



Education with impact: MS Academy

Learning captured from workplace projects 2023

Introduction

There has been a shift in focus over the past few years in MS, with far more services and support provided collaboratively across a range of disciplines, and with a more equal balance across specialised treatment and holistic management. Looking across the Foundation and Advanced MasterClasses projects of 2023, this shift is clearly reflected.

'We are under such pressure in the NHS yet we want to provide the very best services we can, and that really came across this year in projects completed by the Foundation and Advanced delegates. Projects ensuring people have equitable access to the best treatment for them, or embedding specialist care into existing services all improves the experiences of and outcomes for people with MS.'

Dr Wallace Brownlee, honorary academic director

'I was thrilled to see so many projects addressing such patient-centred issues. Supported-self-management is really close to my heart, as is MS services which really see the whole person and all aspects of their lives and needs as essential when providing treatment or interventions. It is fantastic to hear from so many people who feel the same and are working to transform the experiences of people with MS in their area through this lens.'

Ruth Stross, head of nursing

Some of the most impactful ways our workplace projects are affecting services is in their sharing. Where ideas are shared, learned from, and replicated or adapted for use elsewhere, we can capitalise on good practice, increase equity of provision and access, and find new ways to improve outcomes for people with MS. At the end of the report we have pulled out five themes and several ideas to review or improve practice as tried and tested by delegates in their projects. We hope their work inspires you to try something similar in your area.

Lifestyle and supported-self management

Over the past few years, the evidence-base for lifestyle change as a means of both treating and managing MS, when used alongside medications and therapeutic interventions, has become irrefutable ([Giovannoni et al 2024](#)). Alongside this, the importance of [supported self-management](#) both as a means of empowering people with a long-term condition, improving their outcomes ([Dineen-Griffin 2019](#)), and alleviating pressure on NHS services ([Deeney 2018](#); [Barker 2017](#)) has also risen in appreciation. The projects across both Foundation and Advanced in 2023 really reflected this dual shift in healthcare for MS.

[MS support nurse Joanne Cooper](#) was aware that a high number of people attending her local relapse clinic did not require steroids or were reported to be pseudo-relapses. She followed up with those people with pseudo-relapse and decided to improve patient education by developing a self-care plan for MS symptom control. Joanne updated the patient pathway so that those leaving the clinic without steroids would be referred to her for a self-care plan and any other onwards referral for education, therapeutic interventions or other support, enabling them to self-manage effectively at home.

Another initiative supporting self-management was from [clinical nurse specialist Denisse Bongol and senior MS pharmacist Jessica Mensah](#), who developed a pre-clinic questionnaire to help people with MS reflect on their current situation in terms of symptoms, medications and DMTs, and identify their goals for discussion. Evaluating their support email, they found the majority of messages to be to be around DMT use, symptom management or care coordination and feel confident that these can be addressed in clinic to provide more proactive care and reduce email correspondence.

'Effective patient education is the cornerstone to ensuring healthier lifestyle choices', summarised [Gavin Brittain, neurology registrar and clinical research fellow](#) in his project to compare smoking status, alcohol consumption and BMI index across people with MS based in Sheffield, Italy and Germany, as well as with the general UK population. His findings were varied, but all highlighted that more could be done to increase positive lifestyle choices amongst his population. He is overhauling a patient-facing leaflet and parts of their MS service website to inform and engage people around lifestyle choices.

From local to national, [neurology registrar Sean Apap Manigon](#), alongside colleagues, reviewed comorbidity data in the MS Register. Finding a higher prevalence of comorbidity amongst those with MS and higher still in those with progressive MS, Sean highlighted the importance of managing comorbidities within routine neurology care.

Holistic care

In the same way that supported self-management and lifestyle change have become more popular project topics of late, a renewed focus on holistic care is also reflecting the shift towards a personalised, collaborative and inclusive approach to managing long-term conditions, including MS. The holistic projects we have seen this year have addressed areas with distinct crossover with other healthcare departments or institutions, such as across maternity care, polypharmacy from comorbidities, cognition, and research.

Considering how to engage more people with a BME background in MS research, [research nurse Prisca Mpofu](#) and [Neurology clinical research nurse Shanaz Begum](#) looked at BME representation in their neurology trials. BME representation is particularly low generally, despite MS prevalence amongst black and other ethnic minority groups. They identified potential barriers and considered how to overcome them by reviewing literature and developing a staff questionnaire.

[Medicines information and neurology specialist pharmacist Joanna White](#) carried out an audit of whether women diagnosed with MS and known to her local service were being offered pre-pregnancy counselling and advice in line with UK consensus guidance ([Dobson 2019](#)). Joanne found that there were both low levels of adherence to this guidance and low documentation of any information given or plans put in place for patients. She recommended a number of initiatives including learning from other areas, staff education, patient information, and developing a checklist to include in electronic records.

[Lisa Perfect, an MS specialist nurse](#), looked at holistic care around medications, asking whose responsibility it is to manage polypharmacy. Reviewing 66 patients on one of two disease-modifying therapies, Lisa mapped the other medications that were being taken by those patients, finding over three medications per person on average with some on as many as 24. She also found that only 12% of these patients had had a medications review with their GP in the past 12 months. Highlighting the importance of infrastructure and the ideal of shared records, Lisa suggested formalising structured medicine reviews and clear advice on medication dosing be copied to GPs in clinic letters as well as clarified with patients.

