

OXDARE NEWSLETTER

Oxford Dementia and Ageing Research

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Oxford Dementia & Aging Research

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Since OxDARE's summer newsletter, the COVID-19 pandemic has continued to develop and affect all of our lives. You can find the latest news on the University of Oxford's coronavirus research here.

There is now a wealth of research into COVID-19 and it's effects. Members of the OxDARE team have been working on a study looking into the effects COVID-19 has on the body, specifically investigating effects on the brain (page 3). We know that many services have suffered due to the pandemic, but an exciting new service combining both research and clinical provisions has managed to go from strength to strength despite this (page 4)

Everyone has had to adapt to life post COVID-19 and the field of science communication is no different, gone are the days of in-person conferences and networking! See page 5 for some information on an exciting virtual event. OxDARE principal investigator (PI) Vanessa Raymont also gave us an insight into how her role has had to adapt during the pandemic (page 6) and new research assistant Emma Craig explained what it was like to start a new job during this time (page 3).

We know that in order to find effective treatments we need to research the many factors that contribute to the diseases that cause dementia, and this must continue despite setbacks due to the pandemic. An ambitious study investigating a range of predictive factors in the development of Alzheimer's has been able to begin recruitment recently (page 7).

Find out about OxDARE's new digital home on page 8!

The Impact of COVID-19

Alzheimer's Research UK have reported that over a quarter of people who have died with COVID-19 in England and Wales also had dementia. Research has shown that there is a link between an Alzheimer's disease risk gene and severe symptoms of COVID-19, but it is still unclear why this group is being so badly affected. Suspected contributing factors include the high rates of infection in care homes, a reluctance to seek medical attention, and the impact of lockdown measures such as an increase in social isolation. You can find out more about the efforts being made by Alzheimer's Research UK to tackle the issue here.

The pandemic has also had a negative impact on the field of dementia and aging research in a number of ways, but there have also been massive efforts to adapt research projects to go partially or fully remote and, during the first wave, clinical researchers were redeployed to help with the amazing effort to research COVID-19, including potential treatments and the vaccines. Alzheimer's Research UK reports that 95% of researchers have had projects delayed due to COVID -19 with 20% having projects cancelled completely. More worryingly 72% of researchers have reported that future funding opportunities have decreased. However, after the first wave there has been a huge effort to enable research projects to continue inperson activities with additional safety measures and many OxDARE related projects have been prioritised for re-starting.

Research from the Association of Medical Research Charities has found that on average charities are predicting that it will take over four years before their spend on UK university-based research recovers to normal levels. Obviously this is a worrying time for the future of dementia and ageing research and Alzheimer's Research UK have put a call out to the government to deliver on its promise to double funding. You can find out more about this here. Reassuringly, the National Institute of Health Research has reiterated their commitment to continuation of urgent public health research and dementia research is included within this.

COVID MEG Study

The Oxford Centre for Human Brain Activity is part of a new study called 'Capturing Multi Organ Effects of COVID-19 (C-MORE)' which is investigating the potential effects COVID-19 has on the body. Specifically, researchers are interested in the effects COVID-19 has on the brain as it has been found that ~36% of hospitalised patients had an adverse reaction that could cause long term neurological effects [1]. Therefore, by using functional brain scanning, researchers hope to have a better understanding of any brain abnormalities that are associated with the infection. As part of the C-MORE study, participants are being invited to have a Magnetoencephalography (MEG) scan, which measures brain activity on a millisecond level. This type of scan is non-invasive, and volunteers are sat up-right in a chair with the scanner above their head. The team in Oxford hope that the results from this study will lead to other Universities conducting similar scans.

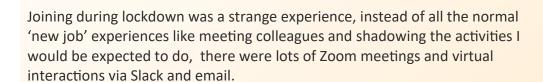


Picture of MEG scanner

Written by Jemma Pitt, sources: [1] Mao et al., 2020.

What is it like joining the OxDARE team during a global pandemic?

Emma Craig joined the OxDARE team in May as a Research
Assistant, principally working on the Deep and Frequent
Phenotyping study. Here are her thoughts on joining the team and
starting a new job during a pandemic.





When I joined the rest of my team were all working remotely, as study visits were all on hold and staff were not yet permitted to work on site. This was a bit of a shock to the system for me as I had previously been working in an NHS research team so had been going into a very busy work environment right up until leaving. Fortunately, I was able to access most of my mandatory training online easily, and the rest of the team were very welcoming. There was even a social Zoom meeting with the team where we all took part in a quiz which was a really nice way for me to be introduced to everyone.

It was difficult to be in 'limbo', unable to see participants. Whilst we know that the over 60s are at a greater risk of COVID and therefore we need to keep them as safe as possible, we are also aware of how important our research is, so it was tough to be unable to conduct any study visits.

In late August we were able to start contacting people again and it was great for me to actually be on site and see some participants! With the vaccines now being rolled out, I am looking forward to being able to schedule more participants.



Oxford Brain Health Centre celebrates high levels of research participation and positive feedback from patients

More than six months since opening, the Oxford Brain Health Centre is going from strength to strength in tod by opening and operating during the pandomic

spite of the challenges presented by opening and operating during the pandemic.

The Brain Health Centre is a new integrated research and clinical environment providing high-quality assessments for patients. The Centre integrates research into clinical services to improve the diagnosis and management of mental health disorders in a way that can rapidly be implemented to provide improved care for patients. At its launch in August the Oxford Brain Health Centre (BHC) had already overcome seemingly insurmountable obstacles to get up and running at a time when much non-covid research had been paused due to the pandemic. Thanks to the BHC's dual clinical and research function, along with the remarkable efforts of its staff, the Centre was able to continue its essential public health research without interruption during the second lockdown.

Since its opening 33 patients have been seen at the Centre and impressively more than 96% of those attending have agreed to take part in research, whether by joining the research database or completing additional assessments during their visit. Patient feedback has also been overwhelmingly positive with attendees remarking that the experience was 'much better than expected' and that their appointment was 'really helpful and good for self-confidence'.

The Centre is already having an impact on the clinical service. Dr Vanessa Raymont one of the Brain Health Centre's investigators says 'It is encouraging that this novel and ground-breaking service development is providing information that is already improving clinical diagnoses and management. As we aim to continue and expand this pilot, we hope for yet more positive outcomes for patients.' She also believes that the BHC will play an important role in the next steps of dementia research and care, saying 'The BHC is a vital step in terms of adapting to the new needs that disease modifying drugs for dementia will bring, and allows us to really start working on how we reduce peoples risks of developing dementias - a long overdue change in clinical services'.

Find out more about the Brain Health Centre here.

Brain Link 2020

Virtual science communication has taken centre stage this year, replacing public events cancelled in the pandemic. Although this move online has disadvantaged some older and economically disadvantaged groups in society [1], it has encouraged others to use the internet in new ways and more frequently; Ofcom reports that 61% of online adults aged 65+ years were making at least one video call each week in May 2020, up from just 22% in February [2]. 'Skype a Scientist', a service that connects scientists with groups of adults or children around the world, has seen its participating scientists escalate from 1,500 pre-pandemic to almost 6,000 now, with live sessions increasing 5-fold [3].

So it's good to see that our own meet-the-scientist event, Brain Link, organised by the University of Oxford and the Wellcome Centre for Integrative Neuroimaging, enjoyed similar success as it went online for the first time in 2020. Brain Link's purpose is to engage members of the public who may be interested in helping to design new neuroscience research through 'Patient and Public Involvement (PPI)'. Scientists participated across 6 themes of stroke, dementia, mental health, movement disorders, vision and pain. They gave a short talk, then met with attendees in breakout rooms for a discussion. We are delighted that 63% of attendees in the breakout rooms volunteered to become PPI contributors, one of them for OxDARE.

Feedback from both researchers and attendees concluded that the format resulted in valuable and enjoyable conversations. Next year the organisers feel that a moderator may help with the management of breakout sessions and they intend to allocate more time to this section of the event. For any enquiries about Brain Link, please contact comms@win.ox.ac.uk

Written by Shona Forster, sources: [1] The Centre for Ageing Better (2020), 'How has COVID-19 changed the landscape of digital inclusion? Available from: https://www.ageing-better.org.uk/publications/how-has-covid-19-changed-landscape-digital-inclusion.

[2] Ofcom (2020), 'UK's internet use surges to record levels'. Available from: https://www.ofcom.org.uk/about-ofcom/latest/media/media-releases/2020/uk-internet-use-surges

[3] Forrester, N. (2020) 'How the coronavirus pandemic is changing virtual science communication'. *Nature*. Available from: https://www.nature.com/articles/d41586-020-02075-0

Think Brain Health

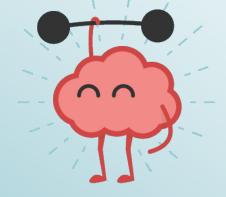
The way forward for brain health?

A 2019 report, "<u>Time matters: a call to prioritize brain health</u>", presents a useful lay summary of the current state of knowledge about neurodegenerative diseases and related healthcare practices. It makes recommendations about what healthcare professionals, policymakers, researchers and the general public could do to promote healthy brain ageing and potentially reduce disease or delay its progression.

A 10 to 20 year window in mid-life is identified as an important opportunity for individuals to tackle a series of factors which may reduce the risk of neurodegenerative diseases; they include exercise, a healthy diet, not smoking and moderating alcohol consumption. The authors also point to the importance of controlling hypertension, obesity & diabetes.

The report is written by an international multidisciplinary group of experts and endorsed by organisations such as Alzheimer's Disease International, Alzheimer's Research UK and the Alzheimer's Society. They have formed an initiative called "Think Brain Health" and the website can be found here.

Think Brain Health also held a virtual conference in November 2020, which you can find out more about <u>here.</u>



Written by Shona Forster

Meet Dr Vanessa Raymont a Senior Clinical Researcher, Honorary Consultant

Psychiatrist and Director of the Oxford Brain Health Clinical Trials Unit and also a Principle Investigator (PI) for OxDARE trials



What do you think the impact of the pandemic has been on dementia and ageing research?

Things have changed such a lot since the pandemic started, it's hard to know where to start. All non-COVID research was paused in March last year and didn't restart until July. After that time all research sites met to prioritise which studies to open first and assess any risks. This review meant a lot of studies didn't actually restart until September or later, but we tried hard to juggle the need to continue with all research as well as the risks of participants coming to take part in studies. There was also less access to research facilities as they were also all delivering the amazing research efforts that gave us treatments and vaccines for COVID-19. So in reality, we have been left with



having to deliver dementia and ageing research in less time with less resources, as we have really tried to keep staff on board even through the lockdown periods. As we have had further periods of lockdown, the pressures have increased and I think for the older population in particular, it has had a dramatic and detrimental effect on their confidence and ability to travel and take part in research.



What has been the impact for you as a PI/how has your role had to change and adapt?

Aside from trying to protect our participants and staff, it has been a real challenge not knowing when we may deliver studies or when results could be translated into clinical services. While COVID-19 has obviously presented an incredibly urgent clinical need, the need for dementia research has not gone away and it's important to be aware that COVID-19 has killed about as many people last year as Alzheimers dementia does every year. All principal investigators of research have had to review their studies to see if any visits could be delivered in other ways, such as via remote consenting or assessments. This has had to be balanced with the possibility that such assessments could be less sensitive or inaccessible to some. As studies have restarted, we have also had to think about conducting more risk assessments for individual participants to minimise the risks for people coming to sites. On top of this, most of our research meetings and discussions are now all happening remotely. In some ways this makes meetings easier to schedule and attend, but we have definitely lost out on some of the subtle interactions we have as teams, that support both our work and each other.



What is important to focus on in dementia and aging research now that we are able to start up non-covid research again?

I think that while the issues of need in dementia research have not changed, how we may best deliver these post-COVID has. Clinical services have often shifted at least some of their appointments to video calls or the phone, and we may not see these changes being completely reversed, at least for some time. We need to focus on how much we have achieved with the success of COVID vaccines and learn from these in terms of how we can deliver research more effectively and efficiently in the future. While we may well need to look even more closely at whether we can do more consents or assessments remotely, we also need to look at whether patients, participants and their families like this 'new normal' for research.



What are your predictions for the future now that there are approved vaccines?

We have always been incredibly fortunate to have massive numbers of immensely altruistic and enthusiastic participants volunteering to take part in dementia and ageing research. But I think everyone will remain very cautious about travelling to and visiting research sites for some time, especially in the older age group. But I also think people remain very supportive of this incredibly vital research and we have had large numbers of people still willing to come in for visits, which is humbling.



What are biomarkers?

The simplest definition of biomarkers is that they are measurable indicators of the presence or severity of a disease. For example, when

cerebral spinal fluid (CSF) is sampled and shows the presence of beta amyloid (the major component of amyloid plaques in the brain, as shown in the <u>Summer 2020</u> newsletter) this is considered a biomarker for Alzheimer's disease.



My Father in his Coracle

I stand at the edge of the Lethe, clinging to a short rope. Calling your name.

Let me moor you.

Stop the burbles and drift, calm the falls of choppy syntax, stop the vowels tumbling into a spray of words.

You are fishing for basics, chumming for the who, what, who, where, of life.

Laying night lines along familiar faces and day poles for trout.
Turning Taf, Towy and Teifi over and over with your paddle.

Your hours slow like pond weed, your own reflection forgotten.

You sit, cradled by lichen and willow in your bulrush boat-for-one.

