



NEWSLETTER

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Photo: River Cherwell from the Botanical Gardens

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Welcome!



This issue of the OxDARE Newsletter recognises the great work of staff and Friends in supporting research during the pandemic, as well as looking forward to the new beginnings we associate with spring. We feature two projects Friends of OxDARE have helped with on page 4 and list further opportunities to take part in research on page 7.

The feature on page 3 explores how remote assessments were fast-tracked during COVID-19 and are now benefiting participants and staff as they are increasingly embedded in clinical research.

A selection of events and initiatives related to brain health are listed on page 8. Whilst many are still online, we hope you might find them interesting.

A return to non-essential research: *the experience of Sarah Clayton, Research Manager*

As a Research Manager for a cognitive neuroscience lab in lockdown, much of the research work paused, allowing me to catch up with all those tasks I had been putting off. Then I took up the post of Research Manager for the Oxford Centre for Human Brain Activity (OHBA) in January. [OHBA](#) is a brain-imaging hub with a range of highly precise methods of measuring brain activity. Part of my role was to oversee the restart of studies.

This is not only a complicated logistical exercise, but one made infinitely harder by a pandemic for which there were no proven protocols. The volume of documentation was extraordinary and it was constantly being updated. I was impressed how everyone worked together to share experiences and get things moving faster.

The first task was to co-ordinate which research would begin in which lab. Most studies had to reduce daily throughput for safety reasons; fewer people were able to occupy spaces and more time was required for cleaning between procedures. Fortunately we were able to install door stops in our corridors, meaning less time spent cleaning handles!



Safety procedures also meant that staff had to book a desk in advance, sign in and out of the building, and there was no social seating for chats at lunchtime. All of these new procedures required checklists for managers and inductions for all staff returning to the building. Project management skills have helped me through, as has my previous experience working as a postdoctoral researcher. Although this is not a prerequisite for my role, I do think it helps me to anticipate the requirements of researchers. Working collaboratively the brilliant team at OHBA has been crucial to managing a smooth re-opening.

Is remote assessment the future of dementia research?

A positive aspect of the COVID-19 pandemic for dementia research is the acceleration of plans for adopting new technology, perhaps by as much as 4 years¹.



What is remote assessment?

Remote assessment is the collection of data when the participant and researcher are not in the same physical space. This could be online memory and thinking tests, telephone/video-based appointments, or continuous monitoring of measures such as mood, sleep and physical activity using mobile apps, fitness trackers and wearable cameras.



Remote assessment is one important aspect of this new technology whereby it is possible to collect a variety of information at multiple time points all from a participant's own home. This not only reduces the risk of COVID-19 exposure but provides a fuller view of a person's life with little inconvenience to them.

The Dementia Industry Group (DIG), together with the National Institute for Health Research, hosted a live webinar asking clinicians and researchers for their views of remote assessment in dementia research. Speakers believed that remote assessment was more convenient and less stressful for patients who could remain in their own home with no need to travel (or battle with hospital parking!). Remote assessment could also reduce the workload for researchers and clinical services, improve data quality and reduce costs.

Of course, there are challenges in moving from face-to-face to remote assessments. Data safety and privacy must be reviewed and, crucially, many assessments have not been designed or validated for remote use, particularly in participants with cognitive impairment. Participants may lack familiarity with, or access to, technology; indeed a recent survey with Oxford Health memory clinic patients demonstrated that although their access to technology was high, confidence in using the tools was not. Overall clinicians and researchers at the event felt that issues could be overcome and a hybrid model of remote and face-to-face assessments would be ideal in future.

Researchers at the University of Oxford are working on several projects using a hybrid of face-to-face and remote assessments to improve understanding of brain health. The Deep and Frequent Phenotyping study includes a variety of assessments such as wearable devices to assess how a person walks at home and in a clinic environment with evidence that changes in gait may be an early indicator in the development of Alzheimer's disease (read more [here](#)). Participants of the Great Minds study can choose which assessments to take part in, including online questionnaires, at home saliva sampling and in-clinic brain imaging (find out more [here](#)).

With more research using remote assessments on the horizon, keep an eye out for opportunities to take part soon

Thanks to Friends of OxDARE for your help during lockdown

Many of you - who had registered your interest in taking part in research and Patient and Public Involvement (PPI) activities - generously gave your time during lockdown to our very grateful researchers. Below are two of the projects you contributed to.



