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Welcome to Issue 8 of the MS Ireland Research E-Zine, a dedicated platform for exploring the latest advancements in MS research. Our mission is to provide a comprehensive view of the ongoing scientific endeavours in the MS space and in each issue, we bring you in-depth insights, breakthrough discoveries, and research-driven knowledge to empower and enlighten individuals living with MS, their families, caregivers, and the broader MS community.

As we journey through the pages of this e-zine, you'll discover a wealth of information on various aspects of MS research. Our articles are carefully curated to provide a clear and concise overview of the research landscape. Whether you are a researcher, healthcare professional, or someone personally affected by MS, we aim to make this e-zine an invaluable resource for you.

This issue is jam packed with updates from both seasoned researchers as well as emerging talent in the space and includes an interactive section on **Page 15** in which you can catch up on our research content from 2023 as well as how you can get involved in MS research.

Pages 3-6 highlights the important work being done in the areas of cognition, anxiety and stigma associated with MS by researchers in both Maynooth University and University College Dublin.

Medical cannabis has been a hot topic in the MS space for many years, Dr Eric Downer provides an update on new avenues for the therapeutic use of cannabinoids on **Page 7**. **Pages 8-9** contain important updates in the areas of exercise and nutrition from researchers at both University College Dublin around the effects of a protein drink plus, online exercise classes on older adults with home care and those in Atlantic Technical University who are exploring people with MS's attitudes and perceptions regarding nutrition as a lifestyle behaviour in MS.

Page 10 contains insights into body image and sexual functioning in people with Multiple Sclerosis with updates on the ongoing work in the School of Psychological Sciences and Health in Strathclyde University to support people with MS with their language skills, to ensure they are able to communicate effectively for as long as possible to be found on **Page 11**.

Pages 12-13 contain updates from the MS Unit at St James' Hospital with **Page 14** highlighting exciting updates from the COB-MS Feasibility trial.

Finally, see some important updates from us at MS Ireland on **Page 15** with information on how you can get involved with MS Research. We would also like to highlight the Researchers Profiles section on our website. This section houses profiles for MS researchers across the country. It can be found here - <https://www.ms-society.ie/researchers-profiles> If you would like to have your profile added, please email alisonc@ms-society.ie to request a profile template.



Alison Cotter
Advocacy and
Research Officer



Dr Rebecca Maguire
Chair of Research Committee

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'MS Research' is the research eZine of MS Ireland. It exists to foster informed debate and comment about issues relating to MS research. The view of contributors are not necessarily those of the Society. No treatments or therapies should be attempted, or products used without qualified medical or professional advice.

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EDITOR & EDITORIAL
Alison Cotter

Stigma in MS

Dr Rebecca Maguire, Department of Psychology, Maynooth University



Although we would like to think that society is a lot more accepting of people with MS today compared to in previous generations, many people with MS (PwMS) may experience stigma in their everyday lives. Stigma can be defined as a set of negative or unfair beliefs that other people have about MS which, if experienced, may leave the person with MS feeling devalued. This stigma may come from others (e.g., employers, family, friends) or even, perhaps more often, from the person with MS themselves.

The experience of stigma may have a considerable impact on the psychological wellbeing and quality of life of people with MS, and, on a practical level, may act as a barrier to participation in numerous aspects of life. In addition, people who experience stigma or who fear stigma in relation to their MS may choose not to disclose their diagnosis to others, or, if they do choose to disclose their MS, may not be fully open about the range of symptoms that they experience. This may mean that they cannot avail of reasonable accommodations or support to which they are entitled. We are currently conducting some research that aims to investigate these issues. Specifically, in our study, we are exploring the extent and nature of stigma experienced amongst people with MS in Ireland and in other countries. Relatedly, we wish to examine the degree to which people with MS hide their diagnosis and symptoms from others. By collecting a range of information on the background and health of our participants, we will be able to determine if there are certain groups of PwMS who are more likely to experience stigma. We also are examining whether certain factors, such as MS acceptance and an individual's level of control over their MS, have any associations with stigma and concealment.

A strength of this project is that it is truly patient-led. As a person with MS myself who has not always been open about my diagnosis, I was motivated to explore whether others have had similar experiences. Beyond my own input into the project design, I sought advice from a panel of four other people with MS, who very graciously shared their experiences and helped shape the study focus. So far, it seems that study into this topic has been welcomed by others in the MS community, with preliminary findings suggesting that stigma is still an issue for many people with MS. Through our findings, we hope to be able to identify ways in which we can tackle stigma and create further supports for people who may fear disclosure of their condition to others.

