Optimal clinical care pathway for adults: Multiple Sclerosis

National Neurosciences Advisory Group (NNAG)

Published: November 2024

Contents

Overview: About the optimal pathway

This pathway is part of a suite of optimal neuroscience clinical pathways that have been developed by the neurological community, with the support of NHS England and the National Neurosciences Advisory Group (NNAG).

The development of this pathway was overseen by NNAG, with input from professional bodies and patient organisations. A 6 week public consultation was held to gather input, views and experience from people affected by neurological conditions and wider stakeholders.

The pathways set out what good treatment, care and support looks like. This includes treatment and support for people who may be experiencing the first symptoms of a neurological condition, right through to people who have lived with a condition for a long time. They set out the aspirations for good care, support improvement of services and enable commissioning of quality services, locally and nationally.

Optimal Clinical Neuroscience Pathways

NEUROSCIENCE

SUBARACHNOID/INTRACRANIAL HAEMMORHAGE
PITUITARY TUMOUR
BRAIN TUMOURS
MULTIPLE SCLEROSIS (MS)
EPILEPSY
AUTOIMMUNE
HEADACHE & FACIAL PAIN
NEUROMUSCULAR CONDITIONS
MOVEMENT DISORDERS
MOTOR NEURONE DISEASE (MND)
FUNCTIONAL NEUROLOGICAL DISORDER (FND)
TRAUMATIC BRAIN INJURY (TBI)

CROSS-CUTTING

TRANSITION FROM CHILDREN TO ADULT SERVICES
NEUROGENETICS
MENTAL HEALTH
REHABILITATION

FIND OUT MORE

Optimal clinical pathways and resources (NHS England and NHS Improvement. NHS log in required): www.future.nhs.uk/about

FutureNHS

VISIT WEBSITE

Optimal clinical pathways and resources (NNAG): www.nnag.org.uk/optimum-clinical-pathways

NNAG National Neurosciences Advisory Group

VISIT WEBSITE

Neurological patient organisation websites & resources (Neurological Alliance): www.neural.org.uk/membership/our-members

THE NEUROLOGICAL ALLIANCE

VISIT WEBSITE

Executive summary

This optimal clinical pathway for people with MS (pwMS) was designed by a working group of healthcare professionals with expertise in multiple sclerosis (MS), people affected by MS and MS Charities (see Appendix for group membership).

There are over 123,442 people with MS in England, or 1 in 450 people. Nearly 7,100 people in the UK are newly diagnosed each year (MS Society UK, 2024). www.mssociety.org.uk/what-we-do/our-work/our-evidence/ms-in-the-uk.

It's most commonly diagnosed in people in their 20s, 30s and 40s although it can develop at any age. It's about 2 to 3 times more common in women than men. Research suggests the proportion of women with MS is increasing. Around 250 children in the UK have an MS diagnosis (MS Trust, 2024).

Understanding the cost of MS to each person, to the health and care system and society in general is important. It can help us to make effective use of resources so we can provide better outcomes for people with MS.

One study estimated the average cost in the UK of MS per person, per year as: £11,400 for people with mild levels of disability; £22,700 for people with medium levels of disability; £36,500 for people with advanced disability. Other studies put these costs as even higher, particularly for people with advanced disability. Living with advanced disability can cost more because of higher community services and informal care costs, and absence or exit from employment (Thompson, et al., 2017).

Hospital episode statistics (HES) data shows that, in 2019/20, UTI was the cause of emergency admission for 9.5% of hospital stays, incurring an average cost of £2710 per emergency admission, with a total cost of £7.9 million (Thomas, 2022).

The group emphasises the need for pwMS to be referred directly to an MS specialist for confirmation of diagnosis and assessment for disease modifying therapies (DMTs). Access to a multidisciplinary team (MDT) with expertise in MS is critical, to ensure timely and responsive care, ensuring all resource and expertise is used most effectively.

Executive summary

The pathway recommends that relapse, disease progression, symptom management, palliative and end of life care could be triaged through a MS administrative coordinator with knowledge of an MS service, with an MS nurse or practitioner available to manage a patient's care plan.

A core principle of this MS pathway is to keep care as local as possible, and delivered in the home, if appropriate, for people with complex issues or those in the severe stage of MS.