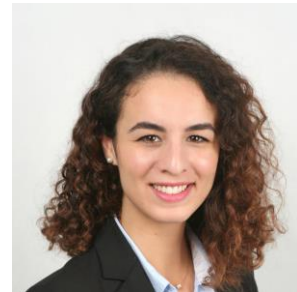
What is the difference between PPI and research?

Participants in both PPI and research contribute to building knowledge about a subject. Participants in research help the researchers better understand a subject whereas a PPI project usually involves participants and researchers exchanging knowledge to collaborate on the design or conduct of a research project. [Click here to learn more.](#)

Shaping a study of ageing

Ageing is often associated with changes in brain structure and cognitive function. 'Brain age' is the prediction of someone's age based on their **brain structure**, as seen on brain scans. These age predictions are made by an algorithm that has previously 'learned' how brain structure changes across different ages, using large samples of brain scans collected from healthy individuals. 'Cognitive age' is also estimated using a similar method, although, instead involves predicting someone's age based on their **cognitive test performance**. There are many reasons why a person's brain or cognitive age may not correlate with their actual age, such as disease or certain lifestyle behaviours like smoking or lack of exercise.

[Melis Anaturk](#) sent out a small survey to understand people's interests in such concepts to inform her future research. All respondents said they would be interested in knowing their brain age and in learning more about the methods used to estimate brain age. 80% said that knowing their brain age would motivate them to change their lifestyle. Respondents also expressed an interest in knowing their cognitive age and agreed this knowledge could help motivate them to change their lifestyle. Most of the respondents also expressed an interest in understanding the methods used to predict cognitive age and brain age, which has encouraged Melis to put together a 'demo' of these methods to share at a future public engagement event.



Research into loneliness in people aged 80 years or more

Jess Hilton, trainee clinical psychologist at the University of Oxford, is running a study looking at factors relating to loneliness in people over the age of 80. She has recorded a 14 minute video that sets the scene which you can see by clicking the photo of Jess.

Jess explains there are many reasons why people may feel lonely, some of which are commonly exacerbated by age, such as losing a partner, poorer physical

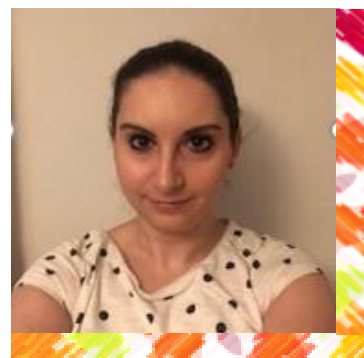
health or changing living arrangements. However, Jess is particularly interested in a cognitive theory of loneliness whereby it is not merely an individual's situation that generates feelings of loneliness, but rather the ways in which the individual may think and behave in response to that situation. She gives many examples, including one where the lack of a smile from another person in a social situation is taken personally by the person experiencing loneliness; in turn, the person experiencing loneliness is not encouraged to smile themselves or seek further interactions, which reinforces their sense of loneliness. Jess provides a compelling context for her research and we look forward to sharing her findings.

If you would like to ensure you have registered your interest in taking part in research or PPI please [click here](#).

Meet **Gemma Butler**, Research Assistant for dementia studies within the Department of Psychiatry, University of Oxford

Please introduce yourself Gemma

I started my new role here in April and am also studying for a Masters degree in Cognitive Neuroscience. I love the fact that my role enables me to practice many of the skills I am learning on my degree course, such as MRI scanning, programming, data analysis and fMRI analysis.



? What experience do you have of dementia research?

My career has never strayed far from dementia research. I started as a Community support Worker for Berkshire NHS Foundation Trust in the Wokingham Memory Clinic, then became an Assistant Psychologist there. I worked with Dr Jacqueline Hussey on a research project which helped the Wokingham Memory Clinic reduce the time to diagnosis for people with Young Onset Dementia (YOD) (dementia that begins in people under 65 years of age) from 9 months to 3 months on average (1). This is because people with YOD often present with language and emotional symptoms in the early stages of the disease instead of memory and cognition difficulties which we often see in people with Late Onset Dementia (dementia that begins over the age of 65 years). For this reason, younger patients are regularly referred to Neurology services or their local mental health team by their GP as dementia is not usually the expected diagnosis. This research highlighted a new way of working jointly with the GPs to encourage more referrals to the Memory Clinic for younger patients with atypical symptoms of dementia. The benefit of a quicker time to diagnosis was faster access to specialised support services via Berkshire's own registered charity - "Younger People With Dementia" (<http://www.ypwd.info/>). This resulted in better wellbeing outcomes for both patient and their loved ones.