At time of writing, we currently have recruited a number of participants for our anonymous survey, however we would love to get further input from additional people with MS. If you are interested in participating, please follow the link below to learn more. We look forward to sharing these findings with MS Ireland when they become available. Further details on study and how to participate can be accessed at www.ms-society.ie/research/latest-news-research/study-stigma-ms

Email: rebecca.maguire@mu.ie for further information

Acknowledgements: Thanks to research assistants Sowmya Shrivastava and Aisling Ahern for their help with the project, and to our PPI panel members.

Cognitive Reserve In MS

Clara Stein, Psychology PhD Student, University College Dublin, and Irish Research Council Scholar

Brain changes and cognitive difficulties

MS can lead to changes in the brain. These brain changes may be associated with cognitive difficulties. Around 60% of people with MS (PwMS) experience some level of cognitive difficulty, which may include difficulty with thinking quickly, following a conversation, or remembering a shopping list. However, brain changes alone cannot fully explain why some PwMS experience more cognitive difficulty than others. Some PwMS seem to be better able to compensate for brain changes. This may be in part due to 'cognitive reserve'.

The potential role of cognitive reserve

Cognitive reserve describes an individual's ability to adapt to brain changes. Thus, someone with greater cognitive reserve may be able to withstand the consequences of brain changes for longer. This concept of cognitive reserve was originally developed in the context of dementia research, but has since been investigated in various other contexts, including MS.

Cognitive reserve cannot be measured directly. Instead, researchers use proxy measures to assess cognitive reserve. Proxy measures include a person's educational and occupational achievements, and their engagement in a wide range of leisure activities (e.g., socialising, volunteering, exercising, reading).

It is proposed that we can help our brains to be more flexible and efficient by participating in these enriching everyday activities. Importantly, cognitive reserve can be built both before and after the MS diagnosis.

Unanswered questions

At this stage, we know little about how common MS symptoms interact with cognitive reserve. Many PwMS experience 'invisible symptoms', including fatigue, depression, and anxiety. Experiencing any of these symptoms may impact an individual's ability to engage in enriching activities. Unfortunately, invisible symptoms are still often overlooked, both in clinical practice and in research.

We try to address this gap in our research.

Systematic literature review

As a first step, we conducted a literature review of existing cognitive reserve research in MS. We found that over half of the studies only investigated cognitive reserve built prior to the MS diagnosis (e.g., pre-MS education and leisure). Of the studies investigating cognitive reserve built post-diagnosis, around half did not consider invisible symptoms when analysing the impact of cognitive reserve on cognitive outcomes.

What's next?

As a team of researchers and clinicians, we designed a study which will investigate cognitive reserve, whilst accounting for common MS symptoms. This research is being conducted in St. Vincent's University Hospital. We are also preparing for an additional piece of data collection accessible to PwMS across Ireland, so watch this space! We will be measuring various aspects of cognitive reserve, including education, occupation, and leisure activities. We are particularly interested in understanding the impact of cognitive reserve built both before and after the MS diagnosis.

To examine whether cognitive reserve protects against cognitive difficulties, participants will complete two brief cognitive assessments. Participants will also self-report

their experience of cognitive difficulties, fatigue, depression, and anxiety.

We are motivated to conduct this research, because understanding the factors that contribute to cognitive outcomes in MS will be important in developing interventions and services for PwMS with a goal of improving quality of care and life.



Anxiety in MS

Austin Fahy, PhD Candidate,
Maynooth University



Anxiety is a common experience for many people with Multiple Sclerosis (PwMS). The unpredictable nature of the MS disease course and the uncertainty surrounding future challenges can lead to feelings of anxiety or worry for many PwMS. Research has linked anxiety in PwMS to a number of unwanted outcomes, including increased levels of fatigue and decreased quality of life. Our research aims to understand the unique experience of anxiety for PwMS, highlighting the challenges faced and the strategies used by PwMS in managing and reducing anxiety.

To date we have completed three studies in this area. Following our first study, which reviewed existing research in the area (Fahy & Maguire, 2022), we conducted a survey with 287 PwMS to investigate whether anxiety can be linked to a set of modifiable factors (i.e. factors that may be amenable to change). Through this analysis, which was recently published (Fahy & Maguire, in press), we found that higher self-efficacy (how PwMS perceive their own abilities), lower intolerance of

uncertainty (how uncomfortable PwMS feel when dealing with uncertain situations), higher social support (how supported PwMS feel by family, friends and peers) and more frequent exercise habits were all linked to lower anxiety. In addition, we examined open-text survey responses to assess the impact that the Covid-19 pandemic had on anxiety. It is worth noting that 58% of our sample reported that their anxiety increased during this time. Themes from this analysis included descriptions of personal health concerns (related to both MS, Covid-19 and comorbidities of MS), social concerns (including challenges of reduced social interaction as well as anxieties about family health), responsibilities and additional external burdens (including anxieties about employment and responsibilities to dependants). However, it was interesting to note that some PwMS reported reductions in anxiety during the pandemic as well.