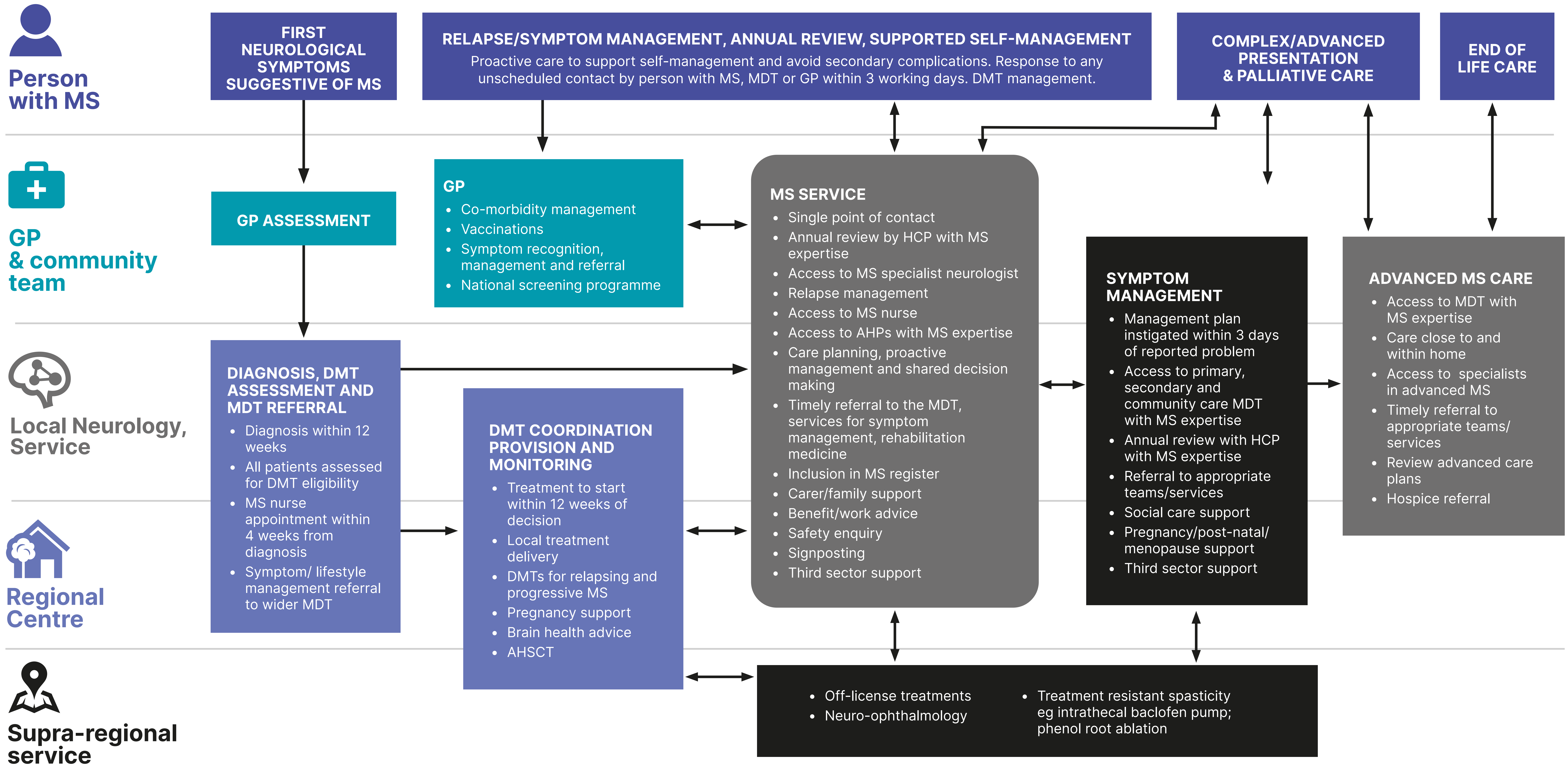
The group emphasises the importance of having access to a specialist MS team and clinic with different healthcare professionals (HCPs) working together. This should be available to every person with MS, regardless of time since diagnosis. The model should be delivered by a network of specialists linked virtually, operating in local services, with access to an infusion centre and systems and processes that support safety monitoring. Blood tests and routine monitoring should be done as close to home as possible.

Key enablers of the optimal pathway include networking between specialists and non-specialists, and timely referral and consultation. Additionally, increased focus on data sharing between and across services, as well as with people with MS, would greatly facilitate communication between clinicians and improve patient care.

Barriers to the optimum pathway include workforce shortages of MS specialist neurologists, MS specialist neuro-radiologists, MS nurses, MS specialist AHPs, MS service administration support, difficulties accessing clinical trials and shortages in rehabilitation medicine specialists.

Multiple Sclerosis Optimum Pathway

GOAL: Appropriate, timely, proactive, quality care at every stage
ON-GOING: Patient and carer information, education, shared decision-making, supported self-management, lifestyle advice, opportunity to participate in research



Person with MS

GP & community team

Local Neurology, Service

Regional Centre

Supra-regional service

FIRST NEUROLOGICAL SYMPTOMS SUGGESTIVE OF MS

RELAPSE/SYMPTOM MANAGEMENT, ANNUAL REVIEW, SUPPORTED SELF-MANAGEMENT

Proactive care to support self-management and avoid secondary complications. Response to any unscheduled contact by person with MS, MDT or GP within 3 working days. DMT management.

COMPLEX/ADVANCED PRESENTATION & PALLIATIVE CARE

END OF LIFE CARE

GP ASSESSMENT

GP

- Co-morbidity management
- Vaccinations
- Symptom recognition, management and referral
- National screening programme

MS SERVICE

- Single point of contact
- Annual review by HCP with MS expertise
- Access to MS specialist neurologist
- Relapse management
- Access to MS nurse
- Access to AHPs with MS expertise
- Care planning, proactive management and shared decision making
- Timely referral to the MDT, services for symptom management, rehabilitation medicine
- Inclusion in MS register
- Carer/family support
- Benefit/work advice
- Safety enquiry
- Signposting
- Third sector support

SYMPTOM MANAGEMENT

- Management plan instigated within 3 days of reported problem
- Access to primary, secondary and community care MDT with MS expertise
- Annual review with HCP with MS expertise
- Referral to appropriate teams/services
- Social care support
- Pregnancy/post-natal/ menopause support
- Third sector support

