

# Optimum clinical pathway: Multiple sclerosis

July 2019

## Executive summary

This optimum clinical pathway for patients with MS (pwMS) was designed by a working group of MS healthcare professionals (see Appendix for group membership), as part of an NHS England specialised neurology programme of work.

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), and suggests that MS nurses and other AHPs could free up MS consultant neurologist time through prescribing and monitoring. The pathway recommends that relapse, disease progression, symptom management, palliative care and end of life care should be triaged through an MS administrative coordinator with knowledge of an MS service, with an MS nurse available to help manage a patient's care plan.

A core principle of this MS pathway is to keep as much care local as possible. The group emphasizes the importance of having access to a specialist MS team and clinic with different HCPs working together. This should be available throughout the MS patient journey. DMTs can be delivered by a network of specialists linked virtually, operating in local services with access to an infusion centre and an IT system that supports safety monitoring. Blood tests and routine monitoring should be done close to home.

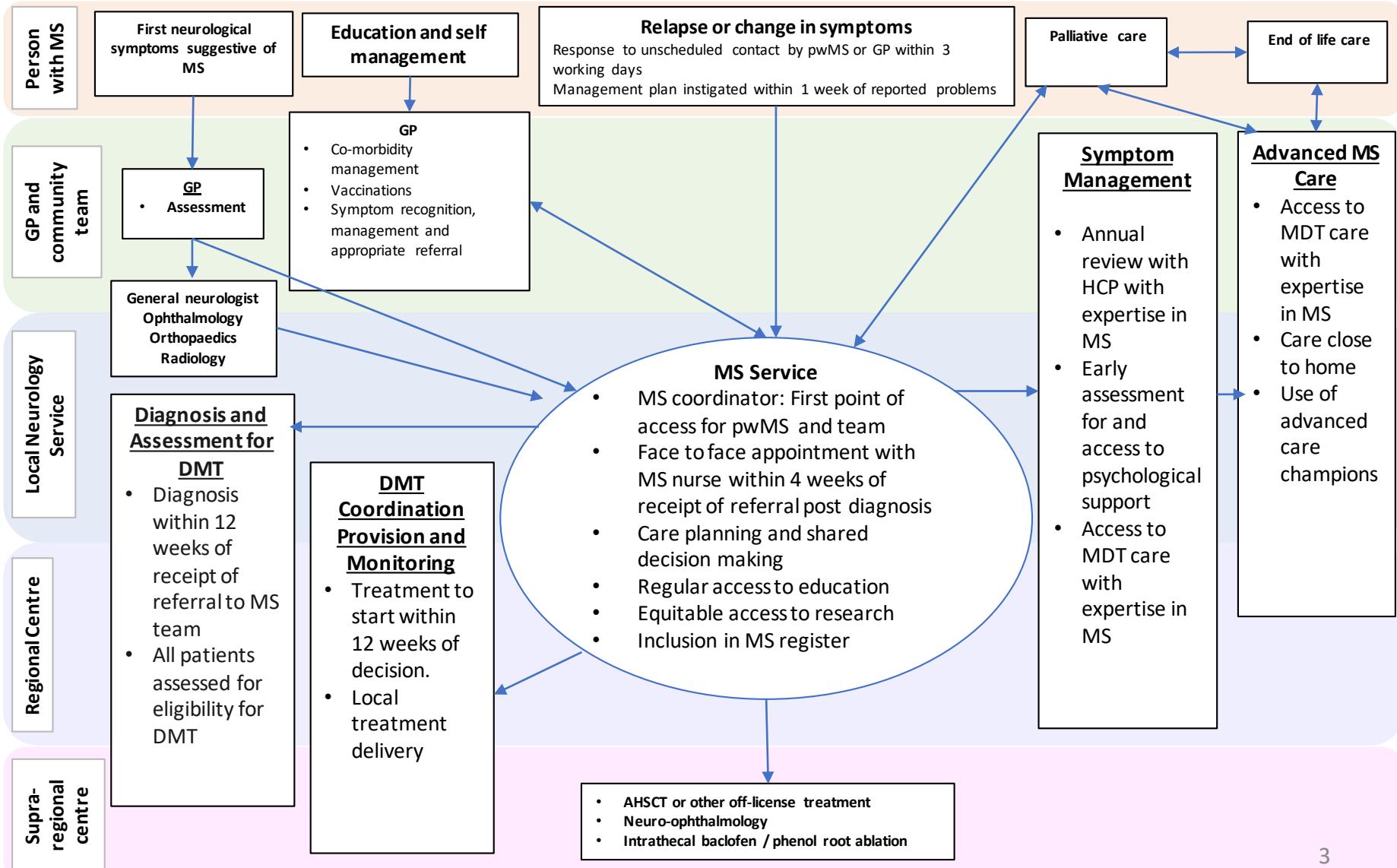
Barriers to the optimum pathway include workforce shortages of MS specialist neurologists, MS specialist neuro-radiologists, MS nurses, MS service admin support and obstructions to access to clinical trials.