In our third study, we wished to explore the experiences of anxiety in PwMS in more depth. To do this, we conducted an interview study with nine PwMS in Ireland. We identified 5 key themes during this study; (1) Anxiety as a familiar experience, (2) The fluctuating impact of Covid-19, (3) Awareness that anxiety can be reduced, (4) The value of support, and (5) Need for personalised care. Interviewees reported the pervasive nature of dealing with anxiety as a PwMS and the considerable additional challenges faced during the pandemic. However, participants identified a set of strategies to successfully manage anxiety, including proactive strategies for dealing with issues that were perceived as actionable (e.g., exercise, information seeking) and acceptance and disengagement strategies for issues that were perceived as outside of their control (e.g., mindfulness, engaging in hobbies). However, there was an overwhelming desire for peer support expressed by participants, suggesting that engaging with other PwMS may be a helpful way to decrease anxiety.

Overall, our project findings highlight the unique experiences of PwMS with anxiety. There is clearly a need for more research in this area and further provision of supports for PwMS who may be experiencing this. In particular, peer support may be beneficial.

References:

- Fahy, A., & Maguire, R. (2022). Potentially modifiable associates of anxiety in people with multiple sclerosis: a systematic review. *Disability and Rehabilitation*, 44(26), 8201-8212.
- Fahy, A., & Maguire, R. (in press). Anxiety in People with Multiple Sclerosis during the Covid-19 Pandemic: A Mixed Methods Survey. *Rehabilitation Psychology*.

SUPPORTING PSYCHOLOGICAL WELLBEING

Supporting psychological wellbeing using connected health technology. A review of research evidence

Joan Alaboson, PhD
Candidate, Maynooth
University

We know that people with MS (PwMS) can experience numerous challenges which put them at risk of low psychological wellbeing. This can also be the case for family members who may act as informal caregivers. In our research, we want to identify ways in which the psychological wellbeing and quality of life (QoL) of PwMS and their caregivers can be better supported. One way in which this may be done is through the use of connected health (CH) technology.

During the COVID-19 pandemic, some health services and support organizations used CH technology to reach clients (e.g., through remote services provision such as video calls). There has also been a rapid growth in the use of apps that may be used to track and monitor health. However, not a lot of research has examined how effective these technology-facilitated approaches are in the context of MS.

Through my PhD research, I want to examine whether CH technologies can support psychological wellbeing and QoL in PwMS and their caregivers. For the first stage of this research, we recently completed a systematic review of literature in this area. By searching through 2,821 articles, we found 47 relevant published studies. These included a combined total of 6,453 participants, most of whom had relapsing remitting MS and could walk unaided.

We found that websites and teleconferencing platforms were the CH technologies most frequently employed in the studies reviewed. These interventions supported self-management (such as physical activity monitoring) cognitive training, telemedicine delivery and social support groups. While some studies found a positive impact of CH on psychological outcomes, there were mixed findings overall.

For example, QoL, anxiety and depression improved for PwMS in some self-management interventions such as digital diaries delivered via websites, but findings were inconsistent and often not sustained over time. Further, while QoL improved following physical rehabilitation exercises delivered via teleconference (such as video calling) this did not affect anxiety or depression. Interventions such as cognitive behavioural therapy also did not have a clear impact on psychological outcomes.

Just four studies in our review included caregivers of PwMS. For these, teleconference-mediated peer support and mindfulness interventions improved caregiver anxiety

but not depression. In studies collecting information on experiences, both PwMS and their caregivers shared generally positive feedback on support group participation, citing convenience and connectedness to other peers.

Overall, our review shows that, while technology has the potential to support psychological wellbeing and QoL for PwMS and MS caregivers, it is unclear how best to go about doing this. Findings also show that there is a need for further studies

exploring other MS types and their caregivers.



Receptors that take their Toll on MS: A new avenue for the therapeutic use of cannabinoids

Researchers at the Department of Physiology in the School of Medicine at Trinity College Dublin (TCD) are undertaking new projects to develop cannabis-based therapeutics that target key cellular mechanisms underlying Multiple Sclerosis (MS) pathogenesis.

Dr. Eric Downer leads the Translation Neuroimmunology Research laboratory at the Trinity Biomedical Sciences Institute (TBSI), conducting research in MS and related neuroinflammatory disorders. In projects funded by the Irish Research Council and the Provosts PhD Project Awards at TCD, the laboratory is investigating cellular targets with relevance to the pathogenesis of MS. The targets are toll-like receptors (TLRs), a family of receptors expressed on immune cells in the human body that act to detect and combat infection by microbes, most notably viruses and bacteria. These receptors control intricate inflammatory signalling responses within cells and tissues. For quite some time, a body of peer-reviewed published research has identified that these receptors are associated with the pathogenesis of MS. Indeed, data published from Dr. Downer's laboratory has shown that in immune cells isolated from people with MS, compared with immune cells from non-MS subjects, the TLR receptor signalling mechanisms are "switched on" in terms of their inflammatory status [1].