ADVANCED MS CARE

- Access to MDT with MS expertise
- Care close to and within home
- Access to specialists in advanced MS
- Timely referral to appropriate teams/ services
- Review advanced care plans
- Hospice referral

DIAGNOSIS, DMT ASSESSMENT AND MDT REFERRAL

- Diagnosis within 12 weeks
- All patients assessed for DMT eligibility
- MS nurse appointment within 4 weeks from diagnosis
- Symptom/ lifestyle management referral to wider MDT

DMT COORDINATION PROVISION AND MONITORING

- Treatment to start within 12 weeks of decision
- Local treatment delivery
- DMTs for relapsing and progressive MS
- Pregnancy support
- Brain health advice
- AHSCT

- Off-license treatments
- Neuro-ophthalmology
- Treatment resistant spasticity eg intrathecal baclofen pump; phenol root ablation

Context

The UK prescribes a lower rate of disease-modifying treatments than other European countries (Nicholas, et al., 2023). 4 in 10 (43%) of people with relapsing MS are not currently taking a DMT (MS Society, 2022).

There is an annual growth rate of 2.4% of people with MS (pwMS) in the UK (Mackenzie, Morant, Bloomfield, MacDonald, & O'Riordan, 2014). There is evidence that the quality of the service is declining, with a sharp increase in the number of emergency admissions with length of stay greater than 2 days in 2017/18 as compared to earlier years. On average, having MS reduces your life expectancy by six to seven years (MS Trust, 2024). Hospital episode statistics (HES) data shows that, in 2019/20, UTI was the cause of emergency admission for 9.5% of PwMS' hospital stays, incurring an average cost of £2710 per emergency admission, with a total cost of £7.9 million (Thomas et al, 2022).

This pack is the output of the Multiple Sclerosis Clinical Working group's efforts to define the optimal pathway for people with MS. The guidance outlines:

- The optimal pathway for patients with MS from first symptoms to end of life care.
- The definition of "specialised" MS care.
- A workforce model to support implementation.
- Quality indicators to support the optimum pathway.
- Identifies barriers and provides recommendations around patient flow, use of technology and research and clinical trials.

Pathway: Referral to diagnosis

Guiding principle:

- People with MS should have an accurate and timely diagnosis, in order to access appropriate therapies efficiently, to minimise the accumulation of irreversible disability. This includes access to DMTs, symptomatic treatments and a multi-disciplinary team.
- People with MS diagnosed by general neurologists (and other doctors), should be referred to an MS specialist neurologist for categorisation of the patients' disease and access to therapies.
- Refer people suspected of having MS for diagnosis by a consultant neurologist or a specialist under their supervision. Contact the consultant neurologist directly if you think a person needs to be seen urgently (National Institute for Health and Care Excellence, 2022).

