



Education with impact: MS Academy

Learning captured from workplace projects 2022-23



Introduction

Multiple sclerosis (MS) Academy has now supported 148 projects over the past 6 years. We reviewed the first 5 years of impact in our report '[Education which transforms services, transforming lives](#)'. This short report looks specifically at the projects presented at the tail end of 2022 and completed shortly thereafter or in early 2023.

'When I volunteered as academic director in 2021, my priority was to create a community of MS professionals from across all the different disciplines and to support them in a shared goal of delivering optimal, integrated care.'

It's exciting to see so many different disciplines represented in these projects, and to hear about their experiences of learning through their peers at the MasterClass, then putting that learning into practice through these projects. '

Dr Wallace Brownlee, academic director

Projects in this report were carried out by delegates from MS Foundation 15 and Advanced 16, and themes covered were incredibly varied, from an audit of testing for differential demyelinating conditions to fatigue management, a systematic review of long-term prognosis to trialling new treatments. This broad range really highlights the current complexity of MS diagnosis, treatment and management across the full spectrum of services, care and understanding needed for people living with MS to receive optimal support.

You can find these and all other projects online at neurologyacademy.org/projects

'I've really enjoyed seeing the breadth of work to come out of MS Academy over recent years - such a variety of topics and approaches to understanding local challenges and meeting them head on.'

I'm particularly delighted to see so much collaborative working in these projects - we know that joined-up care and communication across professionals makes such a difference to people living with MS, and that's our ultimate goal.'

Sarah Gillett, managing director

Medication management

As always, medication was a hot topic for project work across both Foundation and Advanced MasterClasses, although there was a real mix of work within this broad theme. From reviewing time to treatment and monitoring for established disease-modifying therapies (DMTs) like [ocrelizumab](#) and [cladribine](#) to real-world application of AHST, this year also saw two projects reviewing cannabinoid use for symptom management.

The Advanced winning project was for cannabinoid use. Sativex, a THC: CBD oromucosal spray is a NICE-approved treatment for spasticity and clinical nurse specialist Liz Woodhead wanted to make it more accessible for people with moderate to severe spasticity in her area. She [developed a standardised operating procedure and pathway to facilitate this](#). Meanwhile Dr Filipa Narazina, a neurology resident at Barts, [reviewed the literature around newer cannabinoid CB1 agonist nabilone](#) with a view to adding it to the available drugs for pain management offered at the Trust.

A number of projects looked to improve waiting times for referrals and treatment access. Rebecca Harrison, a specialist pharmacist in a patch where disease-modifying treatments are provided via homecare services, realised that there were [significant delays between multidisciplinary agreement to commence treatment](#), and treatment arriving with the patient. She set out to reduce that time lapse by mapping out the ideal process, mapping the delays, challenges and barriers onto this, and generating solutions to overcome these problems. MS specialist nurse Lynne Bezance also focused on [reducing time to treatment](#) for her Advanced project, specifically looking at those who are newly diagnosed accessing effective treatments as quickly as possible.

Some projects dealt with introducing new DMTs, or new administrative forms of established therapies. Specialist nurse Sarah Hughes worked to initiate [new DMT ponesimod](#) into their established MS service, whilst lead pharmacist Niamh Gormley [gathered opinions and concerns from patients currently receiving intravenous natalizumab](#) to find out their thoughts on switching to subcutaneous administration. She used feedback to direct plans for a future service, and determine the content for patient-facing information.

Holistic care

Over the past year or so, we have seen a shift in educational interest from predominantly treatment-related to more holistic, looking to bring together medical and therapeutic management of MS symptoms to better improve, not only each individuals' MS, but their quality of life more generally. This focus was **echoed by the updated NICE guidance** last June and by the project content this past year. From service development to give patients more agency to improving transition points in a patient's journey or between services, there was a strong focus on supporting the whole person.

One of the NICE recommendations was for an annual comprehensive review to ensure all of a person with MS's needs are being considered and met. Community MS specialist nurse Pamela Andrews worked to **develop clear and consistent documentation** for her service to ensure that both the review, and resulting actions, would be effective.

Two projects considering a person's various needs at key transition points won the Advanced project runner's up awards. Specialist occupational therapist Victor Ike developed a **discharge checklist** to support people being discharged from hospital. This was to ensure safety for the patient and communication across relevant staff and departments. MS specialist nurse Polly Kay set out to **improve the patient experience of transitioning to progressive MS**. She audited the current service and experiences, and developed a pathway to enable a consistent, collaborative and supported transition for people.

Other delegates worked to increase autonomy, agency and confidence amongst their patients. Specialist nurse Flordeliza Madriaga and Dr Nicole Japzon won the Foundation project award with their work to **improve patient education** around relapse. Their work had a dual focus: to help people with MS recognise the signs of relapse and understand how to manage them, and to reduce the anxieties people feel around relapse by providing comprehensive information and guidance. Ruth Cutts, clinical lead physiotherapist, had a self-referral system in her service which was under-utilised with patients also being re-referred in from other sources. She developed a **formalised patient-initiated follow-up (PIFU) pathway** with patient-facing information and designated appointments to give patients greater agency and access to the service when they need it.