Following this discovery, the laboratory asked the following question: If inflammation controlled by TLRs on immune cells is heightened in MS, can novel therapeutics in the form of cannabinoids target these receptors to act as anti-inflammatories? Cannabinoids include the "plant-derived" molecules found in the plant *Cannabis sativa* L. (*C. sativa*), alongside a fascinating second cannabinoid group that incorporates the endogenous cannabinoids, commonly known as endocannabinoids. As discussed in a previous ezine issue, basic research continues to elucidate how the cannabinoid system is intricately linked to the function of the immune and nervous systems, and exciting data suggest therapeutic potential of the cannabinoid system in the human body.

In one of the latest research projects funded by the Provosts PhD Project Awards at TCD, Melody Cui Sun, a PhD student in the laboratory, is assessing viral signalling via the TLRs on endosomal compartments within immune cells. Endosomes are vesicles located within cells that act to sort intracellular cargo such as proteins among separate cellular compartments. These organelles also contain TLRs which recognize and respond to components of microbes (nucleic acids). Once microbes are recognized, these receptors

Dr Eric Downer, Associate Professor, Physiology, Trinity College Dublin

trigger cellular responses to combat the infection. Importantly, if this system of defense becomes offset or dysregulated, it can promote inflammatory or autoimmune responses. Melody is assessing the impact of plant-derived cannabinoids on such signalling networks.

Dr. Downer's team was also recently awarded an Irish Research Council Enterprise Partnership Scheme grant in partnership with Dr. Jack Prenderville, Director, Transpharmation Limited. This research will build on the expertise of Dr. Downer's team and Transpharmation's expanding inflammation service portfolio. Under this award, PhD candidate Almudena Otálora Alcaraz, is establishing assays to investigate novel therapeutics in human immune cells, initially focusing on the nucleotide-binding oligomerization domain-like receptor family, pyrin domain-containing 3 (NLRP3) inflammasome. The NLRP3 inflammasome has a well-established function in innate immunity. Importantly, the NLRP3 inflammasome is closely associated with the pathogenesis of neuroinflammatory conditions, and evidence suggests that the inflammasome may be a therapeutic target in disorders such as MS. This project is establishing inflammasome assays in cells associated with MS pathogenesis, and this suite of in vitro assays will provide a platform for assessing novel compounds (including cannabinoids) for anti-inflammatory efficacy. The overarching goal of this project is to define the role of the inflammasome in MS and to identify novel inflammasome inhibitors that have efficacy in cells from people with MS.

Dr. Downer said:

"It is hoped that these MS projects will provide evidence that various components of the hemp plant possess anti-inflammatory properties. We hope that this will broaden the therapeutic consideration of components of the cannabis plant, in addition to currently available cannabinoid-based medicines, in MS."



L-R: Dr. Jack Prenderville (Transpharmation Limited), Dr. Eric Downer (PI), Almudena Otálora Alcaraz (PhD), Melody Cui Sun (PhD)

Photo by: Aidan Kelly

1. Crowley, T., et al., Front Cell Neurosci, 2015. 9: p. 284.

EXPLORATION OF NUTRITION

Exploration of Nutrition and Multiple Sclerosis (MS): people with MS (PwMS) attitudes and perceptions regarding nutrition as a lifestyle behaviour in MS

Elaine Doran, Atlantic Technical University

Approximately 10,000 people in Ireland are living with Multiple Sclerosis (MS) and there is growing interest around diet and nutrition as a process for impacting MS progression and symptoms (Brenton & Goldman, 2016). However, the role nutrition plays with MS has not been extensively researched (Esposito et al., 2018) and this can lead to some uncertainty regarding best dietary or nutrition practices when dealing with MS.

Studies have shown a renewed interest over the last number of years regarding the role nutrition plays in the management of MS (Farfaglia, 2021. Sand, 2018).

There are studies reporting the benefits of particular diets, however, no one diet appears to be practiced internationally by individuals, but dairy, grains and ultra-processed foods appear to be avoided, and other research indicates the Mediterranean diet has a positive impact on Quality of Life (QoL) (Farfaglia et al., 2021).

Studies performed by Russell et al (2019, 2021), found that people with MS (PwMS) feel there is a lack of dietary advice after MS diagnosis and the study suggests health care professionals need to provide current and relevant information to people. PwMS are motivated to manage their disease proactively, also there is need for evidence-based dietary advice to be provided by dietitians and neurologists.