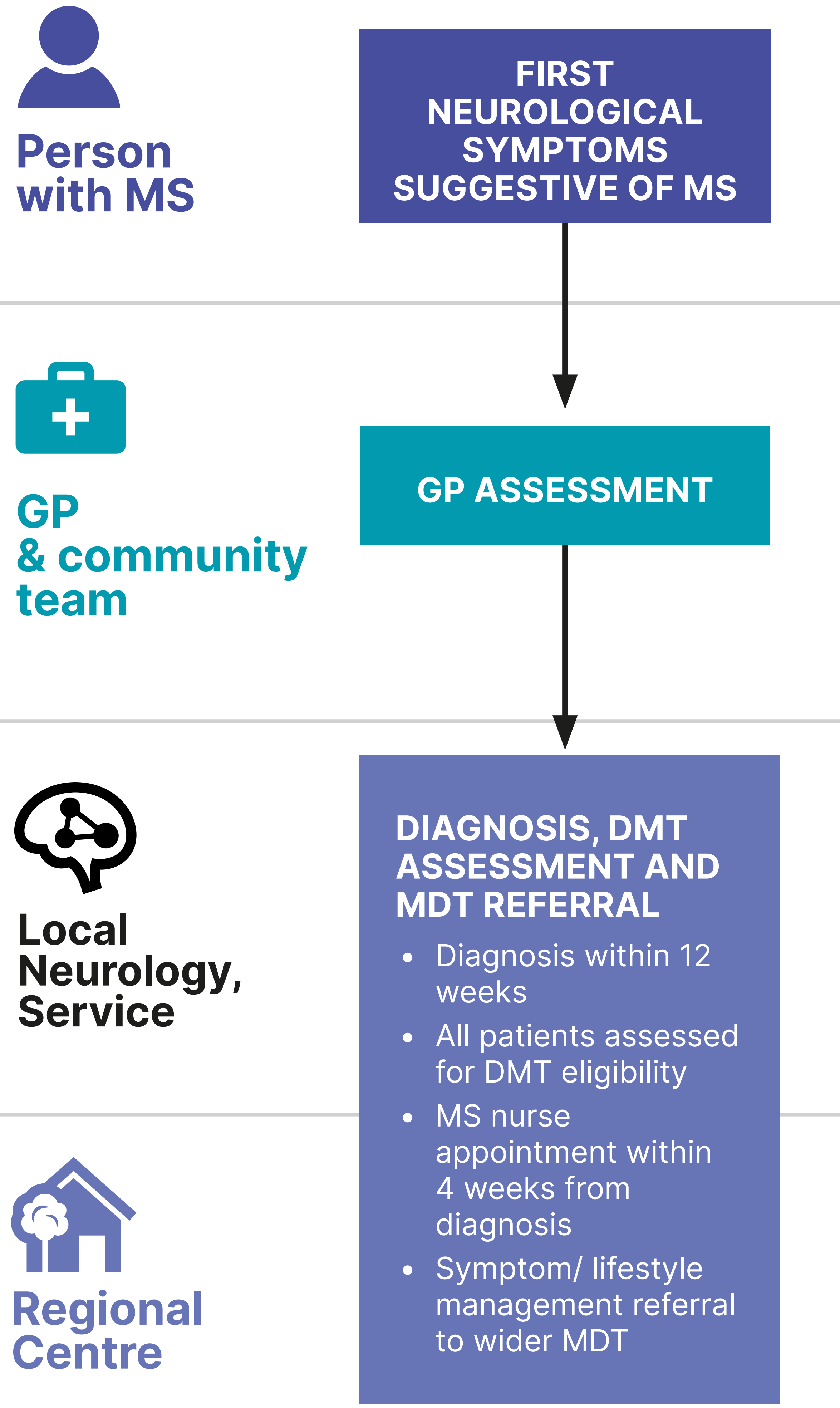
Barriers

One barrier to this model is the capacity of specialist neurologists and diagnostic services such as MRI scans and lumbar puncture. There is a shortage of neurologists in the UK. The ABN calculates that there is 1 Full Time Equivalent (FTE) consultant neurologist per 91,175 (1.1 per 100,000). This is much less than expected for similar high income European countries (e.g. France and Germany both have 1 per less than 25,000) (Nitkunan, Lawrence, & Reilly, 2020). Whilst this needs to be addressed in the longer term, changes also need to be made to the way MS services are delivered in the shorter term to allow a MDT approach that makes use of other staff within the team to deliver the best outcomes for pwMS. It is recognised that with increasing numbers of patients on DMTs & the associated monitoring there is increased pressure on MS services & a reduced capacity for neurologists to see all routine follow ups. A key step in the pathway is confirmation of diagnosis: 20% of people referred for MS specialist services are found not to have MS (Kaisey, Solomon, Luu, Giesser, & Sicotte, 2019).

Enablers

One solution is for MS services to move to a model whereby consultants only see new patients at diagnosis and see those who require an urgent review due to relapse, disease activity, drug toxicity or another specific reason. Routine follow ups could then take place in MS nurse clinics, in person or virtually. This may require an increase in the number of MS Nurses within the service. In turn, the tasks undertaken by the MS Nurse should be reviewed to ensure appropriate use of nursing time. Crucially, people affected by MS report that a timely service response to changes in their condition is a key priority for good care.

Roles that could be undertaken by other staff members should be identified. For example, pharmacists can undertake safety monitoring and prescribing. It is equally important to improve GP knowledge of MS and facilitate GP-consultant communication (e.g. through an advice line).



Person with MS

FIRST NEUROLOGICAL SYMPTOMS SUGGESTIVE OF MS

GP & community team

GP ASSESSMENT

Local Neurology, Service

DIAGNOSIS, DMT ASSESSMENT AND MDT REFERRAL
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Regional Centre

Pathway: From diagnosis to specialist MS service assessment

Guiding Principles

- All people with MS should have a clear care plan (management plan) agreed through shared decision making with a named clinical care coordinator (Rightcare, 2019).
- All people with MS should have a single point of contact for access to the MS service, which could be led by a non-clinical administrator (Rightcare, 2019).
- All patients with MS should be able to access a Specialist MS nurse and AHPs with expertise in MS.
- People with MS should have access to education and opportunities for self-management.
- People with MS should be supported to undertake proactive management of their condition, to support the maintenance of physical and cognitive ability, functional skills and quality of life.
- All people with MS should be offered an annual review by a healthcare professional with expertise in MS (National Institute for Health and Care Excellence, 2022).
- Services should provide rapid access for assessment of changes in a patient's condition (relapse, onset of progression).
- People with MS should be encouraged to maintain physical activity, and advised on lifestyle issues (e.g. smoking). This early support helps people with MS (and their families and carers) to begin to understand what MS is, what treatments are available and how the symptoms can be managed (National Institute for Health and Care Excellence, 2022).
- People with MS should be offered an information prescription to trusted sources from the point of diagnosis and throughout their journey with MS.
- Provide ongoing information and support tailored to the person's changing needs or circumstances, for example, when planning to have children, if their MS is changing to a more progressive phase or as their MS becomes more advanced (National Institute for Health and Care Excellence, 2022).

Enablers:

MS services could be delivered by a network of specialists linked virtually.
MS services should be supported by an administrator (NHS RightCare, 2019).
to help coordinate and triage care.
Advances in data and technology could allow for access to a co-ordinated care plan, supported by shared care records.
Access to MS specialist AHPs from diagnosis to support physical activity, psychological needs, cognitive support, self-management and work-related issues.
Access to rehabilitation and proactive symptom management is critical.

