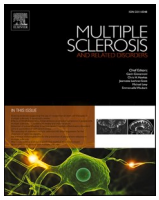
Multiple Sclerosis and Related Disorders 116 (2026) 108033



Contents lists available at ScienceDirect

Multiple Sclerosis and Related Disorders

journal homepage: www.elsevier.com/locate/msard



Review article

Mandatory national clinical audits as a tool to drive improvements in multiple sclerosis outcomes

Gavin Giovannoni [a,*], Paola Zaratin [b], Sara Samadzadeh [c,d], Jelena Drulovic [e], Laura Thomas [f], Ruth Stross [g], Anne Helme [h], Saúl Reyes [a,i], Tjalf Ziemssen [j], Jeremy Hobart [k]

[a] Blizard Institute, Faculty of Medicine and Dentistry, Queen Mary University of London, 4 Newark Street, London E1 2AT, United Kingdom
[b] Research Department, Italian Multiple Sclerosis Society Foundation, Via Operai, 40, Genoa, 16149, Italy
[c] Experimental and Clinical Research Center, Charité – Universitätsmedizin Berlin and Max Delbrück Center for Molecular Medicine, Lindenberger Weg 80, 13125 Berlin, Germany
[d] Neuroscience Clinical Research Center, Charité – Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany
[e] University Clinical Centre of Serbia, Serbia
[f] MS Society, London, United Kingdom
[g] MS Trust, Spirella Building, Letchworth, Garden City, Hertfordshire, SG6 4E, United Kingdom
[h] MS International Federation, London, United Kingdom
[i] Department of Neurology, Fundación Santa Fe de Bogotá, Bogotá, Colombia
[j] Department of Neurology, Center of Clinical Neuroscience, Faculty of Medicine and University Hospital Carl Gustav Carus, TUD Dresden University of Technology, Dresden, Germany
[k] Peninsula Medical School, University of Plymouth, United Kingdom

ARTICLE INFO

Keywords:
Multiple sclerosis
Brain health
National audit
Quality standard
Quality improvement tool

ABSTRACT

Multiple sclerosis (MS) is a complex, time-critical neuroinflammatory condition where diagnostic delays and suboptimal treatment lead to irreversible disability. Despite an international consensus on best practices, equitable access to specialist care remains highly variable. We explore how implementing mandatory, continuous national clinical audit can potentially eradicate unwarranted clinical variation, drive systemic policy reform, secure targeted investment in specialist MS services, and create a positive feedback loop over time as services evolve. Drawing upon the highly successful models in stroke and cancer, we demonstrate how continuous, prospective data collection functions as an agent of change. We apply these mechanisms to MS care, using the internationally endorsed *MS Brain Health: Time Matters* policy recommendations, consensus quality standards, and their associated Quality Improvement tool as a blueprint for a potential mandatory national audit. Other recent initiatives, such as the Norwegian MS Registry, German implementation surveys and the UK MS Trust's Generating Evidence in MS Services (GEMSS) programme, provide proof of concept that standardised measurement improves operational efficiency, reduces non-elective emergency admissions, and generates robust health economic data necessary for strategic MS-related healthcare commissioning. To ensure equitable, cost-effective care and unlock funding for multidisciplinary teams, healthcare systems should be encouraged to invest in the infrastructure required for mandatory, continuous national audits of MS and other brain health conditions.

* Corresponding author at: Blizard Institute, Faculty of Medicine and Dentistry, Queen Mary University of London, 4 Newark Street, London E1 2AT, United Kingdom.

E-mail addresses: g.giovannoni@qmul.ac.uk (G. Giovannoni), paola.zaratin@aism.it (P. Zaratin), sara.samadzadeh@charite.de (S. Samadzadeh), drulovicjelena@gmail.com (J. Drulovic), laura.thomas@mssociety.org.uk (L. Thomas), ruth.stross@mstrust.org.uk (R. Stross), anne@msif.org (A. Helme), saul.reyes@fsfb.org.co (S. Reyes), tjalf.ziemssen@ukdd.de (T. Ziemssen), jeremy.hobart@plymouth.ac.uk (J. Hobart).

https://doi.org/10.1016/j.msard.2026.108033
Received 18 August 2026; Received in revised form 26 October 2026; Accepted 31 October 2026
Available online 1 November 2026
2211-0348/© 2026 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/).

1. Introduction

Multiple sclerosis (MS), alongside neuromyelitis optica spectrum disorder (NMOSD) and myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD), represents complex, lifelong neuroinflammatory conditions that demand coordinated, specialised care (Butzkueven et al., 2025). The underlying pathophysiology of MS shows that irreversible neuroaxonal damage and cellular loss occur from disease onset, necessitating an early and aggressive clinical management strategy characterised by prompt diagnosis, timely intervention, and rigorous, proactive monitoring of treatment effectiveness (Butzkueven et al., 2025; Giovannoni et al., 2022). When left undiagnosed, misdiagnosed, or ineffectively treated, MS generally leads to irreversible disability worsening, resulting in negative outcomes across several life domains and imposing large socioeconomic burdens on healthcare systems (Butzkueven et al., 2025).