In Ireland, a research priorities survey carried out on 415 individuals in 2018 showed diet was ranked fifth out of ten topics when asked 'what research questions regarding MS would you like to see addressed' (MS Ireland). This indicates it is an area that people are extremely interested in.

A survey capturing PwMS perceptions and opinions has been distributed via MS Ireland. This survey is currently ongoing and the full results are expected to be completed by early next year. However, please see below for some information provided on what people living in Ireland feel could help improve PwMS experiences, surrounding nutrition and MS management.

Sample of main themes identified, for potential support improvement -

1. **Access to dietician/Regular contact with dietician**
2. **Clear information & More emphasis on the food/disease connection. Advice, earlier in diagnosis**
3. **Recommended sources that provide facts**
4. **Proactive support system/MS team**
5. **Leaflets and information links to food and lifestyle changes**
6. **Evidence based research**
7. **A holistic approach**

The main benefit of taking part in this research is having an opportunity to have your voice heard, and to give people (clinicians, researchers, policymakers) a chance to become aware of the current state for people with MS in Ireland and their perceptions concerning nutrition. This information will be crucial to gain individuals experiences with MS concerning nutrition and identify if there are appropriate supports in place for PwMS. It might also provide an opportunity to advocate for improvements in this area for the future.



PROTEIN AND EXERCISE PROGRAMME

Protein and Exercise Programme for Older Adults

Catherine Fallon – PhD student at University College Dublin

Researchers at University College Dublin are carrying out a study exploring the effects of a protein drink plus online exercise classes on older adults with home care. The study is being led by PhD student Catherine Fallon and supervised by Principal Investigator and registered dietitian Professor Clare Corish, Associate Professor Caitriona Cunningham (registered physiotherapist), and Assistant Professor Katy Horner (registered nutritionist).

The study is looking for people who may feel they lack the strength to perform activities of daily living like moving heavy objects, getting in and out of the bed or chair or struggling to walk up the stairs.

The POWER Study began in February 2023 to test the feasibility of a protein drink plus an online exercise programme to increase the nutritional status and muscle strength of adults (aged 70 and over) who are receiving home care. As people age, many do not eat sufficient amounts of protein while also reducing their physical activity. These changes can lead to a decline in muscle strength, which affects mobility and independence.

In October, 9 older adults who were receiving supportive home (two males and seven females) started the study. Information was collected at the home-based appointment on the body composition, muscle strength and quality of life. It is important to get an overview of an individual before conducting a research study to measure the differences (if any) after the study.

The participants began the twice weekly, online supervised resistance-based exercise programme via Zoom. Resistance exercises have shown positive results in community-dwelling older adults, contributing to improvements in physical function and quality of life. Assistance with Zoom is available throughout the study.

Half the participants were also asked to consume a protein drink twice a day. The protein drink is provided in 200 mL bottles with 20 g of protein and 10 µg of vitamin D. Protein, essential for building and repairing muscle, can be found in meat, poultry, fish, dairy, eggs, beans, peas, lentils, and nuts, and should be included in every meal. The recommended amount of vitamin D per day is 10-20 µg. Dietary advice was also provided through written materials (cookbooks, leaflets) available from the Health Service Executive to all participants. These resources offer valuable advice on meals that are sources of protein, leucine and vitamin D.

A second home-based appointment will be conducted, when the study is completed by the participants. The results collected from the study will service as a basis in understanding the effects of the protein drink and the feasibility in implementing online exercise programme to older adults receiving supportive home care on a larger scale. The PhD studentship is sponsored by Nutricia Ireland Ltd.



Body image and sexual functioning in people with Multiple Sclerosis

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This research was designed to explore psychological factors that may be related to sexual functioning in people with Multiple Sclerosis (MS). We know that a person’s sexual experience relies on a variety of factors such as adequate sexual functioning, and how a person’s feels about themselves. People with MS may be more inclined to experience issues with sexual functioning which can negatively impact their ability to engage in or enjoy sexual activities. Sexual dysfunction is a term that captures the wide range of physical and psychological issues that can have a negative impact on a person’s sexual experience. Symptoms can include vaginal dryness, issues with bowel and bladder, muscle stiffness and pain, and feelings of sexual inadequacy, for example. Previous research showed that psychological contributors to sexual dysfunction affected more people than some physical symptoms. Therefore, our research aimed to explore how a variety of factors may be related to sexual function, such as, body image and body awareness, symptoms of anxiety and depression, and quality of life.

Our research included a group of 104 people with MS. A control group consisted of 101 people without MS, or any other neurological or physically limiting condition. Participants were invited to complete an online survey that included a variety of questionnaires on the factors discussed. The group of people with MS were compared to those without MS to highlight and understand the differential experiences of people with MS so that interventions can be designed that cater specifically to their needs.