Key enablers of the optimum pathway include specialist networking and virtual consultation. Additionally, increased focus on data sharing between and across services, as well as people with MS, would greatly facilitate communication between clinicians and improve patient care.

# Executive summary

## Multiple Sclerosis Optimum Pathway

**Information, education, advice, supported self- management, shared decision making, access to research opportunities at all levels**



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# Context

There is an annual growth rate of 2.4% of people with MS (pwMS) in the UK, with a 6-10% increase in demand for MS services per year (1). 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. This in turn has led to a £56,000 increase in the emergency activity monthly tariff from 2016/17 to 2017/18 (1). MS reduces life expectancy by 7-12 years(2). The UK prescribes a lower rate of disease-modifying treatments than the US and most European countries (3).

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

- The “optimum” 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 principles:

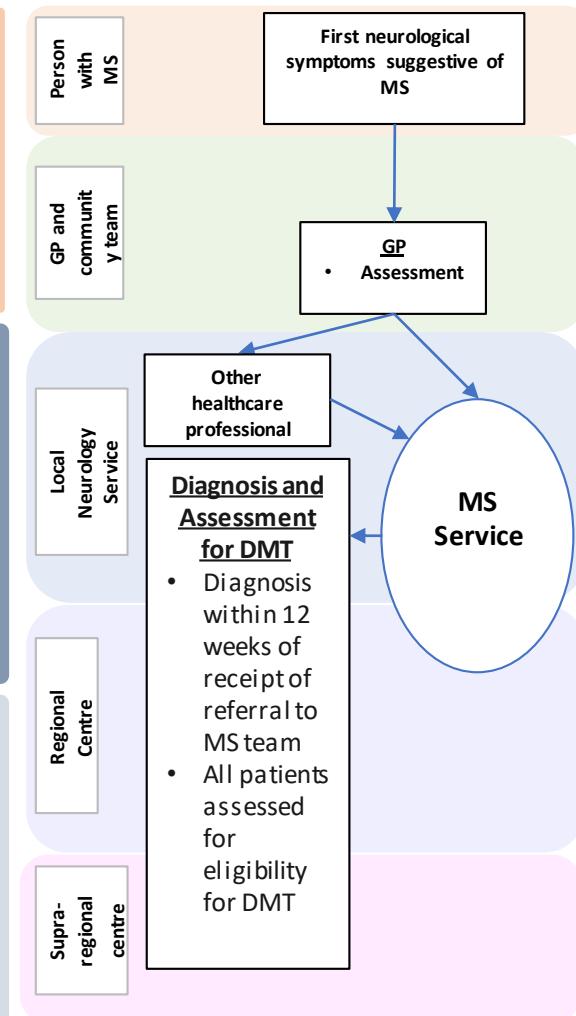
- ❖ People with MS should have an accurate and timely diagnosis, in order to access appropriate therapies efficiently, to minimise the accumulation of irreversible disability.
- ❖ A person with suspected MS should be referred directly to an MS specialist neurologist. People with MS diagnosed by general neurologists (and other doctors), should be referred to an MS specialist neurologist for categorisation of the patients' disease and access to therapies.

## Barriers

One barrier to this model is the capacity of specialist neurologists and diagnostic services such as MRI and LP. It has been recognised that there is a shortage of neurologists in the UK (the UK has one neurologist per 90 000 people; the European average is one per 15 000 (4)). 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 an 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 (5).

## Enablers

One solution is for MS services to move to a model whereby consultants only see new patients at diagnosis & 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 (MSN) clinics, in person or virtually. This may require an increase in the number of MSNs within the service. In turn, the tasks undertaken by the MSN should be reviewed to ensure appropriate use of nursing time. 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).