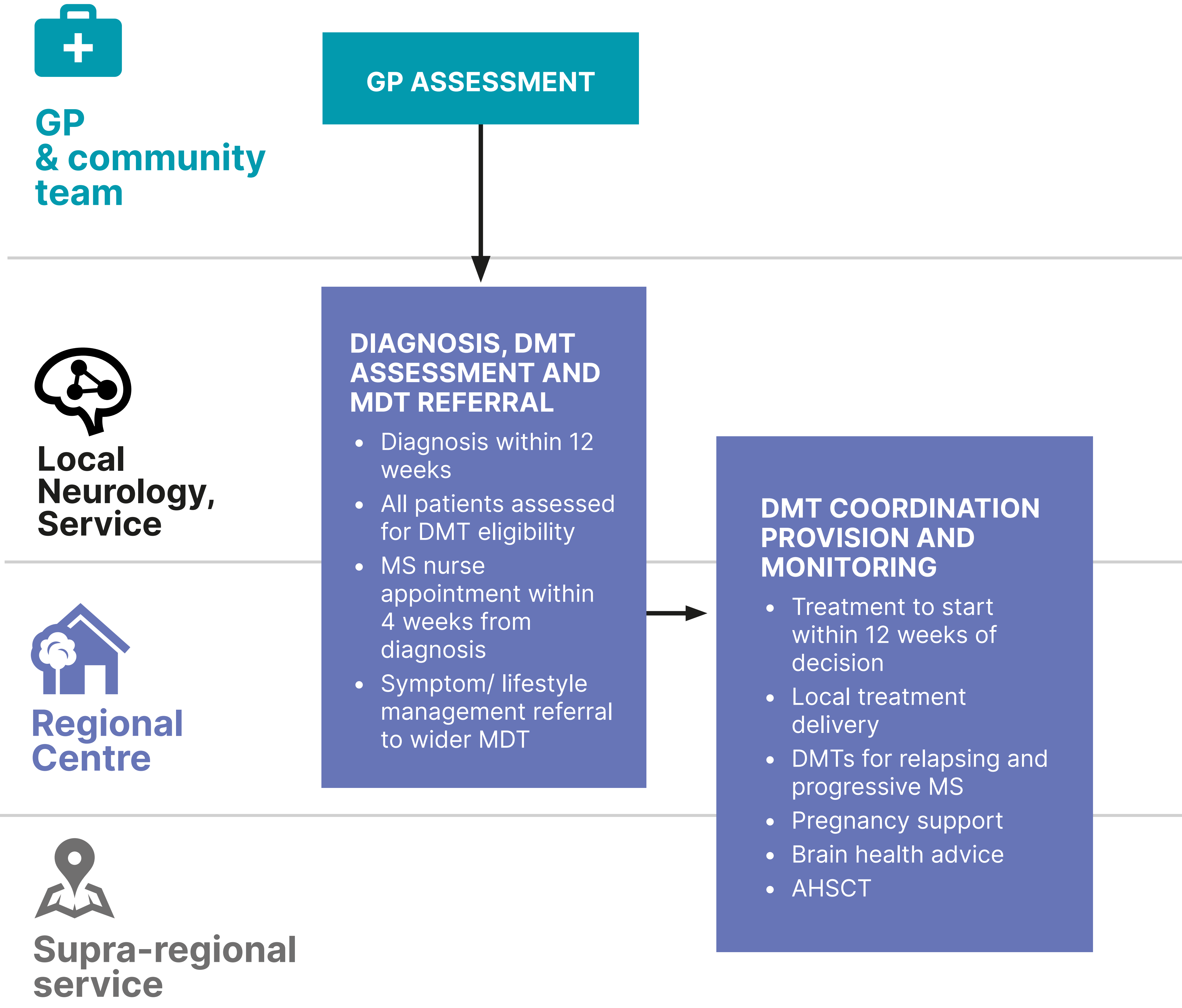
Pathway: Disease modifying therapies (DMTs)

Guiding principles

All people with MS should be assessed as early as possible after diagnosis or after any significant change in symptoms, for their eligibility for disease modifying therapy, given the evidence that early treatment improves long-term outcomes.
All patients, from diagnosis on, should be assessed for symptomatic treatments, psychological support and eligibility for mental health services and referred to the appropriate HCP or team.

Enablers:

- DMTs can be delivered by a network of specialists linked virtually, operating across different settings with access to an infusion centre and an IT system that supports safety monitoring.
- Blood tests could be taken in a location close to patients (primary or secondary care). Results must be available to the treating team. Drugs can be administered in a local infusion centre.
- Routine prescribing and monitoring does not need to be by a consultant neurologist, but could be by a MS nurse or pharmacist with necessary experience and knowledge. EDSS assessments could be done by a physiotherapist with MS expertise or MS nurse.
- An MS specialised service requires competence in prescribing all DMTs.
- Certain disease modifying treatments need to be discussedin a MDT for Blueteq approval. The MDT for disease modifying therapies must include at least two MS neurologists and one MS nurse.
- If a MS service has only one neurologist, then each patient’s case will need to be discussed at a DMT MDT in a nearby regional centre.



GP & community team

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GP ASSESSMENT

DIAGNOSIS, DMT ASSESSMENT AND MDT REFERRAL
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- AHSCT

Pathway: Symptom management

Symptom management and specialist MDT care

People with MS should be offered a comprehensive annual review with a professional who specialises in MS and works in a MDT (National Institute for Health and Care Excellence, 2022). These specialists may meet outside a Neurosciences Centre, but it is important that there is face to face contact of the core MS team on a regular basis, to facilitate team communication.