Main findings

- People with MS were more impacted by issues with sexual function than the control group, despite a majority of MS participants reporting only mild levels of disability.
- Those with MS who were not currently sexually active reported significantly more issues with sexual function than those who were sexually active. This suggests that issues with sexual functioning may impact on a person’s ability or desire to engage in sexual intercourse.
- People with MS were significantly more impacted by both anxiety and depression than the control group. Almost 60% of people with MS reported mild levels of anxiety, while a further 36.5% met the criteria for clinically significant anxiety. Over 12% of people with MS in this study presented with clinically significant levels of depression.
- High levels of anxiety or depression were associated with an increased likelihood of experiencing issues with sexual function.

- The study showed that people with MS felt more negatively about their physical appearance than the control group. Those with MS were also significantly less appreciative of their bodies and reported poorer bodily awareness than those in the control group.
- More negative body image, as reported by the MS group, was associated with more issues with sexual functioning. This is not surprising given that those who evaluate their bodies more positively generally have more sexual encounters with fewer sexual problems.

Conclusion

Overall, these findings suggest that a combination of factors including negative body image, and higher levels of anxiety and depressive symptoms may help to explain the sexual experience of people with MS, and the issues they might face. Given that issues related to sexual functioning are associated with a poorer quality of life, it is essential that interventions are designed and delivered to target these factors that are associated with sexual functioning.



Communication Survey for people with progressive motor conditions

Anja Lowit Professor, Speech and Language Therapy, School of Psychological Sciences and Health, Strathclyde University

People with MS often experience problems with their communication. Communication is not a single concept but breaks down into different parts. To say something, we first of all need to find the right words and then string them together into grammatical utterances. These processes rely on our language skills. We then need to produce a voice and coordinate our lips and tongue to articulate the words we want to express – this relates to our speech skills. Communication breakdown can be due to difficulties with either or both of these levels.



Traditionally, communication problems in MS and many other motor disorders have been considered to be due to speech problems and consequently this has been the focus of clinical research. More

recently, it has been recognised that they can also lead to language problems which appear to be closely linked to difficulties with thinking skills (cognition). However, to date there is no research evidence that guides clinicians in how to support their clients with their language problems. We are currently developing research proposals that investigate how best to treat language difficulties in people

with motor disorders. To make sure that our research actually targets issues that individuals find difficult, we have been asking people with a range of disorders what kind of problems they experience and to what degree they impact on their daily life.

Our survey asked people with MS, as well as Parkinson's, progressive ataxia and Multiple System Atrophy. We found that each group noticed difficulties across all cognitive, speech and language problems but not all carried equal weight. Our preliminary analysis of the 45 people with MS who completed our survey suggests the following: The most common complaint were cognitive problems which were reported by around 75% of respondents, with 42% indicating they occurred "frequently" or "always". Speech problems were less frequently reported but still present. About a quarter of respondents indicated issues with articulating sounds or their voice, but only around 10% reported this as a prominent problem. Slightly more people (34%) said they had problems with fluency, such as getting stuck on words, of which 17% said that this happened frequently or always.

In terms of language, nearly half of all respondents said they had problems with producing language such as finding the right word or constructing complex sentences, with 17% saying this happened frequently or always. Understanding of language was reported as a problem less often, with numbers similar to those for the speech problems above. The impact of these difficulties on daily life was mixed with some reporting major issues and others none at all, most

probably related to the severity of the problem.

As expected, the survey showed us that cognitive problems are common in people with MS and that they also experience issues with both speech and language. What was illuminating is that language problems appeared be more prominent than speech difficulties. This suggests that further research is indeed needed to develop approaches to support people with MS with their language skills, to ensure they are able to communicate effectively for as long as possible.



EVALUATION OF INFLAMMATION

Evaluation of Inflammation in the Peripheral Multiple Sclerosis Retina Using Ultra-Widefield Optical Coherence Tomography: A Pilot Study

Dr Hugh Kearney, Consultant Neurologist, St James' Hospital, Clinical Senior Lecturer Trinity College Dublin, School of Health Sciences

In this study we looked at the back of the eye (retina) using a new technique called ultra-widefield OCT. This study showed that it is technically possible to use this technology in people with MS. The reason we are interested in this is that previous studies have shown that changes can occur in the outermost parts of the retina in MS.