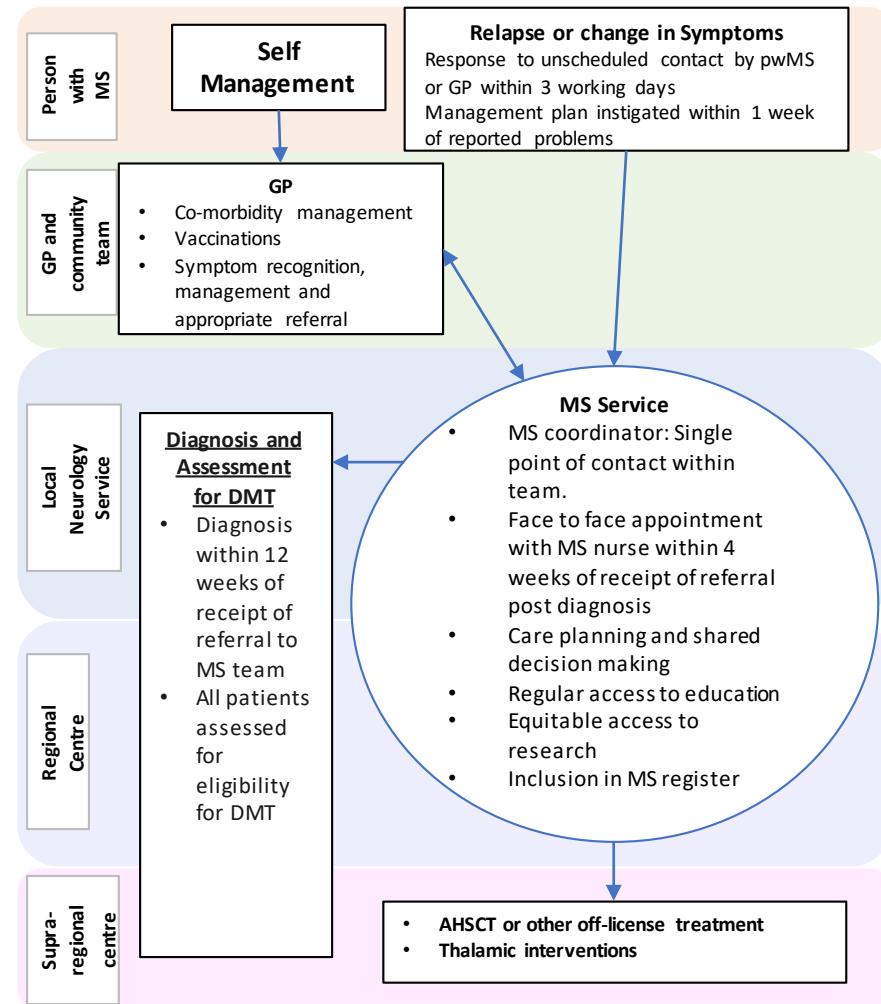
# Pathway: from diagnosis to specialist MS service assessment

## 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 (6).
- ❖ All people with MS should have a single point of contact for access to the MS service, which should be led by a non-clinical administrator (6).
- ❖ All patients with MS should be able to access a Specialist MS nurse.
- ❖ At each stage in the disease history of someone with MS, they should have access to education and opportunities for self-management.
- ❖ All people with MS should be offered an annual review by a healthcare professional with expertise in MS (8).
- ❖ Services should provide rapid access for assessment of changes in a patient's condition (relapse, onset of progression).
- ❖ All pwMS should be encouraged to maintain physical activity, and advised on lifestyle issues (e.g. smoking). See NICE guidelines: Adults with MS are given support by the MS team when first told that they have MS. 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 (7).

## Enablers:

MS services could be delivered by a network of specialists linked virtually, operating in the community. MS services should be supported by an administrator (6) to help coordinate and triage care, and technology can allow patients access to their care plan.