Fatigue

Fatigue affects a high proportion of people with MS (prevalence ranges from 36-97% depending on research). It has a significant impact on other symptoms like mood, pain and cognition, and on wider life including social involvement, relationships and work - and it reportedly affects quality of life more than any other symptom (Young 2021). As we learn more about fatigue and MS, the number of projects focusing on this impactful symptom are also increasing.

Specialist neurophysiotherapist Rachael Kennon set out to understand the level of understanding of **MS fatigue amongst their acute rehabilitation team**, and what this might mean for rehabilitative programmes for people with MS. She did this via a questionnaire, and it has prompted training and identification of resources for the team to use.

Claire Reidy, a neurology research nurse, finds that her team often are in regular contact with people with MS on trials who rely on them for support with their wider MS. She wanted to **provide meaningful signposting to those patients experiencing fatigue**. She created a flowchart for the research nurses to use to share information on treatments for fatigue and some tips from the voluntary sector, as well as onward referral to the specialist nurse if this is needed.

Occupational therapist Love Atere's project was not specifically on fatigue but encompassed it. She **developed a checklist** to use in regular therapy assessment and monitoring to ensure various aspects affecting quality of life for someone with MS are taken into consideration as their condition progresses. This includes pain, mood, cognition, mobility, spasticity, vision, bladder and bowel, as well as fatigue.

Approaches to service improvement

Some of the projects were not focusing on a specific theme or service area. Recognising that 'You don't know what you don't know', they carried out information gathering or risk stratification exercises to get a clearer picture of local service demand, requirements, or experiences.

Sarah German, an MS specialist practitioner new to post at the close of the COVID pandemic felt this was a good opportunity to **listen to patients about their experiences and priorities for future services**. She was able to identify that a comprehensive annual review and a holistic perspective, beyond medication discussions, are both important to people, and that signposting to information and access to social support and an accessible gym are currently gaps in care. This is prompting further patient engagement, an education event, and collaboration with other services and the voluntary sector to establish social groups and advocate for a gym.

Fellow at Barts Dr Saloua Mrabet carried out a **systematic review on stratification of long-term prognosis in MS** examining over 200 studies and 30 prognostic factors. She found that early access to high efficacy treatment can strongly influence someones' long term prognosis. She also found that the most robust drivers of disability were related to the degree of brain damage initially found and its repair capacity, concluding that preventative care by addressing modifiable risk factors should be prioritised. Whilst she did not directly link this research to service change, these findings highlight priority areas for services in MS: the need for early diagnosis, timely access to high efficacy treatment soon after diagnosis, and clear patient-facing information around modifiable risk factors to give them the best long-term prognosis.

Dr Guru Kumar decided to **review and evaluate the MS service** he is lead neurologist for, in order to identify current challenges and areas for improvement in the future. He compared the current service to that of 2020 when he was first in post. Looking across patient data, service resource and configuration, and challenges has helped provide clarity over what service changes have been positive, where there are gaps, and where future challenges can be expected.

Top tips and takeaways

Here are some ideas you could consider replicating based on this project work, and drawing on statements made by the delegates.

1. Improving holistic care and supporting self-management have a significant crossover in these projects and both are highly valued by patients. To impact both these areas, you could:

- Agree a specific approach to the comprehensive review, developing your own document like [Pamela Andrews](#) did, or using the [annual review document provided by TiMS](#)
- Improve patient-facing information to provide agency and give confidence, like [Flordeliza Madriaga and Nicole Japzon](#) did
- Introduce, improve or formalise a patient-initiated follow-up (PIFU) process, like [Ruth Cutts](#)

2. Early access to high efficacy treatment makes a difference to long-term prognosis, as [Salua Mrabet's](#) project highlighted, so reducing waiting times for access to disease-modifying therapies is important. You could:

- Map out the ideal process for treatment access like [Rebecca Harrison](#), or look at your current process, and systemically address the barriers to following it
- Look at a specific cohort of patients and focus on improving their access, like [Lynne Bezance](#) did for newly diagnosed people

3. Transitions can be tricky, and are often where patients fall through gaps in care. You could:

- Develop a formal process or checklist to support patients being discharged from hospital like [Victor Ike](#)
- Look at how your service supports people transitioning to a different 'type' or experience of MS like [Polly Kay](#) did, and consider how to improve that support, or make it more consistent

4. A high number of people with MS experience fatigue which impacts their MS and many other aspects of their lives. Are they well supported in your patch? You might:

- Think about the understanding of staff around fatigue and consider some internal education like [Rachel Kennon](#)
- Look at your patient-facing information around fatigue management like [Claire Reidy](#)
- Develop a prompt or checklist, like [Love Atere](#) did, to make sure fatigue is being considered in relation to various areas of care and throughout the patient journey

5. Sometimes we need to understand where we are to move forward. You might want to deliver the best possible service but aren't sure where to start. Perhaps you could:

- Carry out a patient-facing survey like [Sarah German](#) to understand what is working well from their perspective, and what their priorities are
- Review your own service like [Guru Kumar](#) - whether through an audit or evaluation, taking a good look at your patient database and how people are interacting with your service



Neurology Academy: education with impact

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We specialise in education, networking and mentorship, encourage the sharing of good practice, and promote clinical leadership across a range of conditions. Each condition or healthcare theme has its own 'Academy'.

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