[MS specialist nurse Louise Pawson and MS research nurse Claire Reidy](#) reviewed the incidence of cognitive impairment (CI) in people with MS and, examining two case studies, considered whether routine baseline and ongoing assessment of people with MS using the [symbol digit modalities test](#) (SDMT) would have a positive impact on outcomes. They surmised that, given the low recognition of CI in MS, formalising information gathering early on would allow people to have improved support from the earliest point needed, but need to carry out more research to formalise their recommendations.

Medication meets care closer to home

In both the Foundation and Advanced MasterClass, we saw a high volume of projects looking at medication use and access, from [reviewing patient compliance and understanding for natalizumab](#) to assessing the volume of people requiring an ['as needed' dose of alemtuzumab](#).

We are seeing a distinct move away from projects looking at adverse affects or equity of access. Projects seem more focused now on ease of administration, increased patient self-efficacy and reductions in workforce requirements without compromising safety. NHS England's continued mandate to move care closer to home is now backed with sustained rationale ([Kings Fund 2024](#)) and economical models demonstrating how investment in primary and community care has a downstream effect of improving patient outcomes and reducing overall health costs ([NHS Confederation 2023](#)). This has extended to medication over recent years with a number of MS disease-modifying therapies developing at-home administration, and various service development initiatives looking at infusion clinics in community settings.

[Advanced clinical pharmacist for MS & neurosciences Sukhi Chahal](#) looked to reduce the amount of time to DMT initiation through Homecare use, whilst [advanced clinical practitioner Marco Silingardi](#) evaluated the current DMT service for infusions across natalizumab and ocrelizumab and reviewed whether moving towards subcutaneous administration of the former, or transferring patients to the latter with its less regular infusions, might improve ease of access for patients and reduce demand for healthcare services.

There seem to be both benefits and challenges in moving medications out of specialist settings. [Catherine Graham, a clinical specialist physiotherapist](#), initiated fampridine access across the west of Scotland without additional resources. Initially doing so via a mobile clinic led by a physiotherapist and pharmacist team, high demand required a switch to remote assessment and trial overseen by the MS coordinator. Access to the drug via the remote format was far higher (90 compared with 12 for the mobile clinic) suggesting a more efficient model - yet this was only 30% of those referred suggesting remote assessment was a barrier to many. Catherine noted that the assessment may not be as robust, relying on patient honesty only, and that the overall benefit of additional contact with healthcare professionals was lost including identifying and meeting additional needs and potentially reducing burden on nurse and consultant services.

Optic neuritis

Optic neuritis (ON) is one of the most common ways that MS first presents ([Kale 2016](#)), particularly among young women ([Shams 2009](#)) and causes sometimes painful changes in vision such as blurring, changes in colour perception, or flashes or spots of light.

[Neurology registrar Di Lang](#) notes in his project introduction that despite the commonality of ON, it has often been difficult to determine its aetiology and that 'the diagnostic uncertainties and lack of high-quality evidence has led to significant variations in how clinicians manage a first episode.' Recent findings in biomarkers have advanced the challenges around aetiology to an extent ([Chen 2020](#)). Di chose to focus on the need for updated guidance for his project and carried out a literature review of 67 studies into optic neuritis looking for evidence of consensus good practice. He concluded that there was a lack of up-to-date surveys considering the latest developments in the field and recommended a survey of clinical practices and Delphi-method development of consensus guidance.

From the national picture to local practice, [clinical research fellow Charmaine Yam](#) evaluated the feasibility of incorporating retinal optical coherence tomography (OCT) into the routine investigations carried out in an MS clinic setting, considering the views of both healthcare professionals and patients. She found that patients were highly receptive to the additional investigation but that clinicians were more reticent with barriers cited around resources, lack of referral pathway, and confidence interpreting results.

Top tips and takeaways

Here are some ideas you could consider replicating based on this project work, based around five statements made by the delegates themselves, or featured in recent policy and guidance.

1. Supported self-management is a positive way to empower people to manage their own MS whilst educating them and equipping them with a way to lead interactions with their healthcare professionals. Ideas from delegates this year include:

- Offering a pre-clinic questionnaire to allow people to reflect on their condition and steer their clinic conversations, like [Denisse and Jessica](#)
- Considering patient-facing information and education to enable supported self-management around managing relapse or pseudo-relapse like [Joanne](#)

2. The evidence-base around the impact of lifestyle choices on MS is significant and growing. Ways you could apply this in practice include:

- Reviewing or create information available for people with MS in your area around lifestyle choices to manage symptoms and slow disease progression like [Gavin](#)
- Evaluating how prevalent comorbidities are amongst your MS population like [Sean](#), and considering how you might manage people's comorbidities for overall wellness

3. Holistic care requires collaborative approaches and shared responsibility across services. Examples in this report include:

- Reviewing whether people with MS who are able to bear children are given the opportunity to have pre-pregnancy counselling and create a plan across their MS medication, conception and pregnancy wishes like [Joanna](#), or initiate this in partnership with maternal medicine
- Reviewing current cross-tier practice to find where polypharmacy management seems to sit, and consider developing a collaborative approach to management or initiating routine structured medication reviews like [Lisa](#)

4. Moving care closer to home applies to medication, too. Ways that delegates have tried to move in this direction include:

- Trialling a mobile or remote clinic to assess people's suitability for a DMT like [Catherine](#)
- Reviewing people's willingness to, or feasibility of, switching to a subcutaneous form of administration which can be done at home or in a non-specialist setting like [Marco](#)

5. There is increasing evidence around the significance of optic neuritis to MS, and importance of its recognition. This years' projects suggest:

- finding out perceptions to increasing OCT investigations and monitoring amongst staff members and considering how to mitigate against barriers, like [Charmaine](#)
- joining with others to create a national consensus on practice around optic neuritis like [Di](#)



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