Multiple Sclerosis Academy®

MS education with impact:

education that transforms services, transforming lives

An outcomes report for MS Academy 2016-2022

November 2022

Neurology Academy®

NEUROLOGY ACADEMY: EDUCATION WITH IMPACT

Foreword

Ruth Stross, Head of Nursing at MS Academy

This Education with Impact report is a welcome opportunity to review the Academy's impact to date, and to see so much positivity at both a national and local level. As a practising MS specialist nurse, I have been especially gratified to see the increasing breadth of roles and disciplines supported by MS Academy over the years.

The Academy's recognition of the essential roles that nurses, therapists and allied healthcare professionals play in effective support of people with MS has seen evolving course content, increasing choice in educational format, and deliberate support for their educational and developmental needs. It's wonderful to see so many of the featured projects have been carried out by specialist nurses, and I'm thrilled to see the volume of nurses being educated and encouraged in their practice, particularly at this time, when the nursing workforce is under so much pressure.

MS Academy has played an important role in my personal journey and having witnessed presentations of innovation and transformed services at recent conferences which had their roots in an MS Academy intermodule project, I am confident that many, many others have been similarly impacted.

The projects highlighted in this report demonstrate the many ways we can be motivated to effect change, and provide much needed encouragement and inspiration to continue working to improve the experiences of people living with MS across the UK and beyond.

Sarah Gillett, Managing Director at Neurology Academy

At Neurology Academy, we are so often looking forward: to the next course or conference, the next innovation to share, the next opportunity to support someone; it feels a rare opportunity to reflect on our impact to date. It is so encouraging to consider MS Academy's journey so far and see the positive impact that it has had, whether on individual professionals, local services, or national initiatives and it's lovely to see some of that captured here.

Over the past five years of the Academy's journey there have been many incredible intermodule projects, most of which are not featured here. They can all be found on our website, though, and I would like to encourage you to visit the projects section of MS Academy online to find them. Often the wisdom and learning of others - in successes and failures - can be a support in seeking a solution to whatever local challenge you might be facing.

Beyond an educational space, MS Academy is a community of like-minded healthcare professionals with a common goal - to improve the lives of people living with MS - and it is a privilege to be part of that.

Acknowledgements

Every single piece of work in this booklet comes from the efforts of dedicated healthcare professionals and we are very grateful to each for their updates on these projects, where relevant. We're also aware that, without our Faculty and our speakers, there would be no MS Academy, and are hugely thankful to them, and to our sponsors whose financial support enables so much of our work.

Contents

Has our education had an impact?

Collective wisdom: five years of service transformation

Has our education had an impact?

Now in its seventh year, MS Academy was established in response to a growing need for training and mentorship across all disciplines involved in MS healthcare provision. The Academy set out to support development of a broader range of expertise and collaborative working in MS to tackle unwarranted variance, improve services and positively impact the lives of people with MS. Over the past five years, the Academy has actively supported intermodule projects and encouraged healthcare professionals to put their learning into clear and tangible practice, to the benefit of those living with MS.

Over 1,600 unique individuals who work in MS services, or support someone with MS, have attended one of our MS Academy events to date across roadshows, conferences, webinars, virtual courses and our signature MasterClasses. With many individuals attending several events, 4,031 attendees have scored our education with an average 4.5 out of 5, with more than 90% likely to highly recommend our courses to a colleague.

MS Delegate Education Assessment

4.5/5

Average rating

90%

Likely to highly recommend our courses to a colleage

National education: local impact

> **'A truly fabulous course. I have enjoyed all the sessions and learnt so much and I feel very excited to get back to work and put my knowledge into practice. Thanks to all involved for your time, the passion for MS treatment and diagnosis shone through.'**

We want our education to go beyond the event into the everyday practice of the healthcare professionals in attendance - and then outwards, to the people experiencing those services and support.

Over the past few years this has meant an increase in the amount of virtual and thematic education MS Academy offers, initially in response to professional need during the pandemic, then later in response to a call for ad hoc professional development.

> **'Teachings like these are pretty much the need of the hour especially after about a year of cancellations of educational activities.'**

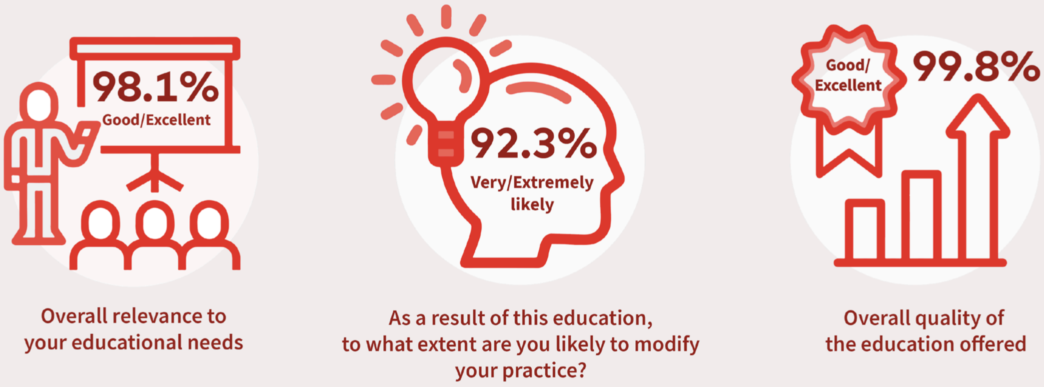
Our free webinars, which run live and are then made available on demand, have had over 2,500 live attendees and more than 25,000 on-demand views, whilst our MasterClasses run virtually during the coronavirus pandemic are now offered with a hybrid option for those who find travel or residential learning a barrier to accessing education.

'The hybrid approach was fantastic and really worked well. Even participating on Zoom I still felt involved and that my questions were answered promptly and adequately.'

In our MasterClasses, the impetus to impact peoples' experiences in the MS community and drive service transformation has meant a gradual move to increasingly case-based teaching, a broader range of practical subject matter, and higher levels of interactive learning. This has been well received, and over 90% of all MasterClass attendees rated the extent to which they will modify their practice after the course as either high or very high.

'High standard of speakers, sessions and timetable well planned and kept to time as much as possible. Use of case studies helped with relevance. Strong links to [the] evidence base.'

