately to ask for their data. The time taken to gather and clarify information before comparison could begin slowed down analysis that could give new insights into a one or more forms of dementia.

In comparison, the DPUK Cohort Finder is far more straightforward. It is an online catalogue where approved researchers can easily browse to see what information is available to them (blood samples, urine samples, brain scans etc.) and even compare what is available across several cohorts. DPUK staff at the University of Edinburgh worked to compile details of each cohort to build a profile of what it offered. A Cohort Directory and Cohort Matrix, summarising this information, are available on the DPUK website.

Professor Craig Ritchie, from the University of Edinburgh, who led the data collation, said: 'The existing cohorts in the UK are an unparalleled resource for advancing research. Engaging with cohorts will be a key strength of DPUK and fundamental to its success.'

A key aim for DPUK is to give researchers better access to the wealth of information on health and lifestyle available in huge population studies. By examining this data researchers can compare healthy people with



people at all stages of dementias and can look at how this is affected by other conditions that people may have.

A rigorous set of policies ensures that personal information is protected while still allowing researchers to be able to get data from over two million people without leaving their desk.

## Provided by Oxford University

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