

PRESS RELEASE

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Major investment in research gives hope to millions living with or at risk from dementia - taking us closer to a dementia-free world

The generosity of British public is key to unlocking a dementia-free future

A major programme of investment into dementia research that has been running for nearly five years, today announced the progress it has been making on improving diagnosis and treatments for people at risk of dementia. Today it also launched the world's most in-depth study into Alzheimer's Disease.

Called **Dementias Platform UK (DPUK)**, it has changed the dementia research landscape by bringing technology, expertise and volunteers together to accelerate the development of new treatments. The success of the programme lies in the access it gives to securely-managed big data which is revealing new findings - for example that anti-rheumatoid drugs halve the risk of dementia and once trialled, may provide new treatments.

DPUK curates - cleans and standardises - cohort data from 3.2 million people, making it easier for researchers to compare different cohorts, uncover changes associated with dementia and test new theories. Cohorts are longitudinal health studies that track information over time.

Big data coupled with cutting-edge imaging and stem cell technology are helping researchers identify the molecular and cellular mechanisms associated with dementia, promising earlier diagnosis and treatment, before dementia irreversibly damages the brain. Researchers are now working to diagnose dementia early enough to disentangle how different forms of dementia start and progress.

Professor John Gallacher of Oxford University, who leads the DPUK programme said: 'Dementia affects over 50 million people worldwide and is the biggest public health crisis facing us in the 21st century. We have stepped up the fight against it with this multi-million pound investment. Whilst the money is crucial, what is also important with a programme of this kind is that what it can achieve is greater than the sum of its parts.

'It's like the way we made great strides in tackling cancer, by working together we are increasing our knowledge of how dementia starts, and as a result can develop more effective treatments and ways to tackle it. Big data can sometimes have a bad reputation, but

DPUK is leading the way in this area. All our cohorts sign off their involvement in our research, and we have curated the data so that the widest range of scientists can use it. However, what is also significant is the critical role of the public in discovering the causes of dementia. Having a critical mass of reliable data wouldn't be possible without volunteers as they are how researchers translate our understanding of the mechanisms of disease into treatments. Ensuring that relationship continues to work well is the key to unlocking a dementia-free future.'

Adding to the already immense and important data it provides access to, **DPUK today also launched the world's most in-depth study into Alzheimer's Disease.** Following a pilot study, the screening phase of what is called the Deep and Frequent Phenotyping study (DFP) is now about to get underway. The study will be examining 250 volunteers over sixty years of age with the absence of dementia but pathological signs of it. The objective of the study is to collect biological samples, brain imaging and identify a variety of complex biomarker - some old some new -so that we can predict the risk of dementia earlier. Once we can identify people at risk of dementia, but not yet showing symptoms, we can improve the success of clinical and drug trials as we are testing the right volunteers, with the right intervention - early in the disease when the brain is still relatively healthy.

Dr Vanessa Raymont of Oxford University, who will be leading on this work for DPUK said: 'We completed analysis of the pilot study early this year and that has demonstrated that not only do the public want to contribute to Alzheimer's research, they are also willing to undertake relatively invasive assessments in the effort to identify new biomarkers and test new treatments.

'Without people being willing to do this we would not have been able to move onto launching the full study, which we hope will reveal phenotypic - or observable characteristics - which may contribute to people developing Alzheimer's Disease. Once the study is complete this data will be part of the DPUK data portal and be accessible to researchers worldwide. This will allow new analysis and opportunities for drug trials to help find a cure and potentially prevent dementia altogether.'

Felicity Steadman, a member of the UK Biobank cohort is just one example of the millions of people in the UK who are taking part in various research trials. She said: 'I have participated in the UK Biobank over the past fifteen years. My father died with dementia and my mother died of metastasised breast cancer, so I would like to do whatever I can to assist research into why these conditions develop and what can be done to prevent and

treat them. As Mahatma Gandhi said: “Be the change that you wish to see in the world.” I participate for my own benefit and for the benefit of all now and in the future.’

Professor John Gallacher concluded ‘I would really like to thank the public for their support so far and would encourage anyone who wants to help support dementia research in either the DFP programme or wider to join a dementia research registry that suits them.

‘It is people like Felicity and millions like her that are helping us fill the knowledge gap of the causes of dementia. This means we are moving in the right direction with some breakthroughs in experimental medicine coming to fruition. We are also working with the pharmaceutical industry so that we maximise the success of clinical and drug trials. As we move into the next phase of this ground-breaking project, I am incredibly optimistic that we have all the right ingredients in place to make even greater strides in tackling this terrible disease that affects so many people worldwide.’