? What aspect of your career, so far, has been most rewarding?

That is a really difficult question as I have been so fortunate in my roles. However, my time as an Assistant Psychologist for the Intensive Management of Personality Disorders and Clinical Therapies Team in Berkshire does stand out for me. As part of a team delivering psychological therapies of Dialectical Behaviour Therapy and Mentalization-Based Therapy, I witnessed the incredible impact that receiving the right therapy and therapeutic approach can make to people's lives.

? Do you have a specific career ambition?

I am really interested in links between brain structure, human behaviour and cognition. My goal is to train as a Clinical Psychologist then qualify as a Neuropsychologist.

? Have you adopted a new behaviour during 'lockdown' that you want to continue?

Lockdown began with me sitting at a computer at home from 9am till 5pm, missing out on the lovely weather. So, I volunteered to walk my neighbours' dogs at lunchtime, partly to help them out with the restrictions imposed by the pandemic, and partly to give me some exercise each day. I love dogs anyway, but I also enjoyed the casual chats along the way which lifted my mood. I will definitely be continuing with it post lockdown!

(1) Hussey and Butler (2019), 'Delays in diagnosis for people with Young Onset Dementia'. Available from: <https://www.alliedacademies.org/articles/delays-in-diagnosis-for-people-with-young-onset-dementia-11241.html>

Dementias Platform UK (DPUK) is a partnership between academic scientists and industry professionals dedicated to detecting and treating dementia earlier than ever before. DPUK helps researchers achieve this aim by powering dementia studies through access to data, technology, funding and volunteers.

Now, DPUK is entering its next phase of work – thanks to renewed funding from the Medical Research Council – which will expand upon the successes of the previous phase. The three main strands of DPUK's work are the Trials Delivery Framework, the Experimental Medicine Incubator, and the DPUK Data Portal.

The DPUK Data Portal is a free resource available to dementia researchers across the world enabling access to data from over 3 million individuals who have been studied over many years. This type of data is called cohort data and is used to study trends in people who develop dementia. In this next phase, the DPUK Data Portal will be developed to become a globally leading data platform for dementia research.

DPUK also regularly hosts Datathon events in which teams of early-career scientists from various fields use the Data Portal to explore their ideas about dementia and in so doing learn how to handle and analyse complex cohort data.

The Trials Delivery Framework is part of a nationwide participant recruitment network alongside NIHR's Join Dementia Research initiative and the Scottish Brain Health Register. The key purpose of this network is to match members of the public who have volunteered for dementia research with studies that suit them. This will help researchers find out as quickly as possible whether a potential treatment is likely to work or not.

Lastly, the Experimental Medicine Incubator supports a wide variety of research projects that investigate the root causes of dementia. One strand of research is looking in depth at how to prevent dementia caused by issues with blood vessels, such as vascular dementia.

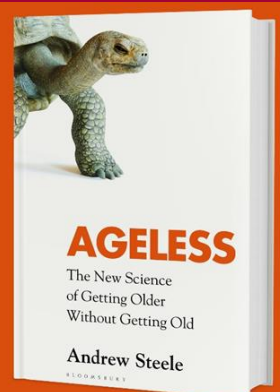
In addition, DPUK will continue to support its Stem Cell Network and Imaging Network, both of which provide researchers with important tools needed to study dementia. Scientists can access stem cells – cells which can grow into different cell types– from the Stem Cell Network and brain scans taken at any of our eight scanners in our Imaging Network.

Through this innovative mix of workstreams, DPUK is helping researchers identify and develop treatment and prevention opportunities to rid the world of dementia.

Written by Josie Clarkson

Getting older without getting old

'Ageless', a recently published book by [Professor Andrew Steele](#), demonstrates just how far the science of ageing has come. Steele explores whether the process of ageing - the leading cause of death and suffering - is necessary. In an accessible page-turner of a book, the author lays out 10 hallmarks of ageing then looks at what we know about how to treat them. The book gives reason for optimism that we may find ways to live more of our later years in good health in the not-too-distant future.