# Pathway: drug treatment

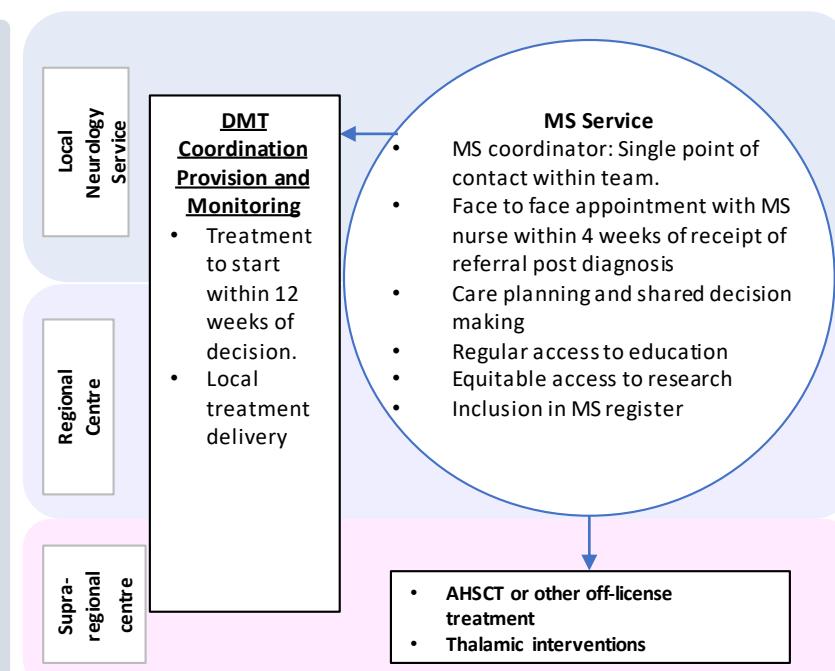
## Guiding Principles:

All patients 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.

## Enablers:

- ❖ DMTs can be delivered by a network of specialists linked virtually, operating in the community 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 treating team. Drugs can be administered in a local infusion centre.
- ❖ Routine prescribing and monitoring does not need to be by consultant neurologist, but could be by nurse or pharmacist with necessary experience and knowledge. EDSS assessments could be done by physiotherapist.
- ❖ An MS specialized service requires competence in prescribing all DMTs
- ❖ Certain higher efficacy treatments need discussing in MDT for Blueteq approval. The MDT for disease modifying therapies must include at least two MS neurologists and one MS nurse.
- ❖ If an MS service has only one neurologist then patients case will need to be discussed at a DMT MDT in nearby regional centre.



# 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 an MDT) (5). These specialists may meet outside a neuroscience 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.

### Core MDT for non-DMT MS care defined in NICE as including

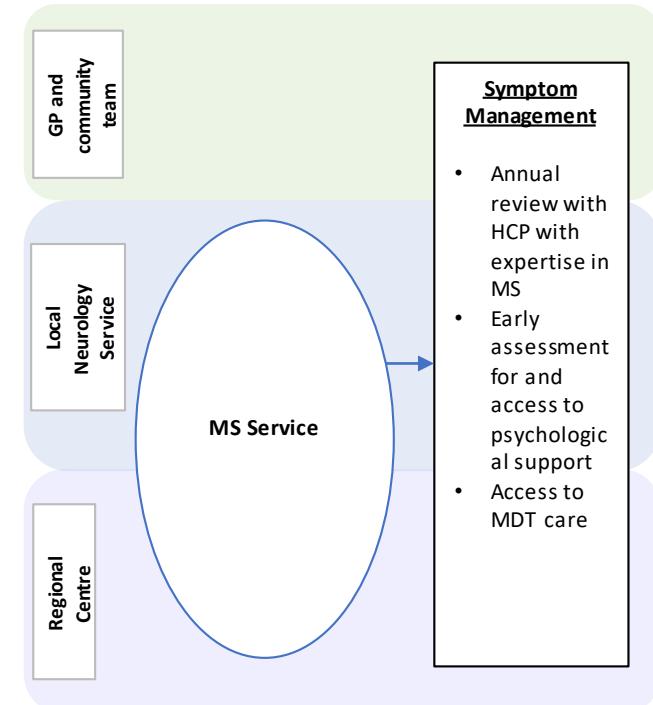
- Physiotherapist (for physical activity, mobility issues, transfers, balance, ataxia, vestibular dysfunction, spasticity and spasm management, standing, respiratory interventions e.g. NIPPY, splinting, and Functional Electrical Stimulation – FES)
- Occupational therapist (for vocational rehab, adaptations and equipment for daily living, housing adaptations, maintenance of independence in all areas of ADL, fatigue management, and splinting)
- Wheelchair clinic
- Speech and language therapists
- Continence advisor
- Pain clinic
- Podiatrist
- Optometrist
- Psychologist
- Tissue viability practitioner
- Respiratory practitioner
- Palliative care / end of life practitioner

### Barriers

Barriers to quality include time, patient engagement with the service, patient activation, and coordination of the service.