MS Delegate Course Assessment



'I felt that this was a very supportive two days and I feel motivated for the future. I cannot believe how beneficial this has been and the wealth of knowledge that has been available, thank you.'

The Academy's education is ultimately intended to transform the services and support available for people with MS, and as well as clinical application, we also encourage local quality improvement and service development projects - something which is a mandatory part of all our two-module MasterClasses.

With mentors available for advice and direction, and peers to engage with and present the work back to, delegates are well supported in their projects which improve or transform local services to positively impact both those providing and receiving MS services.

By sharing the practical 'hows' and the positive outcomes of these projects on our website, that learning can turn from local change to national transformation. The past five years of project work have shown some common threads in both barriers and positive steps to change, which we have featured in this booklet. We believe that by sharing learning, we can enhance understanding and encourage future change.

> **'As clinicians, we have to have a starting point - if there's evidence-based information out there, we need to use it - and having a trusted space to share that can act like a springboard.'**

Equipping leaders

Transforming services cannot happen without healthcare professionals who feel confident and equipped to make positive changes, and the Academy forms a community of like-minded professionals, across many disciplines and backgrounds, all with a common goal and able to mutually learn and grow in their practice.

Many of our delegates go on to become leaders in their field. From Academy speakers or Faculty, to local pioneers or national influencers, we are proud to be supporting professional development at several levels. This is something specifically reported on by MasterClass delegates; 98% feel their professional development has been met well or with excellence within our courses.

Several MasterClass delegates have gone on to lead development of other education with the Academy such as MS Basecamp and Neuropharmacy Academy, both developed by alumni-turned speakers or Faculty.

> **‘If we can start this interest in the early years, we’d have trainees who can take posts where they can take a leading role early on, redesigning services, getting involved. If we don’t change things, we can’t sustain our MS services. Without a specialist interest, the treatment breaks down, it increases variance.’**
> Dr Riffat Tanveer, observations made in a MasterClass intermodule project which led to developing MS Basecamp

Some of our events have specifically focused on encouraging or developing leaders. The 'Raising the Bar' conferences supported healthcare professionals in a grassroots movement to address unwarranted variance in services and seek a national approach to improvement which led to a variety of local and national initiatives.

One of these initiatives was taken on by MS Academy: the development of the MS Leadership MasterClass. Many of those in the first Leadership MasterClass have gone on to lead numerous local and national initiatives from their various roles, influencing policy, services and teamwork for the better.

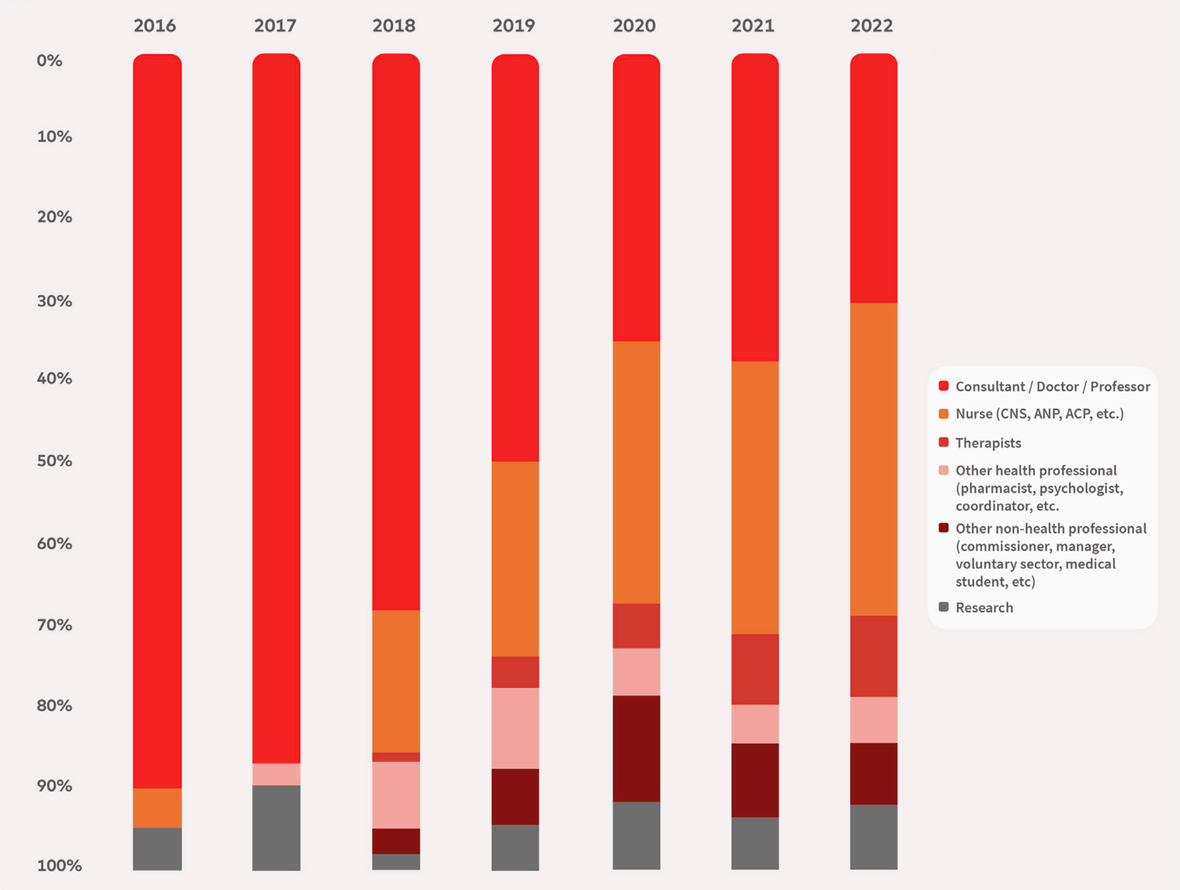
A multidisciplinary approach

Over the past few years we have been consistently working to ensure our education is relevant to, and accessible for, as wide a range of healthcare professionals working in MS as possible, supporting specialists across disciplines and at varying points in their career, and ensuring our content can meet everyones' educational priorities.