Written by Shona Forster

Opportunities to take part in research

New Therapeutics in Alzheimer's Disease ([NTAD](#)) study

Using advanced brain scans and memory tests, this study hopes to identify the earliest features of Alzheimer's disease, observe disease progression over time, and develop new ways to measure the effectiveness of future treatments.

To take part you need to:

- have a diagnosis of either Mild Cognitive Impairment or early Alzheimer's Disease
- be 50 – 85 years old
- have no contraindications to undergo a MRI scan

Contact: Jemma Pitt
jemma.pitt@oxfordhealth.nhs.uk, or
telephone 01865 613126

HOMESIDE study

If you have a diagnosis of dementia, or care for with someone with dementia, you may be interested in participating in this research project.

The HOMESIDE research study will investigate the effects of music and reading for people living with dementia and their caregivers. We will train caregivers to deliver music or reading activities with the person they are caring for. The activities aim to decrease behavioural and psychological symptoms of dementia, as well as improve the quality of life and wellbeing of people living with dementia and their caregivers.

No prior reading or music skills required.

Contact
dementia.research@oxfordhealth.nhs.uk or
telephone 01865 902694 for more information.

MICAD study

The [MICAD study](#) investigates how well a new drug, JNJ-40346527, affects a type of brain cell called microglia, which are involved in the central nervous system's immune defence. Reducing the number of microglial cells may be beneficial in slowing the progression of Alzheimer's disease.

To take part you need to:

- be 50 years old or more
- have a diagnosis of mild cognitive impairment

Contact: Michael Ben Yehuda,
Michael.BenYehuda@oxfordhealth.nhs.uk
or telephone 01865 613113

PATHFINDER study

Pathfinder is a randomised controlled trial (RCT) which is looking at a newly adapted therapy Problem Adaptation Therapy (PATH) for people experiencing dementia and depression.

To take part you need to :

- be over 50 years old
- have a diagnosis of Alzheimer's dementia
- be experiencing low mood, or symptoms of depression (sadness, distress, anxiety)
- and have a caregiver who can support you in the therapy.

Contact
dementia.research@oxfordhealth.nhs.uk or
telephone 01865 902694 for more information.



Alzheimer's Research UK (ARUK) public online event – 17 June 2021

“The journey from Reading to Oxford: Building roads to save memories” is a behind-the-scenes look at the dementia research labs in Oxford and Reading. Scientists from ARUK's Thames Valley Research Network will give you an insight into what life is like inside a busy lab, and they will be showing examples of their experiments and work. Jane Thomas, an Oxford poet, will be performing a piece that she has written specially for this event. Everyone will then be on hand to answer your questions during the live Q&A session. The event will take place online on Zoom, and it is free to attend. It is open to everyone, and no previous knowledge of dementia or research is required. Please register to attend by following the link [here](#).

Free brain health webinars

[Dementia Research Network Ireland](#) ran a series of free webinars between March and May. They included a wide range of information about brain health, from measurement to lifestyle guidance and therapies. They were recorded so you can watch them [here](#) at your convenience.

Think Brain Health

At the beginning of the year, Alzheimer's Research UK (ARUK) launched a new initiative – Think Brain Health – to encourage us all to take our brain health as seriously as we take our heart health. [Think Brain Health](#) has a home on the ARUK website where you can find lots of great information about how your brain works, how to [reduce your risk of developing dementia](#) as well as details of the [latest research](#).



Help shape research into the health and wellbeing of people with Mild Cognitive Impairment (MCI)

In the coming weeks we are embarking on a Patient and Public Involvement (PPI) project to better understand the needs of people following a diagnosis of MCI. We are particularly interested in how ‘social prescribing’ might play a role. Social prescribing is the process of a GP referring a patient to a ‘Link Worker’ who is trained to help them connect with services in the community that may help them with non-medical issues. Non-medical issues might include a sedentary lifestyle, social isolation or financial problems. If you are interested in getting involved, please email Shona at shona.forster@psych.ox.ac.uk for more information.

Alzheimer's Society “Joke's on You, Dementia”

An hour of comedy to benefit Alzheimer's Society took place online on 11th March. It was hosted by Hugh Dennis and involved comedians such as Steven Bailey, Jo Brand, Lucy Porter and Eshaan Akbar. It is [now on YouTube](#).



Remember our new website is at
OxfordHealthBRC.nihr.ac.uk/our-work/oxdare/

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