### Enablers

- Patient activation measures
- Digital technology (e.g. apps for symptom monitoring and improved data sharing)
- Virtual clinics
- Care planning



# 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.

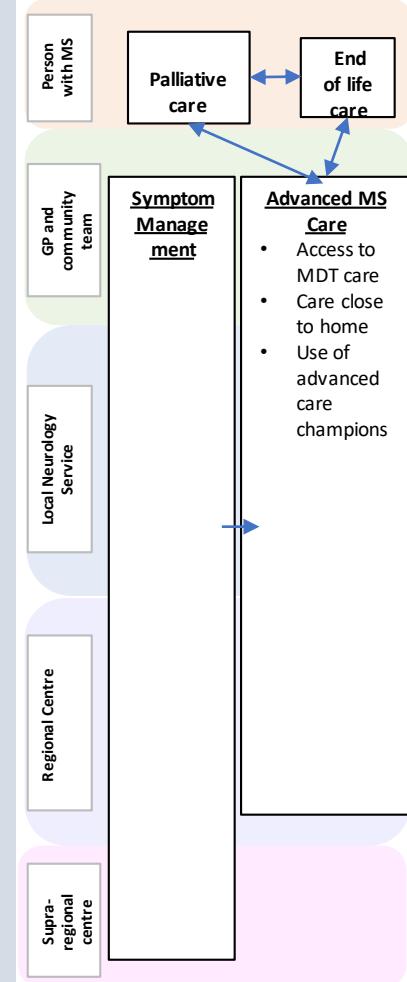
Many people with advanced MS are restricted in their mobility and find attending clinics difficult, and as a result are lost to follow-up.

## Barriers

- defining 'expert'
- finding staff with the expertise needed
- there is only case study evidence for impact of specialist AHPs
- succession planning, patient engagement with service and 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 timely access to a named care coordinator or case manager with expertise in MS. This may be an Advanced MS Champion - this is being piloted by the MS Trust at the moment but *it is imperative that this pilot includes physiotherapists and occupational therapists as it is these professionals who lead on the problems faced by people with advanced MS*.
- ❖ 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 (6). As a minimum these teams should have: occupational therapists, physiotherapists, MS nurse, SLT, dietitian with a designated team administrator.
- ❖ 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.
- ❖ Have access to rehabilitation consultants and others for interventions including ITB/phenol/botox/FES/lymphoedema control/enteral feeding.
- ❖ Have on-going education and advice to enhance self-management for people with MS, family and carers.
- ❖ Have access to support services/housing/social care.



# Pathway: Specialised components of care

## Defining specialised care

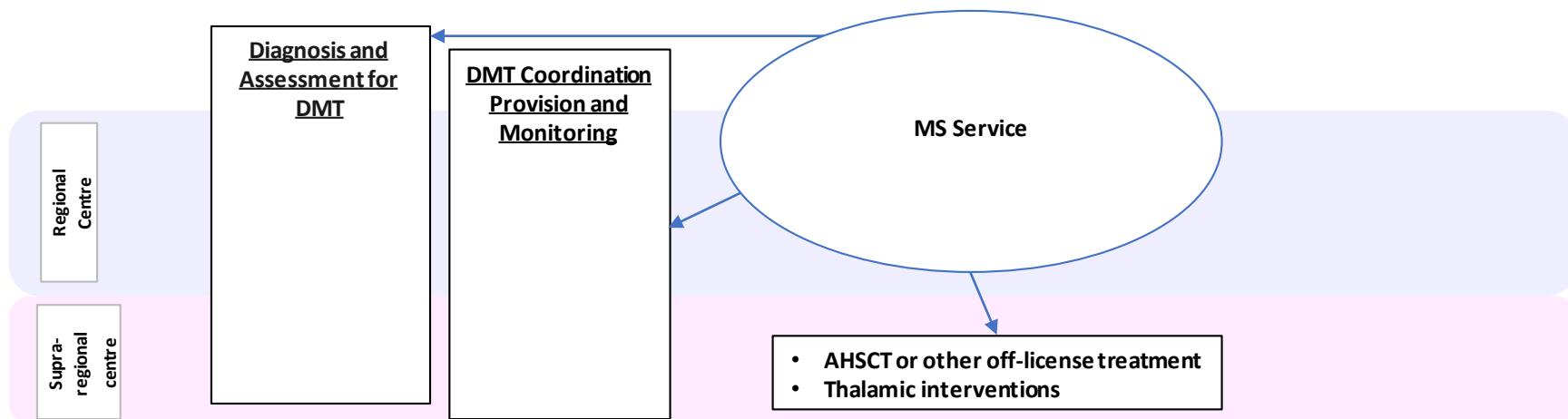
DMTs are currently commissioned by NHS specialised commissioning, through neuroscience centres, with local agreements allowing wider provision.