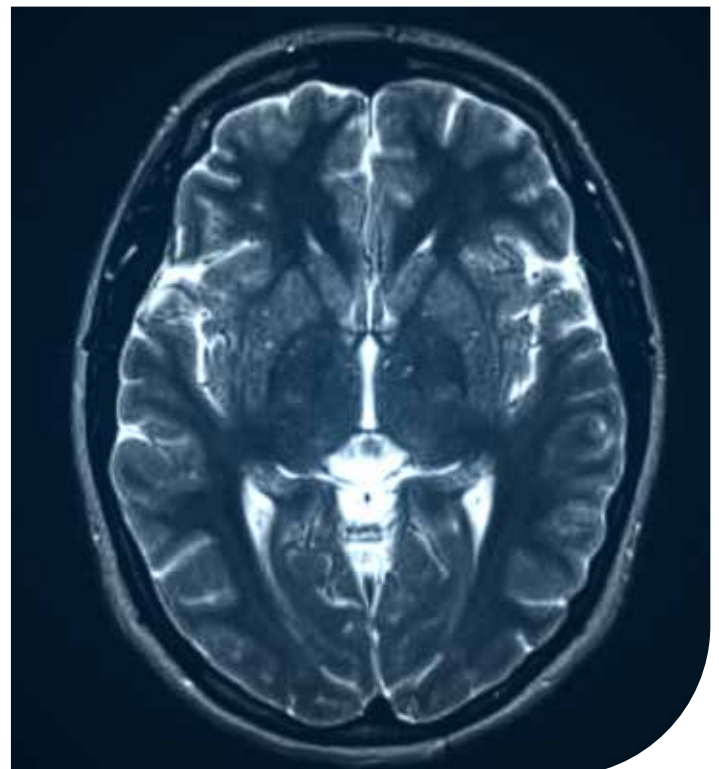
The periphery of the retina is not captured with current technology. Now that we have shown that it is possible, we want to extend this study to see if the changes in the outermost part of the eye can help in reflecting the extent of disease activity.



Neuropathologically informed imaging of cortical grey matter lesions in MS – A pilot study

Previous attempts to see cortical lesions in MS have used techniques that involve all of the brain. But they are very difficult to see on MRI. Cortical lesions are important because they are not seen in many other brain diseases and strongly associate with disability levels. We wanted to develop a new technique to see them.

To do this we looked at post mortem studies and found that two regions in the front of the brain have the highest number of cortical lesions. We then decided to scan 'where the money is' and did a zoomed in scan of the front part of the brain. This approach enabled us to clearly see cortical lesions in MS and we hope that this will assist with future studies to understand their relevance and relationship to treatment response.



Research Update from St. James's Hospital Physiotherapy Department

There are currently two projects underway in the physiotherapy department in St. James's hospital in Dublin.

The first study is exploring the prevalence of vestibular dysfunction in people with Multiple Sclerosis attending the outpatient service in St. James's hospital, and investigating the usability and effects of Vertigenius™, a mobile health application developed for rehabilitation of dizziness and balance disorders. This research work is being led by Dr. Gillian Quinn, Clinical Specialist Physiotherapist in MS and Dr. Hugh Kearney Consultant Neurologist and Dr. Dara Meldrum, Senior research fellow, Trinity College Dublin. This research study is being done to firstly see how common vestibular type symptoms are among people with MS. These include symptoms of vertigo, dizziness, imbalance and tinnitus among others. The second part of this study involves a treatment called vestibular rehabilitation which involves head and eye tracking and balance exercises. The research team want to see if new technology that Dr. Meldrum has developed can help rehabilitate people who have dizziness and balance problems.

To date 62 people have participated in the prevalence part of the study (filling out a self-report questionnaire about vestibular symptoms) and 13 people have completed the intervention part of the study (doing vestibular rehab exercises using the mobile health app, Vertigenius™). Initial analyses show that vestibular symptoms are very common among people with MS, reported by 86% of participants, with vertigo and dizziness most commonly reported. The majority of participants reported recurrent episodes with the most common frequency of these symptoms occurring being 1-3 times per week. Regarding using the mobile app Vertigenius, there were significant improvements seen in patient reported measures of dizziness, imbalance and oscillopsia ($p < 0.05$)

and in physical measures of balance and dynamic visual acuity ($p < 0.05$). There was a mean of 5.5, (range 3-7) exercise programs prescribed through the app over a mean of 13.2 weeks. Usability was high at 80 ± 15 meaning people found the technology easy to use and were happy to use it and did not experience any particular barriers. It also saved people time and money as consultations could be done remotely and parking/transport/time off work were not limiting factors.