Patients should also be assessed for ability to self-manage and self-refer without the need for such frequent or regular follow up (For example by Patient Initiated Follow Up (PIFU).

People with MS should receive regular assessment of symptoms. Common symptoms in MS include fatigue, depression, bladder and bowel issues and pain. Symptoms could be assessed using a formal validated tool, such as LUNS-MS (Mohamed Abu Baker A, 2023).

Services should be organised on a population health basis to ensure in conjunction with partner organisations so that people affected by MS have equitable access to integrated care between hospital and community providers for all elements of their care across the whole pathway.

Enablers

- Digital technology (e.g. apps for symptom monitoring and improved data sharing).
- Virtual clinics.
- Care planning.
- Creation/continuation of neurospecialist AHP posts.
- Established links with local Social services and community teams.
- Patient activation measures.

Barriers

Barriers to quality include time, patient engagement with the service, patient activation, and coordination of the service. Lack of access or capacity in the workforce, including specialist rehabilitation, specialist AHPs, or AHPs with expertise in MS.

MS services should facilitate access to the following core MDT within a region:

- Physiotherapist (for physical activity, mobility issues, transfers, balance, ataxia, vestibular dysfunction, spasticity and spasm management, standing, respiratory interventions e.g. NIPPY, splinting, and Functional Electrical Stimulation – FES).
- Occupational Therapist: to support maintenance of daily living activities, affected by the physical, psychological and emotional impacts of MS, in all spheres of life- ie at home, work, socialising or with leisure activities. This includes: teaching skills to cope with change in function, education (e.g. newly diagnosed/symptom management programmes), fatigue management, cognitive and vocational rehabilitation, prescription of equipment for daily living, housing adaptations, psychological and emotional support, orthotics, support for participation in preferred hobbies and interests and support to promote 'activation' and self-management).

Pathway: Management of advanced MS

Advanced MS is not the type of MS people have but how it impacts on them.

The MS Trust define advanced MS as:

- multiple, ongoing and often complex symptoms which may occur simultaneously;
- dependence on others for some or all care and support needs, or;
- significant disability.
- Many people with advanced MS are restricted in their mobility and find attending clinics difficult, and as a result are lost to follow-up.

Barriers

- Finding staff with the expertise needed.
- Succession planning.
- Patient engagement with service.
- Coordination with local authorities.

People with advanced MS should

- Be on the formal centre database/clinical management caseload to ensure follow up (and ideally also on the MS Register).
- Have access to timely rehabilitation.
- Have timely access to a named care coordinator or case manager with clinical expertise in MS. This may be a specialist in advanced MS - this has been piloted by the MS Trust. The pilot has demonstrated the success of the AMSC role to manage seamless care and reduce fragmented services to maximise the function and quality of life for people with advanced MS, with cost savings of emergency admissions £465,376 per site per year (MS Trust, 2022).
- Have timely referral to the appropriate member of the MDT. The MDT should include a local, community-based, neuro rehab team with a designated lead for MS (Rightcare, 2019). As a minimum these teams should have: occupational therapists, psychology, physiotherapists, MS nurse, SLT, dietitian, designated team administrator and a link to a rehabilitation medicine specialist.
- Have prompt access to continence teams, neuro psychologists and respiratory teams.
- Have an annual review by an AHP with expertise in MS, utilising a comprehensive annual review form covering all elements of NICE recommendations.
- Have access to specialist equipment when required including seating/wheelchairs/pressure care/environmental control systems/home adaptations/orthotics/respiratory interventions e.g. NIPPY/cough assist/lung volume recruitment bags.
- Consider the use of telerehabilitation, particularly for those who live away from MS centres.

Pathway: Reproductive and gender-specific health

Guiding principles:

- Discussions around reproductive and gender-specific healthcare should be initiated proactively across the course of MS.
- All pwMS should have access to gender specific reproductive healthcare including, but not limited to, advice regarding fertility, assisted conception, pregnancy and post natal care.
- The desire to start a family should not be a barrier to high efficacy disease modifying therapies where these are indicated.
- Women who wish to breastfeed should be given up to date advice regarding DMT compatibility.
- Fluctuations in MS symptoms throughout the menstrual cycle is reported and more research is needed to better understand this.
- The symptoms of menopause and perimenopause overlap with MS symptoms. Having MS or being on a DMT is not a contraindication to hormone replacement therapy (HRT).
- It is currently not known whether the menopausal transition triggers a shift in MS inflammatory activity and/or rate of progression; evidence to date is limited and conflicting. PwMS experiencing changes in MS disease activity should be treated according to best practice DMT algorithms.
- HRT has benefits for bone health which may be particularly relevant for post menopausal women with MS.
- Lifestyle management and advice remains a key component of MS care.

Barriers

- Lack of access to specialist advice.
- Uncertainty regarding long term implications of DMT exposure around pregnancy.
- Awareness and communication between primary and secondary care regarding overlap symptoms of MS and menopause and knowledge around HRT safety in MS.
- Lack of research regarding gender-specific healthcare.

Enablers

- Specialist pre-conception/pregnancy and MS clinics.
- Education of MS specialists and primary care professionals in the benefits of managing menopausal symptoms in women with MS.
- Empowerment of women to access menopause treatment from primary care.
- Improved cross-specialty communication and knowledge sharing.