“Specialised services” are those which require technology only involved in neuroscience centres. In the care of people with MS, this consists, for instance, of the rare examples of surgery for MS and AHSCT. 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 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 an MDT within a regional centre.



# Alternate workforce models

## Case study: DMT Coordinator

The MS service in Leeds has a MS Treatment coordinator dedicated to managing the administration of DMTs. The coordinator is a band 4 administrator, working 20 hours per week, co-ordinating care for approximately 550 people with MS treated with DMTs. 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 Huddersfield 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 support for PwMS with non-clinical DMT queries that receives between 10 - 20 calls 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

- PwMS on DMDs 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 DMDs are effectively tracked - the DMD coordinator maintains a database detailing monitoring events and alerts that are followed up if missed ensuring that monitoring is effective and timely.

### Responsibilities

- Monitoring for patients on injectable DMDs:
  - Monitoring and support for patients on mitoxantrone, natalizumab, fingolimod, alemtuzumab, teriflunomide and any future drug treatments for MS.
- Risk sharing scheme study
- Prescription management:
  - New patients (including those referred from outlying MSSNs)
- Clinic management:
  - Communications with patients
  - Support for research and clinical trials

# 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 (6).

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.

# MS Quality Standards and associated metrics

	<b>Quality Standard</b>	<b>Clinical metric</b>	<b>Patient self-reported metric</b>
1	Diagnosis of uncomplicated MS to be confirmed and communicated to the patient within 12 weeks of receipt of GP referral by specialist MS team	Percentage of people who have a confirmed diagnosis of uncomplicated MS <sup>2</sup> within 12 weeks of receipt of referral to specialist MS team	Did you get a confirmed diagnosis of MS within 12 weeks of being referred to the specialist MS team?
2	A face-to-face follow-up appointment with a specialist MS nurse is offered within 4 weeks of receipt of referral post-diagnosis	(a) 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  (b) Percentage of people with confirmed diagnosis of MS who are offered <b>and attend</b> a face-to-face follow-up 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?
3	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 of people with a confirmed diagnosis of MS and eligible and want to start treatment start DMT within 12 weeks of 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?
4	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?

1. N/A, not applicable as unlikely to know timings pre-diagnosis of internal communications among HCP teams; Uncomplicated MS, defined by typical clinical and MRI features and presence of oligoclonal bands if CSF tested; MDT should include as a minimum an MS Nurse Specialist and a neurologist. Additional clarity and specifics of what constitutes an annual review will be provided in the data collection form (see notes on this slide for more details)

# MS Quality Standards and associated metrics

	Quality Standard	Clinical Metric	Patient self-reported metric
5	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 you 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?
6	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?
7	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?
8	Every person with MS has been offered comprehensive education within the last 2 years <sup>1</sup>	Percentage of people with MS offered comprehensive education in the last two years <sup>1</sup>	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?
9	Every MS service should maintain a current database of people with MS	Percentage of MS services maintaining a current database of people with MS	To your knowledge, are you signed up to an MS register?
10	Every patient should be offered the opportunity to take part in research, including clinical trials (where eligible)	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?

1. Specifics of what constitutes 'comprehensive' education or examples will be provided in the data collection form (see notes on this slide for more details); This will be a YES/NO response in the audit data collection tool allowing single unit/centre assessment. Comparison of responses across units/centres will be relevant for national/regional benchmarking or audit; N/A, not applicable