> **'Thoroughly enjoyable, learned so much, brilliant speakers, aimed at exactly the right level so that it wasn't too overwhelming for us new starters in MS.'**

Initially very consultant-heavy, our events have seen a steady increase in the variety of roles attending, speaking and leading, and whilst spikes in some professionals tally with specific courses, the general trajectory is of a wider community of professionals being supported, and a broader spread of topics and perspectives being shared.

MS delegate demographic



[All quotes from MS Academy delegates since 2019 unless otherwise stated]

Collective wisdom: five years of service transformation

We have chosen to highlight some of the different ways, big and small, that delegates have changed services and impacted people with MS over the years. The projects featured in this booklet are a very small selection from a much greater body of work - the collective work of hundreds of delegates - and it is our privilege to bring together some of the wisdom learned from those projects.

Unpick what you currently have

Data is just information, and in all its forms, from patient notes to Blueteq forms, surveys to stakeholder meetings, Hospital Episode Statistics (HES) to patient reported outcome measures (PROMs), it can help us to understand current challenges, focus improvements, monitor change and ensure service developments are having a positive impact on outcomes.

Over the years, we have offered sessions in MasterClasses to help demystify data, and promoted use of audit and data analysis to help delegates find their 'baseline' to improve from, or get a better understanding of what some of their most significant challenges might be. This was the springboard for the fantastic work carried out by specialist nurses Gale Metcalfe and Audrey Owen in their project around 'nurse-led interventions.'

Data can also be used to make a compelling argument for change - and we know that developing business cases is a skill that many healthcare professionals are trying to develop currently. Specialist nurse Samantha Browne's project showcases the value of unpicking costs and resources to make economical service changes which improve patient care.

> **'Be clear about what the problems are. After that, any step in the right direction is a step in the right direction.'**
>
> *Prof Ben Bridgewater, speaking at an MS Academy event, 2018*

Nurse-led interventions to reduce unplanned admissions

Gale Metcalfe, MS specialist nurse, Leeds Teaching Hospitals NHS Trust, and Audrey Owen, MS specialist nurse, Calderdale and Huddersfield NHS Foundation Trust

This project was part of the 9th MS MasterClass (Advanced) in 2020.

Hospital Episodic Statistics (HES) details admissions, outpatient appointments and A&E attendances in hospitals across England and is a form of data that can provide meaningful information about hospital services (NHS Digital 2022).

After being shown HES data highlighting steeply rising national non-elective admissions for MS at an Advanced MasterClass in 2020, MS specialist nurses Audrey and Gale decided to work together to unpick HES data in their patch and collectively work on some nurse-led solutions over a twelve month period focusing on preventative care and thus reducing emergency admissions.

Service development

Initial HES data highlighted high emergency admission rates, so they introduced a post-discharge specialist nurse appointment and developed successful business cases for a single point of contact for MS patients within both hospital's MS teams.

Many of the admissions were urinary tract or bladder-related so they established a bladder clinic to provide timely management, and improved patient information to include education around bladder dysfunction.

The data showed a reduction in emergency admissions by over 13% from Feb 2018-Jan 2021.

It also highlighted that falls were another cause of unplanned admission in MS. Gale therefore set up a weekly MDT clinic with a neuro-physiotherapist for falls prevention and follow-up for those recently discharged from falls-related stays whilst Audrey began informal weekly meetings with her community rehabilitation team for newly discharged patients.

Non-elective admissions had reduced by 22% by January 2022 (since Feb 2018), and as a result of introducing nurse-led follow ups for every non-elective admission, their percentage of people with MS experiencing a second or third admission has dropped - it is now lower than the NHS England average.

Continued efforts to reduce bladder-related admissions and UTI-exacerbated relapse have seen the home UTI testing kit (Thomas & Stross 2021) rolled out to detect infection early on and enable swift treatment to avoid escalation of problems.

They have also each worked with their own hospitals to improve coding accuracy and communication to ensure the HES data is reflective of true practice, one via their data department, the other through their Quality Improvement team.

The importance of the MS coordinator

Samantha Browne, MS specialist nurse, Community Aerodrome House, South Health NHS Foundation Trust

This project was part of the 13th MS MasterClass (Foundation) in 2021.

The increasing variety of disease-modifying therapies (DMTs) available for people with MS, alongside the broader proportion of the MS population that these now serve including people with Clinically Isolated Syndrome (CIS) and progressive MS, is placing significant burden on services to both provide these therapies and safely monitor those receiving them. Changes in administration of some DMTs such as natalizumab means community-based nurses are now responsible for intravenous administration at community sites.

For the community MS team in Gosport, this increase in workload coincided with a significantly reduced staff - one nurse managing a caseload of just under 1,000 people with MS. This workload was further compounded by the pandemic and its associated impact on health services and patient wellness.

After unpicking these numbers and reviewing the options, Samantha found a cost-effective solution.

Service development

Samantha proposed initiating a Band 4 MS coordinator, who would allocate 28 hours per week in DMT-related monitoring and patient support. This resulted in:

- 56 freed up clinic appointments per week in place of a specialist nurse carrying out the same tasks
- savings of £13,046.76 across the course of a year
- 'invaluable' support to patients due to the single point of contact and reassurance around blood results and management plans when results are not as expected
- better compliance amongst patients, especially where people experience cognitive impairment, providing phone or written reminders to patients a week or two prior to blood monitoring
- improved communication and coordination by liaising across patients, specialist nurses and the wider multidisciplinary team.

*The work of a band 4 coordinator requires expertise in administration and logistics, procedures and protocols - and understanding of how people with MS experience their condition and how that impacts this administration. The challenges around discrepancy between banding and expertise needed, and of working location, can be barriers to obtaining this post which makes Samantha's project all the more commendable.

Work collaboratively

Whether informal partnerships or joint service agreements, improved coordination or combined services, collaborative working often creates transformative care from the perspective of the person with MS.

The joint MS and maternal care service that Dr Ahmed Mohamad led development of as a registrar is a fantastic example of a formal collaborative service which meets multiple aims to provide the best outcomes for individuals with MS, in line with policy and best practice.

Another element of collaborative working is recognising the value of everyone involved in service provision and making best use of them. Specialist nurse Daisy Cam's acupuncture clinic demonstrates the value of shared thinking across different teams and specialisms to develop new solutions and meet a common goal.