Pathway: Specialised components of care

DMTs are currently commissioned by NHS specialised commissioning, through Neurosciences Centres, with local agreements allowing wider provision.

"Specialised services" are those which require technology only available in neuroscience centres. In the care of people with MS, this includes, for instance, AHSCT or rare examples of surgery for MS.

Specialist clinical staff can work in and outside of a specialised centre.

MS specialised care

Almost none of MS care needs to take place in a specialised centre, with the exception of neurosurgery and complicated neurological procedures such as stem cell therapy. While neuroradiology specialists should interpret scans, the scanning itself can be done locally. The most important thing is that care is coordinated and that specialist support is available when under generalist/ local care.

Effective networking and communication can allow sole neurologists in smaller centres to prescribe and provide DMTs, in collaboration with an MDT within a regional centre.

Workforce: Alternate workforce models

CASE STUDY

DMT Coordinator

The MS service in Leeds has two MS Treatment coordinators dedicated to managing the administration of DMTs. The coordinators are band 5 administrators, working 24 hours per week, co-ordinating care for approximately 1200 people in Leeds and Bradford 1.2 wte. Leeds is a regional prescribing centre for DMTs and manages treatment not only for people within Leeds but also outlying areas such as Calderdale and Kirklees and Harrogate where there are locally based MSSNs. The coordinator is responsible for liaising with consultant neurologists, pharmacists and home delivery services to ensure the timely renewal of DMT prescriptions, and provides direct telephone and email support for pwMS with non-clinical DMT queries with between 40-50 contacts per week. The coordinator is also responsible for managing clinic lists for pwMS in order to best utilise clinic capacity and co-develops patient pathways for new DMTs with the MS team based on pharmaceutical guidelines and NICE technological appraisals.

Benefits	Responsibilities
■ PwMS on DMTs have a direct point of contact for non- clinical issues and an advocate to deal with problems involving home delivery companies and pharmacies. ■ Although part-time, the coordinator is able to respond to calls the same or next working day. ■ Non-clinical yet complex administration tasks are relieved from clinical staff. ■ Individual pwMS on DMTs are effectively tracked - the DMT coordinator maintains a database detailing monitoring events and alerts that are followed up if missed ensuring that monitoring is effective and timely.	Monitoring for patients on all DMTs working with the MSSN team: Prescription management: ■ New patients (including those referred from outlying MSSNs). Clinic management: ■ Communications with patients. ■ Support for research and clinical trials.

Technology: Use of technology

Key recommendation:

- To take advantage of local and national technology and clinical management systems in order to maximise the efficiency and quality of MS Care (Rightcare, 2019).
- To consider the use of telerehabilitation for people affected by advanced MS.

This includes introduction and expansion of the following:

- Use of a clinical management tool to assist care.
- Entry of a minimum data set in a national register.
- Data sharing between:
  - professionals (including access to advice from national experts);
  - MS registers that do exist;
  - Key sets of national and local data (e.g. HES, Blueteq, PROMS); and
  - People with MS (all pwMS should have access to a care record).
- Patient portals, to access clinic letters and blood results, and for education and encouragement for self-management.
- Local IT systems for bloods to be sent to specialists.
- Network of specialists linked virtually, operating in the community with access to an infusion centre and an IT system that supports safety monitoring.

Standards & Metrics: Quality standards and associated metrics

Quality Standard	**Clinical metric**	**Patient self-reported metric**
Diagnosis of uncomplicated MS to be confirmed and communicated to the patient within 12 weeks of receipt of GP referral by specialist MS team	Diagnosis confirmed within 12 weeks of receipt of referral	■ Did you get a confirmed diagnosis of MS within 12 weeks of receipt of GP referral?
A face-to-face follow-up appointment with a specialist MS nurse is offered within 4 weeks of receipt of referral post-diagnosis	Percentage of people with confirmed diagnosis of MS who are offered a face-to-face follow-up appointment with a specialist MS nurse within 4 weeks of receipt of referral ■ Percentage of people with confirmed diagnosis of MS who are offered and attend a face-to-face followup appointment with a specialist MS nurse within 4 weeks of receipt of referral	■ Once you had been diagnosed with MS, were you offered a face-to-face appointment with a specialist MS nurse within 4 weeks of getting referred?
People with a confirmed diagnosis of MS who are eligible and want to start treatment start DMT within 12 weeks of shared treatment decision	Percentage starting treatment 12 weeks after shared treatment decision	■ Were you told that you were eligible to start DMT? **If yes**, did you start treatment within 12 weeks of the shared decision to start?
People with MS have a review at least once every 12 months carried out by healthcare professionals with an expertise in MS	Percentage of people with MS who have a review at least once every 12 months carried out by healthcare professionals with an expertise in MS	■ If you have had a diagnosis of MS for one year or more, have you had an annual review? **If yes**, were you asked a range of questions about MS disease activity, lifestyle (e.g. smoking, exercise, diet, sleep), other medical problem (e.g. high blood pressure, diabetes), your symptoms, social, family and employment issues? ■ Do you smoke or are you an ex-smoker or never smoked in your life?