The second study currently ongoing is a study to examine the orthotic effect of the exoband on walking related outcomes in people with Multiple Sclerosis with hip flexion weakness. The exoband (Moveo company) is a low-tech device that includes a belt around the waist and around each thigh that helps to lift the hip during walking and thus improve floor clearance and walking pattern for the person wearing it, and potentially decrease the effort required to walk and ultimately increase their walking endurance. This device is currently not available through the HSE in Ireland and is only available through a private rehab clinic. If shown to be effective at improving walking for people with MS, the HSE may be more likely to fund this device and it may be more readily accessible for the general population of people living with MS in this country. The study involves measuring hip strength, doing a short and long timed walk and measuring energy expenditure. It is a multi-site study involving MS Ireland sites in Ireland, St. James's hospital and Tallaght hospital. It is being led by Dr. Gillian Quinn in St. James hospital, Eoin Synnott in Tallaght hospital and Dr. Susan Coote in MS Ireland. To date 10 participants have been recruited and assessed in St. James's and once all sites have collected data full data analyses will be carried out. The aim is to recruit 50 participants in total across 5 different clinical sites.



CLINICAL RESEARCH

Evaluating Public and Patient Involvement in Clinical Research – a newly developed evaluation tool with application to the COB-MS Feasibility trial

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Patient and Public involvement (PPI) directly involves patients in clinical trials. This collaboration helps to improve the quality of the research question, study design and overall impact of the research outcome. It allows people to voice their concerns and expertise advice on conditions that they live with every day. Patients can be involved in recruitment, right through to dissemination of results and publication. Unfortunately, some research includes PPI for benefits such as grant and funding application only instead of the wider advantages to both the research and PPI team. Assessing the methods of PPI helps to identify proper or tokenistic participation. Currently, there is no 'one-size fits all' method to evaluate PPI. The aim of this research was to review current frameworks that evaluate PPI within trials based on relevance, comprehensiveness, and specific question type. Selecting one, or creating a new checklist was important with the overall aim to apply it to the COB-MS trial.

The COB-MS Feasibility randomised controlled trial aimed to improve cognitive interventions for people living with cognitive difficulties due to Multiple Sclerosis. About 40-65% of people living with Multiple Sclerosis experience this. These can affect attention, information processing, problem-solving, language processing etc. Living with these impairments can have major impacts on a person's quality of life, even effecting their employability. These also correlate symptoms such as fatigue, depression, and difficulty to maintain social activities and self-care. Cognitive rehabilitation delivered by occupational therapists aims to improve these symptoms and allow patients to regain their quality of life. It is a very effective method of individualised cognitive intervention.

An extensive review of the current frameworks used to assess PPI resulted in the decision to develop a new framework based on and including aspects of the ones previously reviewed. It was important to consider the themes that need to be addressed to allow a flexible and comprehensive design. To avoid bias and allow individual expression, two surveys were created: for the research team, and the PPI member team. These addressed very similar questions and topics in a language suitable for each cohort. Both

qualitative and quantitative questioning were included in the final surveys.

Applying this new framework to the COB-MS trial showed huge promise in the potential of the surveys and also reflected the use of PPI throughout the trial itself. It revealed true participation from beginning to end within the trial and efforts to accommodate and facilitate the PPI team. Having two surveys helped to identify divergence in opinions between the research and PPI team. This was important to highlight the strengths and weaknesses that could be considered in future research.

The use of PPI within trials is increasing, which helps to create quality research that has potential to improve clinical outcomes for people. However, regulation of PPI use is important to prevent improper methods. The framework generated in this research aimed to provide a flexible and comprehensive guideline to assess PPI. Its use was reflected in its application to the COB-MS trial which showed impressive results that will have potential to guide future research.



The Dean Medal 2023/24

As we conclude another impactful year, we are thrilled to announce that the Dean Medal has been awarded to Dr. Brendan Kelly. Established in 2010, the Dean Medal, aims to nurture new researchers by facilitating their travel to centres of excellence, expanding their knowledge and expertise in the field of MS.

We are excited to share that Dr. Brendan Kelly, the deserving recipient of the Dean Medal, intends to utilise this honour to visit the esteemed Prof Pearse Keane Artificial Intelligence in Medicine Lab at University College London. His goal is to extend a current AI change detection project, integrating the newest transformer-based models. The lab, being among the leading academic institutions globally, boasts unique links to Google DeepMind, a pivotal player in recent AI history with groundbreaking advancements like AlphaGO and AlphaFOLD. This opportunity to work at the cutting edge of innovation, at the intersection of different specialties, has the potential to propel Dr. Kelly's research in MS to the next level.

This announcement reaffirms our commitment to fostering the spirit of discovery and innovation within our community. Stay tuned for further details on this significant recognition, and join us in applauding Dr. Brendan Kelly, whose journey will undoubtedly shape the future of MS research.



Get Involved in MS Research:

MS Ireland helps researchers with their projects by offering advice, data and access to our MS community. We encourage people with MS to get involved in research that is ethical, appropriately organised by a recognised institution and sanctioned by that research authority.

Scan the QR code below to see our current research requests:

