

News from the South Wales MS research team – January 2021

Welcome to our annual newsletter which includes information on work we've recently published, and studies we're currently working on. Our research is based on data and samples from the 'SNOWDONIA' project and the Welsh Neuroscience Research Tissue Bank. Many of you have contributed to these studies, so thank you to all our participants!

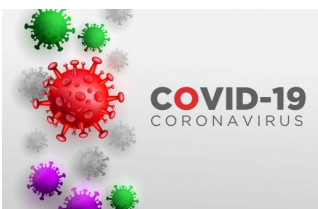
SNOWDONIA (formerly 'Epidemiology of MS Project')



This longitudinal study which began in 2006 was re-approved by the Regional Ethics Committee in 2019. Ethical requirements mean that we need to update consent of our participants. We are trying to re-consent as many people as possible by post. If you are still happy to take part in this research study, **we would appreciate it if you could complete the enclosed consent form and return in the envelope provided**, along with your annual questionnaire. If you have not received a consent form this means we have already approached you to re-consent at a clinic visit or via post.

2020 was an unusual year, but we continued to collect data via telephone and in-person clinic appointments. We also collected biological samples where people attended appointments in-person. Although we were unable to send annual questionnaires during the first half of the year, we are now back up and running. However, we have received approval to use an online version of the questionnaire. If you would prefer to complete the questionnaire online in future, please tick the box and provide an email address on Page 1 of the enclosed questionnaire.

COVID-19 study



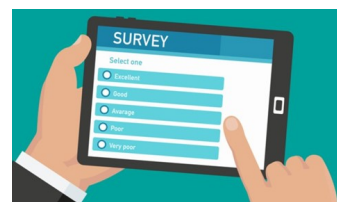
During the first wave of the pandemic you may have received a questionnaire asking about your health and wellbeing in relation to COVID-19. This data is

currently being analysed and will provide us with a picture of how the pandemic has affected people with MS in southeast Wales.

We are now building on this data with further research looking at patterns of COVID-19 disease in people with MS. Importantly, we aim to investigate whether COVID-19 infection in people with MS relates to disability level, disease-modifying treatments, and other factors. We are also interested in looking at the response of people with MS to the COVID-19 vaccines.

Participants will be asked to provide a 'dried blood-spot', which can be sent through the post and tested to see if they might have had COVID-19 in the past. You may already have received a study pack, so many thanks if you have already taken part in this important research. If you have not received a pack and would like to take part, email msdata@cardiff.ac.uk.

Working with MS during COVID-19 (collaboration with Nottingham University)



COVID-19 has had a significant impact on lives and livelihoods. The national lockdowns and social-distancing rules have forced us to change the way we work and how we interact with others.

The University of Nottingham (in collaboration with Cardiff University, University of Leeds, and Queen Mary University of London), are conducting a study to understand how COVID-19 has impacted the employment of people with MS.

We are looking for volunteers to complete an online survey that takes between 20-25 minutes and explores your experiences of working during this year. The survey includes questions about the support that you received at work (if any) during the national lockdown, and what further support you might have liked to receive. Your answers to the survey questions are anonymous. If you would like to take part in the survey, please see the separate advertisement with a link to the survey.

For information on the C&V Neuroinflammatory Service and Covid-19 information see:

<https://cavuhb.nhs.wales/our-services/ms-multiple-sclerosis/>

Serum neurofilament and outcomes in MS



Neurofilament-light (NfL) is a component of axons, which are the nerve fibres that carry signals between your brain and other parts of your body. The presence of NfL in the blood is thought to indicate axonal damage.

This study used blood samples from people at the time of their diagnosis with MS. We looked at whether NfL measured in these samples could help predict future clinical outcomes up to 5-years later. We found that NfL levels at diagnosis were associated with the level of disability at this time. However, NfL levels at diagnosis did not predict future disability when we took into account the age of participants, and other factors such as whether people were taking disease-modifying treatments.

We concluded that blood NfL levels at diagnosis are of limited use for predicting future disability. However further studies are needed to decide if blood NfL measurements at diagnosis may provide other useful information. See the full abstract: <https://tinyurl.com/y3uej7>.

Meet a Team Member: Professor Neil Robertson



Neil leads the MS research team, and has been working in Cardiff since 1999. Over the last 20 years he has been instrumental in building a comprehensive clinical service for MS across south east Wales, which integrates with academic research.

Neil says: "I consider myself very fortunate to have been able to work with some very talented neurologists and scientists over the years. As clinical academics, we have a unique role in interpreting the problems that we see people with MS encounter, into the right questions for science to solve. Our success in south Wales is entirely due to the enthusiasm and participation of our people with MS for which we will always be very grateful. It seems only yesterday that we started with a very small MS team that has now grown to more than 30 people from a wide range of backgrounds, all dedicated to helping people with MS. Key to that success has been creating a supportive and happy working environment for the team and some balance to life. For me that has been making time for family (including our new puppy Daffodil!), keeping active and trying to keep up with my children and wife who always seem to be exercising in some way. If the truth be known though, sometimes, I like to just sit and watch the rugby."

Eligibility for disease-modifying therapy in PPMS

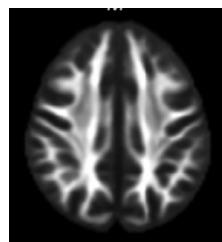


In 2019, ocrelizumab became the first drug to be licensed for the treatment of adults with primary progressive MS (PPMS). However, only people with PPMS who meet certain clinical and MRI criteria are allowed to receive ocrelizumab.

We analysed data from our population of people with PPMS to calculate the proportion who would have met the eligibility criteria for ocrelizumab i) at the time of their initial diagnosis, and ii) currently. This information will help to plan the services required to introduce ocrelizumab in PPMS. We found that 16% of people with PPMS fulfilled all eligibility criteria at the time of their initial diagnosis. In people who currently have PPMS, 5% fulfilled eligibility criteria. We found many people were not eligible due to lack of a recent MRI.

We therefore estimated the proportion of people with PPMS who would be eligible to receive ocrelizumab if they had an up to date scan: approximately 40% of people at diagnosis and 15% of our current PPMS population. See the full abstract: <https://tinyurl.com/y5hkju2>.

Predictors of recovery of function in MS



Currently, predicting recovery of function in individuals with MS is based on clinical expertise. More accurate prediction of a person's capacity for functional improvements could allow more personalised strategies for rehabilitation.

This study investigated factors that might predict a person's potential for recovery of visuomotor function (where vision and movement work together to produce actions). 118 people with stable MS were assessed for disability and had a detailed MRI of the brain. They then did 4 weeks' practice of a task that measured arm/hand performance. Improvement in performance on this task was used as a measure of functional recovery.

The study found that younger age, better visuo-spatial abilities (ability to relate visual information to the surrounding space), better hand dexterity, less severe disease burden, and use of disease-modifying treatments predicted functional improvements. MRI measures did not predict improvement in task performance over and above these measures. See the full paper: <https://tinyurl.com/y58787ab>.



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