

News from the South Wales MS Research Team – Feb 2023

Welcome to our latest research newsletter. Thank you to all our participants who have continued to contribute data and samples this year to the SNOWDONIA project (formerly 'Epidemiology of MS' project) and the Welsh Neuroscience Research Tissue Bank. Your support makes this research possible!

SNOWDONIA (formerly 'Epidemiology of MS' project)



Our ongoing longitudinal study of MS in South East Wales continues to collect clinical information and blood samples from participants, and this data is used in many of our research studies. This includes information collected through online and postal questionnaires, so we do appreciate you filling them in!

We are still re-consenting participants to SNOWDONIA if they previously consented to the 'Epidemiology of MS' project. As such, you may receive (or have already received) a letter asking you to complete a consent form, or you may be approached at a clinic appointment. So far we have over 600 participants who have consented to take part in SNOWDONIA. If you have any questions please contact msdata@cardiff.ac.uk.

Neuro-inflammatory service website



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Our occupational therapist Jo Rutkowska has worked hard with the IT team to update the neuro-inflammatory service webpages (link below). The webpages provide information about the Cardiff MS service, and also contain a section on MS research. This includes information on clinical trials that are currently open for participation.

Patient-Reported Outcome Measures



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Cardiff and Vale Health Board is working with *My Clinical Outcomes* (www.myclinicaloutcomes.com/nhswales) to start routinely collecting Patient-Reported Outcome Measures ('PROMs') online. PROMs allow people to report their own health outcomes, such as quality of life and employment status.

The neuro-inflammatory service is expecting to roll out collection of PROMs in the summer (2023). A link to register with My Clinical Outcomes will be sent to you by the NHS. Once registered, you will be able to complete information relating to your health. This can be viewed by you and your clinical team, and used to track your health and wellbeing over time. It could help inform your MS management by the clinical team.

Atlas of MS (www.atlasofms.org)



The 'Atlas of MS' is the most extensive worldwide study of MS epidemiology (how common a disease is within a population, as well as its causes and risk factors). Our research team leader Professor Neil Robertson provided data and expertise to the international MS Atlas initiative. As a result, an interactive website (www.atlasofms.org) now allows exploration of the number of people with MS in different countries, as well as hosting additional resources for people with MS.

For information on the Cardiff and Vale Neuro-inflammatory Service see:

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

A contemporary study of disability in multiple sclerosis in South East Wales



Understanding how disability evolves in MS is essential for managing the disease in individuals, and for planning studies of new treatments.

Data from over 2000 people with MS was used to analyse disability progression, and variation in disability. Disability was based on the Expanded Disability Status Scale (EDSS) score, which is usually based on an examination by a neurologist, and ranges from 0 to 10.

The data suggested that compared with earlier (historic) populations, it is taking people with MS longer, on average, to reach certain levels of disability (e.g. needing a stick to assist with walking). This suggests that improvements in MS treatments and general healthier lifestyles seem to be affecting long-term outcomes in a positive way.

In addition, we found that people with MS who have low levels of disability seem to vary the most (with scores that can up or down over time), whereas people with higher levels of disability stabilised, with longer time spent at each EDSS level.

Read the abstract at <https://tinyurl.com/5cyukt55>.

Meet a Team Member: Dr Valerie Anderson

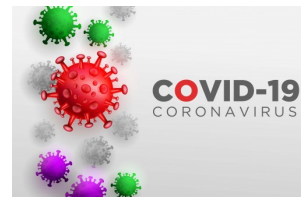


Valerie joined the research team in 2015 as a Research Assistant and is now Research Manager within the group.

Her work includes managing regulatory approvals for research studies, data management, and public engagement and involvement work. She also works on the DELIVER-MS trial, and contributes to the NEuRoMS and DECISive studies.

Away from work Val enjoys the outdoors, spending time with family and friends, and playing netball and tennis.

COVID-19: Assessing risk perception, patient behaviours & access to disease-modifying treatment



During the first wave of the Pandemic we surveyed our patients on how at risk they felt of COVID, their shielding behaviour, and the impact of the pandemic on employment and disease-modifying treatment (DMT).

We had 1000 responses, with 82% of people reporting they felt vulnerable to COVID. Feeling vulnerable was more common in people with higher disability scores and those receiving high-efficacy DMTs. People on high-efficacy DMTs were more likely to have had an interruption to their treatment (50%) compared to those on moderate-efficacy DMTs. Most people with MS experienced a change to their working environment, but were satisfied with the adjustments.

Read the research at <https://tinyurl.com/2s3cam7x>.

Carbon footprint of disease-modifying treatments



Medical trainee Matthew Upcott recently submitted an abstract to the Association of British Neurologists conference with work looking at improving the sustainability of delivering infusion

-based DMTs (alemtuzumab (Lemtrada[®]), natalizumab (Tysabri[®]), and ocrelizumab (Ocrevus[®]).

Data was gathered for building/energy use, travel, and procurement of equipment required to deliver an infusion-based DMT.

The carbon footprint to deliver a single-day of infusion-based DMT was 19.97 kg CO₂eq, the equivalent of driving 110km in a petrol car. Procurement of medical equipment was the highest contributor to overall emissions (69.3%).

This work will help to identify approaches for lowering the carbon footprint of infusion-based treatments. (NB. This work will not impact clinical decisions regarding appropriate DMTs for patients).