Standards & Metrics: Quality standards and associated metrics

Quality Standard	**Clinical metric**	**Patient self-reported metric**
People with MS have a defined point of contact within the MS service	Percentage of people with MS who have a defined point of contact within the MS service	■ Do know who to contact within the MS team if you have any questions or concerns? ■ Does your care plan outline a description of the person, what matters to them and all the necessary elements of MS treatment and care you need this year?
Response to any unscheduled contact by a patient, MDT or GP reporting a patient problem within 3 working days *Key driver to reduce emergency admissions	Percentage of responses conducted within 3 working days of any unscheduled contact by a patient, MDT or GP reporting a patient problem	■ Do you know who to contact within your MS service to report a problem? ■ Have you needed to contact your MS service unexpectedly or outside of your normal scheduled visits to report a problem? **If yes**, did you receive a response within 3 working days of contact? **If yes**, did you feel you received a helpful response?
Formation and evaluation of a care plan within 1 week of the patient, a member of the MDT or GP reporting a problem	Percentage of problems reported by the patient, a member of the MDT or GP that have a care plan formulated and evaluated within 1 week of reporting	■ Have you ever had to report a problem to your MS service? **If yes**, was a care plan developed within 1 week of your report? ■ Does your care plan outline a description of you, what matters to you and all the necessary elements of MS treatment and care you need this year?

Standards & Metrics: Quality standards and associated metrics

Quality Standard	Clinical metric	Patient self-reported metric
Every person with MS has been offered comprehensive education within the last 2 years1	Percentage of people with MS offered comprehensive education in the last two years1	■ Have you ever been offered regular opportunities to learn more about MS and how it can affect you or been given or shown resources that you can use to learn more? ■ Do you feel as though your MS team has kept you adequately informed about your condition? ■ Have you been offered to support to self-manage?
Every patient with complex rehabilitation needs should have a Rehabilitation Prescription	Percentage of people with MS with a rehab prescription	■ Have you received a rehabilitation prescription?
Every MS service should maintain a current database of people with MS	Percentage of MS services maintaining a complete database of people with MS, such as the UK MS Register.	■ To your knowledge, are you signed up to an MS register?
Every patient should be offered the opportunity to take part in research, including clinical trials (where egilible)	**Percentage of eligible patients who have been offered to take part in research in the last 12 months**	■ In the last 12 months have you been asked to take part in a clinical trial or research?

Research & Trials: Access to research and clinical trials

Barriers	Potential solutions
■ Under-costing of trials and lack of funding. ■ Clinicians not given funded time to conduct trials. ■ Need greater incentives for clinicians and providers to participate. ■ Inadequate CRN funding for neurological research nurses. ■ Unmet need for research on living with MS and symptom management ■ NICE focus on RCTs. ■ Excess treatment costs. ■ Awareness of trials. ■ Inequity in access to trials amongst minoritized communities.	■ Culture that is supporitve of research. This may include measures such as: research as an agenda item in all MS clinical MDT meetings; develop supportive working relationships between MS clinical and research teams; research updates for MS clinical teams – local (Neurology research teams and Research Delivery Service) and national (eg from Association of British Neurologists) ■ Clinicians must be allowed time for clinical trials. ■ Higher R&D budgets. ■ Better financial incentives. ■ CRN funding to be reprioritised. ■ Improved signposting to trials among pwMS and clinicians.

Clinical guidance: Disease modifying service provision

Disease modifying service provision should include the following:

- Shared decision making and care planning **including pre-conception and pregnancy planning.**
- MDT to suggest appropriate DMTs: MDT to define treatments for which a person is eligible and give their recommendations, also to be clear of "unknowns”.
- Coordination / safety monitoring: It is important that drugs are administered/infused only when it is safe, that is when the patients are complying with safety monitoring and results are OK. This could be done by a centralised IT system (e.g. Bloodwatch in Australia).
- Preferably include a **non-medical** prescriber (pharmacist or MS nurse) to support the neurologists.
- Disease activity monitoring (MRI).
- AE management (endocrinology etc).

MDT members:

- Specialist neurologists (min. 2)
- MS Nurses
- Pharmacist
- Radiologist
- Administrator/co-ordinator

Appendix: 2019 Clinical working group membership

Name	Profession	Organisation
Alasdair Coles	■ Workstream Clinical Lead, Consultant Neurologist	■ Cambridge University Hospitals NHS Foundation Trust
Colin Bannon	■ GP	■ Retired
David Martin	■ CEO	■ MS Trust
Georgina Carr	■ Chief Executive	■ The Neurological Alliance
Helen Ford	■ Consultant Neurologist	■ Leeds Teaching Hospitals NHS Trust
Jeremy Hobart	■ Consultant Neurologist	■ Plymouth Hospitals NHS Trust
Kate Petheram	■ Consultant Neurologist	■ South Tyneside and Sunderland NHS Foundation Trust
Pam Bostock	■ Occupational Therapist Consultant	■ Independent Practitioner (Member of Therapists in MS)
Rachael Dorsey	■ Senior Lead Neurosciences Pharmacist	■ Imperial College Healthcare NHS Trust
Sarah White	■ MS Clinical Nurse Specialist	■ St George’s University Hospitals NHS Foundation Trust
Wendy Hendrie	■ MS Specialist Physiotherapist	■ MS Therapy Centre, Norwich

The pathway was revised in 2024 with input from endorsing organisations.

Appendix: References

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NNAG National Neurosciences Advisory Group

THE NEUROLOGICAL ALLIANCE

National Neurosciences Advisory Group c/o The Neurological Alliance (England)
www.nnag.org.uk

The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

www.neural.org.uk

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