## Access to research and clinical trials

### Barriers

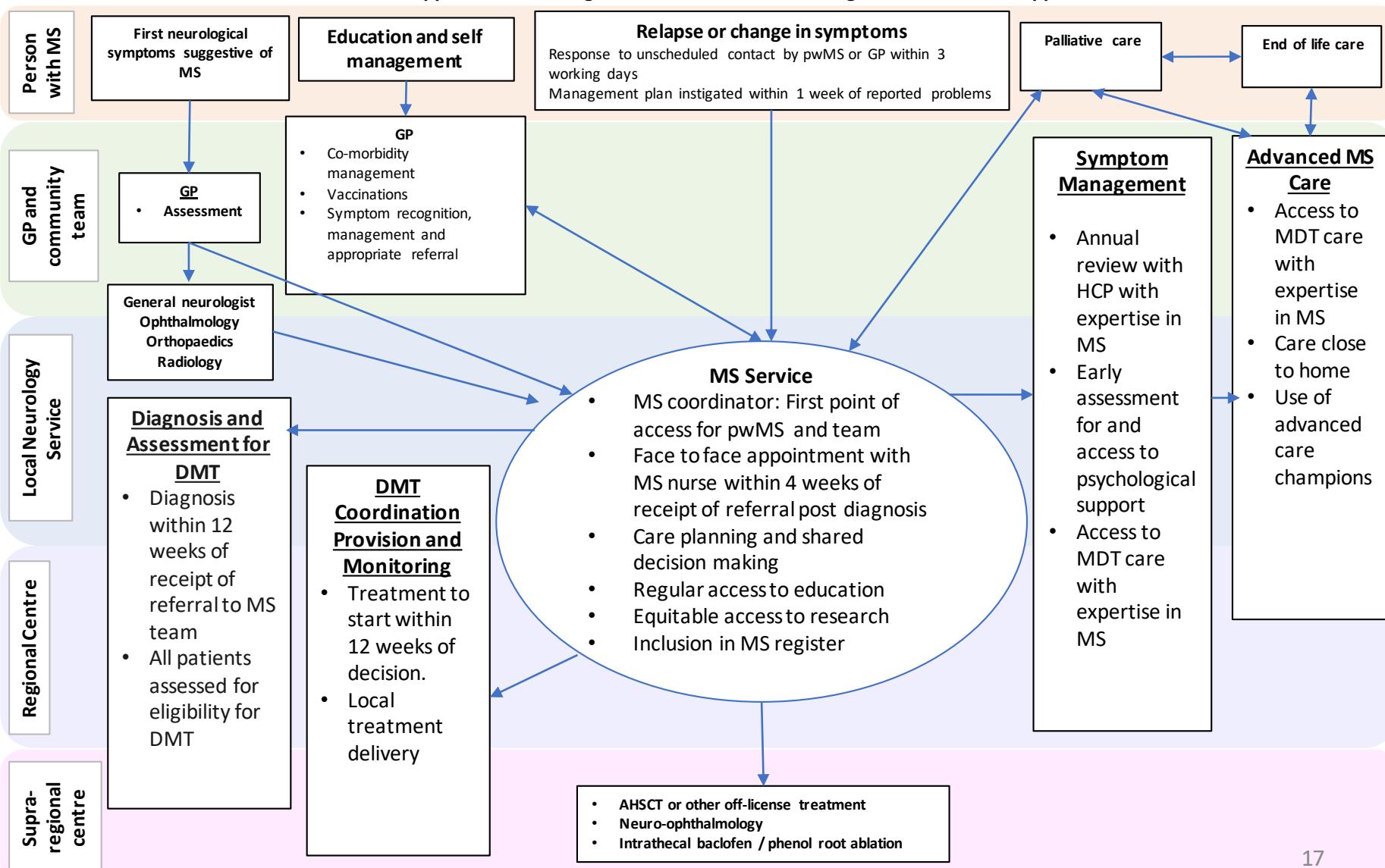
- Under-costing of trials and lack of funding.
- Clinicians not given funded time to conduct trials.
- Need greater incentives for clinicians and providers to participate.
- Inadequate CRN funding for neuro research nurses.
- Bias toward medical research ignores secondary progressive patient needs
- NICE focus on RCTs.
- Excess treatment costs.
- Awareness of trials.

### Potential solutions

- ❖ Culture change.
- ❖ 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.

# Map of the optimum clinical pathway for pwMS

Information, education, advice, supported self- management, shared decision making, access to research opportunities at all levels



# Clinical guidance: Disease modifying service provision

## Disease modifying service provision should include the following:

- ❖ Shared decision making and care 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  
(minimum 2)

MS nurses

Pharmacist

MS radiologist

Administrator /  
Co-ordinator

Plasma Exchange  
service

# Appendix 1. Guidelines for primary care

## Primary Care and MS

Primary care is under enormous pressure at the moment and so nothing will happen due to simple advice and requests without resources being allocated. The means of achieving change, therefore are through contractual arrangements; local shared care agreements and the Quality and Outcomes Framework.