Ends

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More detailed information about the breadth of DPUK’s work can be found at www.dementiasplatform.uk and below are some key statistics and outcomes from the programme.

DPUK key facts

DPUK’s Data Portal is the world’s first data storage, curation and access platform for analysing multiple cohort and diverse data types - phenotypic, genetic, and imaging.

- It incorporates 35 cohorts consisting of over 3.2 million individuals
- It has 216 registered international academic, government & industry users
- There are currently 72 active projects accessing data through the Data Portal
- It is increasing the richness of the UK Biobank cohort by reimaging 10,000 participants, cognitive tests with 120,000 and using the health records of 500,000 to predict risk of dementia
- It is also working with other cohorts including imaging 500 participants from the National Survey of Health and Development cohort for amyloid proteins; testing cognitive health of 1000 HealthWise Wales cohort participants and is running genotyping on 1000 Airwave cohort members

DPUK has significantly increased the UK's capacity to do experimental medicine (people based research).

- It has created the first national MR-PET imaging network and state-of the-art stem cell labs
- To date it has submitted 122 publications with other research in progress
- It has brought £10.8 M from industry to fund collaborative projects

DPUK major achievements

These are just some of the achievements from the programme over the last five years. Many of them interlink and one would not be possible without the other.

Experimental medicine - by discovering the underlying mechanisms that cause dementia in volunteers, experimental medicine can target the promising treatments.

- For example, research looking at blood pressure in cohort data has changed our understanding about raised blood pressure. We now understand that even a small increase in midlife - even within normal levels - is a risk factor in dementia. This can help us shape future health policy of regular midlife testing and management of hypertension.
- The state-of- the-art MR-PET imaging network is also changing the way researchers work. MRI and cutting-edge molecular imaging are fully integrated as one and this has allowed researcher for the first time to picture significantly higher levels of activity of astrocytes in the brain. These important 'housekeeper cells' keep neurones - and our brains - healthy. New research has been able to look at how these cells behave in healthy individuals compared to those with memory problems indicating that developing treatments which target astrocytes may offer a treatment for those with dementia.

Data imaging network - cutting edge imaging is helping us diagnose dementia before irreversible brain damage and identify treatments.

- DPUK has established the world's first multicentre imaging network. This means that researchers are using the same processes and interpretation as all the scanners record comparable data. DPUK's approach is now giving a critical mass of reliable data insights into the earliest molecular changes associated with dementia. This means that we are starting to diagnose different forms of dementia earlier than ever before and are able to run nationwide clinical trials like the Deep and Frequent Phenotyping study.
- With the innovation behind these powerful techniques, this year researchers started a programme to map the earliest signs of different forms of dementia* by imaging the relationship between tau proteins, amyloid proteins and nucleotides - the building blocks of our genes. Through revealing disease, specific patterns of these molecules, researchers will be able to diagnose a specific dementia earlier, leading

to targeted treatments earlier in the progression of these diseases and before the brain becomes irreversibly damaged.

*(Parkinson's, Alzheimer's, progressive, supranuclear palsy (PSP) Lewy bodies and vascular dementia).

Stem cell network - Stem cell technology accelerates the discovery of therapeutic drugs by using living brain cells to target the mechanisms that cause dementia.

- Stem cell research has come a long way since Dolly the sheep - it has changed our understanding of the causes of diabetes, MS, and Parkinson's disease. By using the latest stem cell techniques, DPUK researchers have reprogrammed skin and blood cells (from cohort samples) and induced these to develop into 150 different samples of human brain cells. These 'disease in a dish' models can be used to investigate disease mechanisms or test potential treatments.
- Researchers have used these stem cell lines to demonstrate that an approved cancer drug blocks a protein that represses certain genes associated with Parkinson's, as well as accelerating the testing of drugs that can selectively block 'bad' forms of tau protein - tangles of tau proteins are associated with Alzheimer's Disease - whilst sparing good forms.

For those interested in participating in dementia research there are a number of research registries you can join:

The Deep and Frequent Phenotyping Study: <http://www.dfpstudy.co.uk>

Join Dementia Research: <https://news.joindementiaresearch.nihr.ac.uk/>

Brains for Dementia Research: <https://www.brainsfordementiaresearch.org.uk/>