> **'In recent years, our best outcomes have been achieved when organisations have collaborated.'**
>
> *NHS England: Integrated care 2022*

Development of a combined multiple sclerosis and maternal medicine service

Dr Ahmed Mubarak Mohamed, consultant neurologist, Royal Hallamshire Hospital

This project was awarded first place at the 12th MS MasterClass (Advanced) in 2020 when Ahmed was a neurology registrar.

MS commonly affects more women than men and is often diagnosed during a child-bearing age. Delaying disease-modifying treatment (DMT), for instance, until after a person has created the family they want, can lead to irreversible disability in the person with MS, yet the wide-ranging DMTs available and the complexities of managing someones' MS around family planning can be hugely challenging for healthcare professionals.

Improved understanding of the effects of pregnancy and DMTs on MS is associated with improved family planning counselling for women and men, leading to informed choices, shared decisions, and optimal outcomes (Dobson et al, 2019).

Ahmed decided to work with the obstetric maternal medicine team to establish a joint service with the MS team for both men and women with MS to plan their families and experience the journey through pregnancy safely, whilst also providing the best care for their underlying MS.

Service development

- A quarterly pre-conception clinic is run in-person with attendance from the MS consultant, obstetric consultant and MS specialist nurse.
    - Available to all MS patients planning for pregnancy, offering in-depth pre-conception counselling including fertility preservation for patients planning for AHSCT.
- A monthly antenatal clinic is offered to review patients who are pregnant (three slots per month).
    - This is run with in-person attendance from the obstetric consultant and virtual attendance from the MS consultant and specialist nurse.
- A single clear pathway enables transparency of access to the service across both teams and standard agreed patient pathway proforma is used in discussions.

The service has now been running for 18 months and has seen seven births to women who have attended both the preconception and pregnancy clinics. Patient feedback has been very positive and the service is currently being audited.

This unique service is thought to be the only formal collaborative maternal care and MS service of its kind in the UK.

Acupuncture treatment in people with MS-related pain

Daisy Cam, MS specialist nurse at the Royal Hallamshire Hospital, Sheffield

This project was part of the 4th MS MasterClass (Specialists) in 2018.

People with MS can experience many different types of pain, neuropathic pain being considered the most directly related to MS (Murphy et al 2017; Heitmann 2020). Between 35% and 70% of people with MS experience pain and as many as 80% of people with MS experience pain at some point in their journey (Piwko 2007; Foley 2013;MS Trust 2022a).

Pain has been found to increase or compound other MS-related symptoms such as fatigue and depression, and to have links with disability (Heitmann 2020 & 2022), yet successful pain management is difficult, with conventional management involving a range of oral and topical pharmacological options.

Acupuncture, used to manage pain in Eastern medicine for over 3,000 years, has recently been used more in Western medicine as a complementary therapy and may support those with neuropathic pain (Demitrova 2017). There has been insufficient robust evidence to confirm its benefit in MS (Karpatkin 2014, MS Trust 2022b) but recent studies reviewing brain imaging during acupuncture have shed light on how and why the treatment impacts pain processing, increasing its potential as a pain management option (Theyson 2014; Xu 2022).

MS specialist nurse Daisy Cam had witnessed the benefit of complementary therapies such as acupuncture when working in oncology, and after training with the British Medical Acupuncture Society in 2009, Daisy collaborated with the local pain specialist nurse to run a monthly acupuncture clinic for people with MS experiencing pain.

Service development

Daisy and the local pain nurse collaborated to provide a monthly acupuncture clinic within the MS service for anyone with MS in their area who experienced pain. A six month rolling audit of 53 people receiving the service for an average of four years found:

- An average of 62-70% pain relief for an average duration of 4.7 weeks from treatment.
- 91% had an improved feeling of wellbeing
- 38% felt their sleep had improved
- 32% had reduced their medication
- Mood appeared improved (lower Gad7 and PHQ9 scores than expected)
- Patients reported heightened pain during the pandemic (during which time the service was unavailable) and have noticed a significant difference since it has restarted reporting that their pain levels are much better.

Start small and grow

A number of the bigger projects in this booklet had a considerable vision for change, yet started with small changes and grew the idea or service iteratively. The work at Epsom is a great example of how Dr Jananee Sivagnanasundaram reflected on the challenges in her area and slowly introduced services and interventions to improve on these, year on year.

The 'red tape' within the NHS can be a real barrier, and finding ways around it can require patience and lateral thinking. Specialist nurse Sinéad Jordan's project is a real testament to tenacity - a larger-scale vision which is taking longer to get fully off the ground than anticipated yet which she has adapted and continued to work towards despite the challenges.

One of the concepts encouraged in our MS Leaders' MasterClass around leading for change is that planning for gradual change can be positive, accommodating the challenge of some of these barriers and allowing for continuous reflection and adjustment of plans as needed. Whether starting a big rollout with a single site or a pilot project, or choosing a 'low hanging fruit' and building on that, starting small can help with relationships and energy levels too - and give enthusiasm boosts throughout the change process of a bigger project.

> **'Celebrate small (and big) wins... it may feel as if you and your team are not accomplishing what you had planned. Intentionally look for, share, and celebrate each positive action or accomplishment. Recognising positive responses and celebrating their completion can be very rewarding and not just recharge your own batteries but refill your team's energy bank as well.'**
>
> *Barbara Hoese, Leadership coach and Faculty for MS Leaders Academy via 'Leading in a crisis' 2020*

A model of care for subcutaneous natalizumab in the community

Sinéad Jordan, MS clinical nurse specialist, St Vincent's University Hospital

This project was awarded runner up within the 14th MS MasterClass (Advanced) in 2022.

The growing focus in healthcare for providing better care closer to home (NHS 2019;2022), highlighted in the ten-year Irish initiative Sláintecare (2018) was the driving force of Sinead's project.

Sinéad's local MS service was supporting around 2,000 people with MS, around 70% of whom are on a disease-modifying therapy (DMT). A lack of capacity, resources and staff in the hospital-based infusion unit was leading to delays in their access to treatment.

By delivering more DMTs in the community, aligning with Sláintecare's focus, Sinéad knew she could positively impact patient experience, create capacity in hospital-based infusion suites, and reduce cost to the NHS overall (Kings Fund 2014), so she sought to establish satellite clinics for natalizumab infusion in the community.

Service development

Sinéad's aim is to establish community-based satellite clinics across the patch to provision all people with MS using natalizumab currently receiving infusions at St Vincent's Hospital.

- Projected cost savings based on 100 patients transitioning out to the satellite clinics are in excess of €250,000 per annum.
- Potential further savings could be made by equipping the Advanced nurse practitioner to complete the safety reviews at the clinic.

Sinéad successfully established a satellite clinic, but there were problems with the site and she has had to relocate to a hospital setting - although she has kept the service outside of the IV suite which has still positively impacted patient flow. She is currently looking for a new satellite site.

Workforce changes mean Sinéad is currently managing the service solo and has had to cap the number of hours she can offer. However, her tenacity to see this service vision through means she is currently writing a business case to seek additional nursing support and extend the service out to more patients.

MS service development at Epsom district general hospital

Dr Jananee Sivagnanasundaram, consultant neurologist at Epsom and St Helier University Hospitals NHS Trust

This project was awarded first place at the 11th MS MasterClass (Intermediate) in 2021.

When Jananee first went into post, she was tasked with reviewing current practices for MS services and comparing them with other services across the country, best practice and national guidance, then making recommendations for change, and implementing these.

She found that, with no specific MS neurology lead in place at Epsom, there were three different possible hospital sites for patients to be supported at depending on their needs and preferences. However, they were all under care of the same community MS nursing team - which in turn supported people with MS from other Trusts as well.

There were challenges in professional communication and people's care was not being coordinated across the various services, affecting continuity of care and patient experience.

Service development

Over the course of a year Jananee slowly improved coordination of care and communication across MS teams by introducing a new joint monthly MS clinic in Epsom across consultants and nurses with referral in from multiple sites and a virtual weekly MDT meeting. She also updated the pharmacy prescription pathway and reviewed and updated the local community MDT monitoring to reflect the local tertiary unit's pathways, improving coordination of care with other teams who contribute to the services received by those with MS.

She established a new community MS coordinator to improve coordination from the patients' perspective. To better support more people with MS within the Epsom site, she deliberately upskilled herself from a general neurologist to having an MS specialism through training and virtual attendance of the MS centre's MS MDT meeting.

More recently, Jananee has been liaising with the community MS nursing team who have been reviewing and developing care pathways. She has been the lead consultant working on the new cognition and mood pathway they are developing (led by MS specialist nurse Ruth Stross and also featured in this booklet).

Jananee has more ideas to further improve local services and continues to chip away at them, from extending the monthly MS clinic to another nearby site therefore improving coordination of more people's care, to formalising space for MS-specific consultation time within her job plan so she can support more of the local population with MS within Epsom itself, reducing their travel and improving the continuity of their care.

Utilise strategy

Service change or improvement can be affected by an individual or group with a clear goal, although often there can be challenges in putting plans into action, maintaining positive changes through formal agreements, or establishing ongoing funding. After seeing previous efforts fail due to a lack of clarity around process and referral pathways, specialist nurse Susan Harrison utilised collaborative working and development of a clear patient flow to ensure her service to support mood and cognition in MS was accessible and worked practically within the wider service.

Understanding when and how to write a business case for a new role, or how to trial and create a robust evidence base to 'sell' an idea to management or commissioners are challenging skills that many healthcare professionals are learning. Specialist nurse Ruth Stross used a feasibility study to test her service concept and gather evidence in order to see systematic baselining, assessment and appropriate management of cognitive impairment in MS firmly cemented into local practice.

Understanding current policy drivers or new guidance and aligning an initiative with this can be a good way of making a clear case for the service, as can having a robust evidence-base for the initiative. Many of the initiatives in this booklet align well with the current NHS priorities including the integrated care agenda (2021) and things like prevention, self-directed health and treatment closer to home, set out in the NHS long term plan (2012).

> **'We've shared information along the way and had a lot of help. We're happy to help others too. It's very do-able, finding different approaches, it can just look daunting to start with!'**
>
> *Gale Metcalfe, MS nurse specialist, Leeds Teaching Hospitals NHS Foundation Trust*

Improving management of cognitive impairment in MS

Ruth Stross, MS specialist nurse, Epsom and St Helier University Hospitals NHS Trust, and Dr Victoria Wallace, neurologst ST6, St George's University Hospitals NHS Foundation Trust

This project was part of the 14th MS MasterClass (Advanced) in 2022.

Cognitive impairment affects around one third of people at diagnosis increasing to 50% within five years, and up to 91% of those with primary progressive MS experience it, suggesting it worsens with progression ((Reuter et al, 2011; Ruano et al, 2017). It may acutely worsen during relapse (Benedict et al, 2020), and can hugely impact a person's quality of life, relationships, ability to work and socialise, experience of other MS symptoms, and compliance with medication. NICE suggests comprehensive review by a neuropsychiatrist, but access to these roles is limited, and there are no national or local pathways in place to support this.

Ruth had previously carried out an MS service gap analysis and pathway development across the Surrey area (Stross & Cociascu 2019) and noticed challenges in the flow of services for mood and cognition. Determined to see a systematic approach to assessing and appropriately managing cognitive impairment in people with MS, she established a feasibility study for screening for cognitive impairment in MS and improving its ongoing management alongside colleague Dr Victoria Wallace.

Service development

Ruth carried out a feasibility study for using the Symbol Digit Modality Test (SDMT) for cognitive screening at diagnosis and follow up including identifying costs, training requirements, workload impact, referral triggers and cut offs and onward services (Benedict 2012; 2017; 2020).

She piloted the SDMT with 100 people with MS of different presentations and stages across four MS centres in the area to understand the prevalence of cognitive impairment in those with MS across the Surrey region and to help identify the level of unmet need for neuropsychology input for people with MS.

She has used this information to support collaborative business case development to submit to management and ensure assessment and monitoring of cognition is a core part of the MS comprehensive review locally. She has also begun care pathway creation to ensure clarity and consistency of practice across the whole service.

A new approach – MS and neuro health psychology

Susan Harrison, MS specialist nurse, RVI, Newcastle upon Tyne

This project was part of the 13th MS MasterClass (Foundation) in 2021.

MS is often associated with impaired cognitive functioning, mainly around attention, information processing speed, executive functions and memory. Additionally, many people with MS struggle to accept their diagnosis.

Clinical trials such as COMPASS (MS society online Oct 2021) are helping patients access services to help with mindfulness and cognitive behavioural therapy (CBT) and previous research has found that group therapy can improve mood (Crawford et al, 1985) and reduce cognitive impairment in people with MS (Bilgi et al, 2015).

The coronavirus pandemic caused delayed referrals and longer waiting lists for many services including MS, and Susan and her colleagues were looking for new approaches to better support their patients.

Previous attempts to improve access to CBT and mindfulness had been impacted by confusion around referral templates and this had occasionally led to inappropriate or incorrect referrals, and prolonged waiting lists.

Susan, alongside her wider MS team, decided to take a more strategic approach, and collaborated with the neuropsychology team to design a service intervention which would reduce waiting times, improve clinical support and people with MS's interaction with healthcare professionals, and reduce 'Did not attend' occurrences.

Service development

The MS team and neuropsychology team together developed a plan for group sessions, held in the medi-cinema which would seek to support people with MS across mood and cognition - both significantly impactful symptoms - by addressing generic needs relevant to the group, and promoting CBT and mindfulness.

They agreed on a flowchart proposed by the neuropsychology team, ensuring patients were referred from the MS team into neuropsychology services via the best pathway and creating consistency across the service.

The service remains in early stages of development but the teams are continuing to work together to take the initiative forward.

Give agency to others

From self-directed health to patient activation, there are many terms used for supporting, encouraging or enabling people to take control of their own health journey, and the NHS white papers of late firmly advocate this for benefits to both patients and the NHS alike.

Healthcare professionals have an important role in supported self-management for people with MS, and some of the projects over the years have focused on different elements of this. Specialist nurse Bhawani Devi Mainali's coffee mornings for people with progressive MS, for example, combined opportunity for socialising and peer support with themed educational talks and lifestyle advice, encouraging learning, confidence, camaraderie and wellbeing in one simple - and very well-received - intervention.

A large part of supporting people is offering appropriate information at the right time, providing useful tools to self-monitor or signposting to where people can find space to grow in confidence in making positive changes. Ciara O'Meara's incredibly simple project filled an essential gap in information access for people at the point of diagnosis; her fridge magnet of information directs people with MS to trusted sources of information and online communities for much needed solidarity, advice, support, and encouragement - when they feel ready for it.

> **'The challenge for how we can share information well, and encourage people with MS to take control of their lifestyles is becoming an essential aspect of treatment in MS.'**
>
> *Dr Agne Straukiene, consultant neurologist, Torbay and South Devon NHS Foundation Trust via 'NHS Reset and Reform' 2021*

MS coffee mornings: a novel approach to meeting the needs of people with progressive MS

Bhawani Devi Mainali, MS nurse specialist, Royal Free NHS Foundation Trust

This project was part of the 9th MS MasterClass (Advanced) in 2019.

Following a focus group meeting for another purpose, MS specialist nurse Bhawani learned that people with MS supported by her service were keen to have a local forum to access specialist advice and support. She established a stakeholder meeting of 40 of her patients who proposed a monthly coffee morning which might support self-management such as through expert advice from specialists or perhaps movement classes.

Bhawani set out an idea of the coffee mornings, with examples of talks that might be offered or movement classes such as pilates, and used links with local MS charities to advertise them, as well as sharing information via email and word-of-mouth with her own patients.

Service development

A monthly coffee morning is held at the neurorehabilitation centre combining informal discussion and learning via a guest speaker. It is funded by a local MS charity, managed by Bhawani and supported on the day by a rehabilitation assistant.

- 11 events across 12 months saw 400 people with MS, 300 with progressive disease, attending the monthly coffee mornings.
- 40 people attended regularly.
- The coffee mornings proved so popular that the team had to move to a larger venue.
- The number of calls to MS nurses reduced during this period.

"The meetings give those in the MS Club the opportunity to take advantage of the advice and explanations and suggestions of the speakers, meet up with others and just talk among themselves, perhaps exchanging experiences and ideas. The care of Bhawani, who started this group and her assistant Jenelyn is fantastic." A person with MS who has attended regularly

Bhawani adapted the coffee mornings to suit a virtual setting during the pandemic, which continue to run monthly and are open to people with any form of MS.

She has also now established a face-to-face newly diagnosed course after recognising the benefit people were finding to meeting up and both sharing experiences and learning together.

Navigating MS through the world of social media: steering away from 'Dr. Google'

Ciara O'Meara, college lecturer at the National University of Ireland Galway (NUIG)

This project was awarded first place at the 13th MS MasterClass (Foundation) 2021.

At the time of her project, Ciara was a clinical research nurse living with MS, giving her a unique perspective on how to be a healthcare professional meeting the needs of someone newly diagnosed with MS.

Aware of both how dense the information being given at diagnosis was and the role that the internet and social media can play - for good and for ill - in patient-facing education, Ciara felt there was - and still is - is a responsibility for healthcare professionals to help patients access reputable and supportive online information. However, with so much information available, and so many social sites, healthcare professionals themselves can be overwhelmed with what information to share, whilst people with MS, faced with too much or too little information, are often tempted to try the perceived simplicity of a search engine.

Ciara decided to develop a simple, validated tool to empower patients to access reputable information and valid online outlets to expand their understanding of MS and its management. This would hopefully encourage a move away from the unreliability, misinformation and subsequent fears that can come from undirected online searches.

Service development

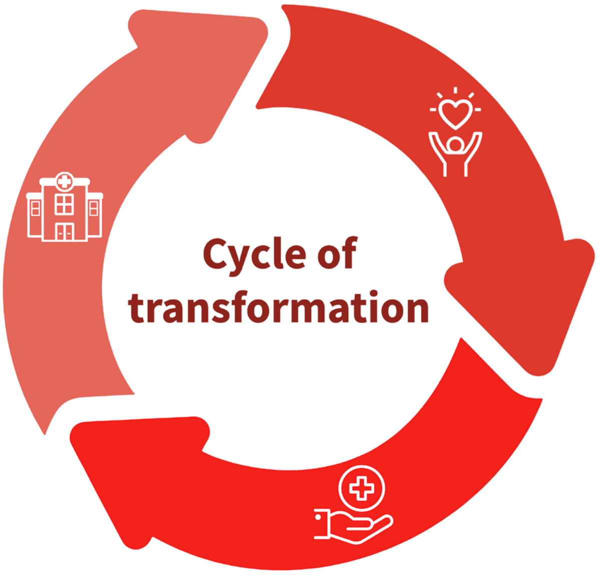
Using stakeholder engagement Ciara developed a compilation of trusted online sites and social media forums to direct people newly diagnosed with MS to. She then turned it into a simple grid to give to people who are newly diagnosed, and validated it with her stakeholder group of people with MS and local specialist nurses. All participants said access to this tool:

- would have supported their acceptance of and learning around MS
- would have facilitated social engagement and increased interaction opportunities with others living with MS

Ciara has worked with designers to turn the tool into a fridge magnet to ensure its accessibility and convenience, to be given out at diagnosis. The essential signposting can be popped on the fridge until the individual is ready to find out more - at which point they can find it easily, and via trusted sites and social networking.

Conclusions

Education which impacts healthcare professionals which impacts services which impacts people's lives… whose experiences shape our education. This is the cycle of transformation which MS Academy believes so wholeheartedly in.



Over the past seven years, the Academy has been privileged to engage with and support more than 1,600 healthcare professionals in the MS community, hopefully positively impacting the lives of many thousands of people living with MS.

We know that many specialist nurses have a caseload far above the recommended 315 (MS Trust 2021), and that neurologists support an average of 1,815 people living with MS each (MS Society 2021). These sorts of numbers alongside delegates' assurances that our education changes their practice for the better, tell us that our courses will have had a tangible and meaningful impact on the lives of many, many people living with MS - which is our central mission and our ultimate goal.

We hope that the coming years see ever more healthcare professionals, across even more varied roles, access the education they need to transform their practice, lead local change, and improve the experiences of those with MS who they support.

References

These are listed alphabetically, not in the order they appear in the report.

1. Benedict, RH et al., (2012). Brief International Cognitive Assessment for MS (BICAMS): international standards for validation. BMC Neurol Jul 16;12:55.
2. Benedict, R. H., et al. (2017). Validity of the Symbol Digit Modalities Test as a cognition performance outcome measure for multiple sclerosis. Multiple Sclerosis Journal, 23(5), 721–733
3. Benedict RHB, Amato MP, DeLuca J, Geurts JJG. (2020) Cognitive impairment in multiple sclerosis: clinical management, MRI, and therapeutic avenues. Lancet Neurol. Oct;19(10):860-871
4. Department of Health and Social Care, Health and social care integration: joining up care for people, places and populations, 11 Feb 2022, accessed https://www.gov.uk/government/publications/health-and-social-care-integration-joining-up-care-for-people-places-and-populations/health-and-social-care-integration-joining-up-care-for-people-places-and-populations#the-health-and-care-workforce-and-carers
5. Department of Health (Ireland), Slaintecare, accessed https://www.gov.ie/en/campaigns/slaintecare-implementation-strategy/
6. Dimitrova A, Murchison C, Oken B. Acupuncture for the Treatment of Peripheral Neuropathy: A Systematic Review and Meta-Analysis. J Altern Complement Med. 2017 Mar;23(3):164-179. doi: 10.1089/acm.2016.0155. Epub 2017 Jan 23. PMID: 28112552; PMCID: PMC5359694.
7. Dobson R, Dassan P, Roberts M, Giovannoni G, Nelson-Piercy C, Brex PA. UK consensus on pregnancy in multiple sclerosis: 'Association of British Neurologists' guidelines. Pract Neurol. 2019 Apr;19(2):106-114. doi: 10.1136/practneurol-2018-002060. Epub 2019 Jan 5. PMID: 30612100.
8. Edwards A, Community services: How they can transform care, Kings Fund, Feb 2014, accessed https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/community-services-nigel-edwards-feb14.pdf
9. Foley, PL, Vesterinen, HM, Laird, BJ, et al. Prevalence and natural history of pain in adults with multiple sclerosis: Systematic review and meta-analysis. Pain 2013; 154: 632–642.
10. Heitmann H, Andlauer TFM, Korn T, Mühlau M, Henningsen P, Hemmer B, Ploner M. Fatigue, depression, and pain in multiple sclerosis: How neuroinflammation translates into dysfunctional reward processing and anhedonic symptoms. Mult Scler. 2022 Jun;28(7):1020-1027. doi: 10.1177/1352458520972279
11. Heitmann H, Haller B, Tiemann L, Mühlau M, Berthele A, Tölle TR, Salmen A, Ambrosius B, Bayas A, Asseyer S, et al; German Competence Network Multiple Sclerosis (KKNMS). Longitudinal prevalence and determinants of pain in multiple sclerosis: results from the German National Multiple Sclerosis Cohort study. Pain. 2020 Apr;161(4):787-796. doi: 10.1097/j.pain.0000000000001767. PMID: 32197038.
12. Horse, Barbara, 'Keep Calm and Carry On, Or What I Learned from Reading 50 Articles About Leading in a Crisis', Neurology Academy, pub online 27 Apr 2020 accessed https://neurologyacademy.org/articles/barbara-hoese-keep-calm-and-carry-on-or-what-i-learned-from-reading-50-articles-about-leading-in-a-crisis
13. Karpatkin HI, Napolione D, Siminovich-Blok B. Acupuncture and multiple sclerosis: a review of the evidence. Evid Based Complement Alternat Med. 2014;2014:972935. doi: 10.1155/2014/972935. Epub 2014 Jun 18. PMID: 25045394; PMCID: PMC4086829.
14. Leray E, Marrie RA, Robertson N, La Rocca N, Uitdehaag B, van der Mei I, Wallin M, Helme A, Angood Napier C, Rijke N, Baneke P. Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS, third edition. Mult Scler. 2020 Dec;26(14):1816-1821. doi: 10.1177/1352458520970841. Epub 2020 Nov 11. PMID: 33174475; PMCID: PMC7720355.
15. Multiple Sclerosis Academy, NHS Reset and Reform: A new direction for health and care in multiple sclerosis, February 2021, https://neurologyacademy.org/ms-academy/resources/nhs-reset-and-reform (accessed 17.08.22)
16. Multiple Sclerosis Academy, Projects: Stross R & Cociascu I, 'Mapping Pathways in Multiple Sclerosis across Surrey Downs Health & Care', December 2019 accessed https://neurologyacademy.org/ms-academy/projects/mapping-pathways-in-multiple-sclerosis-across-surrey-downs-health-care
17. MS Society, 2021, Neurology now: the case for a new approach to neurology services, accessed https://www.mssociety.org.uk/sites/default/files/2021-10/Neuro%20Report%20V3.pdf (08.11.22)
18. MS Society and Public Health England, MS Prevalence Report January 2020,https://www.mssociety.org.uk/sites/default/files/2020-08/MS-in-the-UK_2020.pdf (accessed 17.08.22)

References

19. MS Trust a, A-Z: Pain accessed https://mstrust.org.uk/a-z/pain (17.08.22)
20. MS Trust b, A-Z: Acupuncture accessed https://mstrust.org.uk/a-z/acupuncture (17.08.22)
21. MS Trust c, 'Multiple sclerosis specialist nursing in the UK 2021:results from the MS Trust nurse mapping survey, November 2021, accessed https://mstrust.org.uk/sites/default/files/ms-trust-specialist-nursing-UK-2021.pdf (08.11.22)
22. Murphy KL, Bethea JR, Fischer R. Neuropathic Pain in Multiple Sclerosis—Current Therapeutic Intervention and Future Treatment Perspectives. In: Zagon IS, McLaughlin PJ, editors. Multiple Sclerosis: Perspectives in Treatment and Pathogenesis [Internet]. Brisbane (AU): Codon Publications; 2017 Nov 27. Chapter 4. Available from: https://www.ncbi.nlm.nih.gov/books/NBK470151/doi: 10.15586/codon.multiplesclerosis.2017.ch4
23. Optimum clinical pathway: multiple sclerosis, July 2019, https://www.neural.org.uk/wp-content/uploads/2020/07/Optimum-pathway-for-patients-with-MS_updated.1.pdf (accessed 17.08.22)
24. Neurology Academy, 'Specialist nurses share their experiences with data – and encourage others to do the same' 1st July 2021, accessed https://neurologyacademy.org/articles/specialist-nurses-share-their-experiences-with-data-and-encourage-others-to-do-the-same
25. NHS Digital, 'Hospital Episodic Statistics (HES)' accessed https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics
26. NHS England, Integrated care, accessed https://www.england.nhs.uk/integratedcare/
27. NHS Long Term Plan (2019) accessed https://www.longtermplan.nhs.uk/
28. Piwko C, Desjardins OB, Bereza BG, Machado M, Jaszewski B, Freedman MS, Einarson TR, Iskedjian M. Pain due to multiple sclerosis: analysis of the prevalence and economic burden in Canada. Pain Res Manag. 2007 Winter;12(4):259-65. doi: 10.1155/2007/128681. PMID: 18080044; PMCID: PMC2670736.
29. Reuter F, Zaaraoui W, Crespy L, Faivre A, Rico A, Malikova I, Confort-Gouny S, Cozzone PJ, Ranjeva JP, Pelletier J, Audoin B. (2011) Cognitive impairment at the onset of multiple sclerosis: relationship to lesion location. Mult Sclerosis. Jun;17(6):755-8. Rouleau, I., Dagenais, E., Tremblay, A., Demers, M., Roger, É, Jobin, C., & Duquette, P. (2018). Prospective memory impairment in multiple sclerosis: A review. The Clinical Neuropsychologist, 32(5), 922–936.
30. Ruano L, Portaccio E, Goretti B, Niccolai C, Severo M, Patti F, Cilia S, Gallo P, Grossi P, Ghezzi A, Roscio M, Mattioli F, Stampatori C, Trojano M, Viterbo RG, Amato MP. (2017) Age and disability drive cognitive impairment in multiple sclerosis across disease subtypes. Mult Sclerosis. Aug;23(9):1258-1267.
31. Theysohn N, Choi KE, Gizewski ER, Wen M, Rampp T, Gasser T, Dobos GJ, Forsting M, Musial F. Acupuncture-related modulation of pain-associated brain networks during electrical pain stimulation: a functional magnetic resonance imaging study. J Altern Complement Med. 2014 Dec;20(12):893-900. doi: 10.1089/acm.2014.0105. PMID: 25389905; PMCID: PMC4270153.
32. Thomas S, Bradley J, Cole G, Girvan M, Metcalfe G, Naik P, Owen A, Solomons M, Stross R, Yaes A, Webb M, White S, Young J, A consensus bladder and bowel management pathway for multiple sclerosis: process and application, BJNN, Vol 18 no.sup3, Published Online:4 Aug 2022, https://doi.org/10.12968/bjnn.2022.18.Sup3.S6
33. Thomas S & Stross R, Translating data into service change: Bladder & bowel management for MS,2021, poster accessed https://cdn2.assets-servd.host/mushy-parakeet/production/assets/resources/Sue-Thomas-Ruth-Stross-MS-bladder-and-bowel-management-poster-translating-data-into-service-change.pdf (19.08.22)
34. Xu J, Xie H, Liu L, Shen Z, Yang L, Wei W, Guo X, Liang F, Yu S, Yang J. Brain Mechanism of Acupuncture Treatment of Chronic Pain: An Individual-Level Positron Emission Tomography Study. Front Neurol. 2022 May 2;13:884770. doi: 10.3389/fneur.2022.884770. PMID: 35585847; PMCID: PMC9108276.

Multiple Sclerosis Academy®

Neurology Academy®

Neurology Academy: education with impact

Multiple Sclerosis Academy is part of Neurology Academy.

Neurology Academy is an innovative educational provider for healthcare professionals including consultants, specialist nurses, pharmacists, therapists and other allied health professionals. Our courses are developed by practising specialists who combine their experience and expertise into case-based learning designed to create specialists in their field with confidence in effecting change.

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'.

www.neurologyacademy.org

Neurology Academy
1 The Edge Hillsborough Barracks
Langsett Rd
Sheffield
S6 2LR

☎ **01143 270 230**
✉ **info@neurologyacademy.org**
🐦 **@TheNeuroAcademy**