### 1. Shared care arrangements.

- i. These define shared care between specialists and primary care and are negotiated between CCG's Trusts and the BMA's Local Medical Committees. There are quite a few examples of these already in place, for instance for [leflunomide](#) (7) for rheumatoid arthritis and [azathioprine](#) (8) for inflammatory bowel disease. They can include prescribing as well as monitoring. The [full local shared care agreements](#) (7) for South Devon offer further examples.
- ii. It would seem entirely possible to negotiate agreements at CCG level for people with MS to have blood tests, as well as other agreed prescribing and monitoring done in primary care.

### 2. QOF Indicators.

- i. There is opportunity for the development of new indicators
- ii. To summarise, points can be developed to ensure that people with MS are on a register, (which is a given with computerisation), and they have an annual review, which would include screening for diabetes, hypertension, as well as lifestyle issues being addressed.

### 3. Direct Enhanced Services

- i. These are nationally arranged services that practices can opt into. An example of this are annual health checks for people with learning difficulties.

## Appendix 2. Clinical working group membership

Name	Profession	Organisation
Alasdair Coles	Workstream Clinical Lead, Consultant Neurologist	Cambridge University Hospitals NHS Foundation Trust
Helen Ford	Consultant Neurologist	Leeds Teaching Hospitals NHS Trust
Jeremy Hobart	Consultant Neurologist	Plymouth Hospitals NHS Trust
Kate Petheram	Consultant Neurologist	City Hospitals Sunderland NHS Foundation Trust
Pam Bostock	Consultant Occupational Therapist	Virgin Care Ltd
Colin Bannon	GP	Retired
David Martin	CEO	MS Trust
Georgina Carr	Head Of Campaigns And External Relations	MS Society
Sarah White	MS Clinical Nurse Specialist	St George's University Hospitals NHS Foundation Trust
Rachael Dorsey	Senior Lead Neurosciences Pharmacist	Imperial College Healthcare NHS Trust
Wendy Hendrie	Specialist Physiotherapist	MS Therapy Centre

## References

1. Secondary User Services (SUS) database
2. Public Health England. (2018). *Deaths associated with neurological conditions in England 2001 to 2014*. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/683860/Deaths\\_associated\\_with\\_neurological\\_conditions\\_data\\_analysis\\_report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/683860/Deaths_associated_with_neurological_conditions_data_analysis_report.pdf).
3. Gitto. Living with Multiple Sclerosis in Europe: Pharmacological Treatments, Cost of Illness, and Health-Related Quality of Life Across Countries. In Multiple Sclerosis: Perspectives in Treatment and Pathogenesis. Zagon IS, McLaughlin PJ, editors. Brisbane (AU): Codon Publications; 2017 Nov 27
4. BMJ. (2015). Inadequate neurology services undermine patient care in the UK. Available at: <https://www.bmj.com/content/350/bmj.h3284>.
5. Kaisey M, Solomon AJ, Luu M, Giesser BS, Sicotte NL. Incidence of multiple sclerosis misdiagnosis in referrals to two academic centers. *Mult Scler Relat Disord*. 2019 May;30:51-56. doi: 10.1016/j.msard.2019.01.048. Epub 2019 Feb 2. PubMed PMID: 30738280.
6. NHS RightCare. (2019). *Progressive Neurological Conditions Toolkit DRAFT*. Last updated 04 April 2019.
7. National Institute for Health and Care Excellence. (2014). Multiple sclerosis in adults: management, *clinical guideline [CG186]*. Available at: <https://www.nice.org.uk/guidance/CG186>.
8. MS Trust. (2015). *MS Forward View*. <https://www.mstrust.org.uk/ms-forward-view>
9. Devon CCG. *About Us*. Available at: <https://devonccg.nhs.uk/about-us>
10. NHS Lothian. *Shared care agreement: Azathioprine*. Available at: <https://www.ljf.scot.nhs.uk/SharedCareofMedicines/Shared%20Care%20Agreements/SCA/azathioprine%20IBD%20SCA%20v1.0%20FINAL.pdf>