The Deep and Frequent Phenotyping study

The Deep and Frequent Phenotypying study (DFP) will recruit 250 people from across the UK who are over 60 and in good health, but with a family history of dementia. DFP aims to combine both established and novel biomarkers (see left) to identify a biomarker set that can be used in future trials. Volunteers will undergo a range of tests over a year-long period, including brain scans, tests of memory and thinking, eye imaging, and blood tests. They will also use technology such as smart watches to measure movement, gait and ongoing cognitive abilities. This will be the most comprehensive set of assessments ever completed in this group of people.

The OxDARE team have already begun recruitment into DFP although they have faced significant barriers due to the pandemic. There have been several successful screening visits, however with the second more severe peak in COVID cases arriving in December there have been more delays whilst the process for safely carrying out visits is finalised.

You can read more about the study <u>here</u> and contact the team via dfp.oxford@psych.ox.ac.uk

Jane is a poet based in Oxford who is currently writing a poetry collection about Alzheimer's. She draws on her experience of caring for her father but also looks at the condition through the angles of memory, identity and language. Her Alzheimer's poems have been published in leading literary magazines and she was commended in The Rialto this year. She has run workshops for people with dementia and carers and she volunteers regularly for the Alzheimer's Society. She is keen to hear from any researchers, academics or clinicians who can see a place for poetry in expanding, engaging or amplifying their work. You can find out more about her at www.janethomas.org



Potential New Target to Prevent or Delay Dementia

Researchers at the University of Oxford and University College London investigated 542 older adults who received two measurements of aortic stiffness, at 64 years old and 68 years old. Subsequent cognitive tests and brain magnetic resonance imaging (MRI) scans assessed the size, connections and blood supply of different brain regions.

The body's largest artery (the aorta) gets stiffer with age, and the study found that faster aortic stiffening in mid-life to older age was linked to markers of poorer brain health such as reduced structural connectivity between different brain regions and worse memory.

Medical interventions and changes of lifestyle made earlier in the lifespan could help to slow down arterial stiffening. In an ageing society where we expect a near tripling in the number of people living with dementia by 2050, identifying ways to prevent or delay its onset could have significant societal and economic impact.

Dr <u>Sana Suri</u>, Alzheimer's Society Research Fellow, Department of Psychiatry, University of Oxford, said "Our study **links heart health with brain health**, and gives us insights into the potential of reducing aortic stiffening to help maintain brain health in older ages. Reduced connectivity between different brain regions is an early marker of neurodegenerative diseases such as Alzheimer's disease, and preventing these changes by reducing or slowing down the stiffening of our body's large blood vessels may be one way to maintain brain health and memory as we grow older."

Dr <u>Scott Chiesa</u>, Research Associate at the UCL Institute of Cardiovascular Science, said, "With no cure for dementia, there is an increased focus on understanding how to prevent or delay its onset. Importantly, our study helps us understand when in the lifespan it will be best to target and improve cardiovascular health to benefit the brain."

Adapted from full article <u>here</u>

Dementia Enquirers Programme

Whilst academics increasingly involve people with lived experience of dementia in the design and communication of research, people living with dementia rarely have the opportunity to lead *their own* research projects. The **Dementia Enquirers** programme from the Dementia Engagement and Empowerment Project (DEEP) aims to address this using a new approach to research that is led and controlled by people living with dementia.

Funded by the National Lottery Community fund, the Dementia Enquirers programme will support 20 DEEP groups to identify research topics, plan and undertake their own research. Projects already underway address topics such as having to give up driving and use of virtual assistant artificial -intelligence technology, such as Alexa.

In addition to developing and conducting research, the Dementia Enquirers programme has produced a set of dementia-friendly guides to carrying out research and ethics gold standards for dementia research, available to download online.

Dementia Enquirers is led by 6 Pioneers, all people living with dementia, in collaboration with Innovations in Dementia. In this webinar hosted by the NIHR's Dementia Researcher network, Philly Hare — co-director of Innovations in Dementia, and George Rook — Dementia Enquirers Pioneer, discuss the Dementia Enquirers programme, and progress and impact so far: https://www.youtube.com/watch? v=TYcoHJiDJrM&feature=emb_title

More information on the Dementia Enquirers programme, including links to the research guides, can be found here: https://

www.dementiavoices.org.uk/dementia-enquirers/

Written by Clare O'Donoghue



OxDARE is pleased to announce its new <u>digital home</u> on the Oxford Health Biomedical Research Centre website. This move reflects OxDARE's role in fostering connections and collaborations between ageing and dementia researchers within, and beyond, the Oxford Health Biomedical Research Centre.