Despite major pharmacological advancements and a growing international consensus on best practices, the international delivery of MS care remains highly variable. Patients frequently experience protracted delays in diagnosis, restricted access to high-efficacy disease-modifying therapies (DMTs), and highly inequitable access to multidisciplinary specialist services (Butzkueven et al., 2025). To rectify these systemic deficiencies, healthcare policymakers and clinical leaders in many countries increasingly rely on continuous clinical auditing. National clinical audits function as change agents, systematically evaluating the performance of healthcare services against established, evidence-based standards to drive quality improvement. By identifying unwarranted variations in care and benchmarking institutional performance, clinical audits help to translate clinical guidance into measurable operational performance metrics that inform healthcare commissioning (Hobart et al., 2019). National audits may be particularly relevant in low- and middle-income countries, where fundamental barriers to MS care persist (Carnero Contentti et al., 2021). As demonstrated by maternal health audits in Africa, standards-based audits can drive measurable improvements even when baseline resources and infrastructure are limited by identifying low-cost, high-impact interventions (White et al., 2024).

Here we examine the transformative potential of national clinical audits to drive policy change, secure investment in specialist MS services and improve patient outcomes. Drawing on the highly successful operational models of the UK's Sentinel Stroke National Audit Programme (SSNAP) and the National Cancer Audit Collaborating Centre (NATCAN), we show how continuous data collection can influence healthcare commissioning and service redesign (England, n.d.). These lessons could be applied to MS care widely, beyond the UK, utilising the international *MS Brain Health: Time Matters* policy documents, consensus quality standards, and quality improvement (QI) tool as the blueprint for a continuous, prospective national MS audit infrastructure (Butzkueven et al., 2025; Hobart et al., 2022, 2019)(Butzkueven et al., 2025; Giovannoni et al., 2016).

1.1. Consensus standards on timing framework

The *Brain Health: Time Matters in Multiple Sclerosis* policy reports provide a conceptual framework for standardising and auditing MS care (Butzkueven et al., 2025; Giovannoni et al., 2016). This international initiative, endorsed by leading neurological societies and patient advocacy groups, called for a paradigm shift in the management of MS. The core philosophy, 'time is brain', argues that maximising lifelong neurological reserve requires the earliest possible intervention to suppress MS disease activity before irreversible neurodegeneration accumulates (Butzkueven et al., 2025; Giovannoni et al., 2016). A holistic, person-centred management approach should integrate medical treatment with lifestyle optimisation (exercise, smoking cessation, and comorbidity management) to protect and maximise brain health (Butzkueven et al., 2025).

To operationalise this philosophy, an international panel of MS specialist neurologists from 19 countries utilised an iterative, modified Delphi process to establish consensus quality standards for brain health-focused care (Hobart et al., 2019). These standards move beyond generalised clinical guidelines to define specific, measurable timeframes for core interventions across the patient pathway. The guidelines are stratified into 'core' (minimum acceptable), 'achievable' (good practice), and 'aspirational' (high-quality) targets, covering time points relative to symptom onset, referral, diagnosis, treatment initiation, routine monitoring, and management of new symptoms (see Table 1) (Hobart et al., 2019).

One example of an 'achievable' good-practice target timepoint is the standard requiring that anyone who reports symptoms possibly related to MS to a healthcare professional should be referred to a neurologist within 10 days, or 4 weeks at minimum ('core' standard) (Hobart et al., 2019). Without such defined parameters, healthcare systems cannot accurately measure operational efficiency or diagnostic latency. Metrics such as these are universally important; however, even in countries with advanced health systems, they are not easy to implement. In a national survey of 71 German MS experts, the time from referral to neurological consultation was, on average, 21.8 days, compared with the MS Brain Health (MSBH) 'achievable' target of 10 days and 'aspirational' target of 5 days. Discrepancies between MSBH recommendations and clinical practice in Germany were observed across the entire care pathway (Voigt et al., 2024a) Table 2.

Such gaps appear to be substantially greater in low- and middle-income countries. For example, in Latin America, lack of private insurance independently predicts lack of access to neuroimaging; global surveys reveal that 94% of low- and middle-income countries face at least one major barrier to early MS diagnosis compared to 78% for high-income countries (Carnero Contentti et al., 2021; Solomon et al., 2023). Quality standards may thus serve not only to benchmark performance against targets, but also to identify the most critical resource gaps.

1.2. Quality improvement tool to benchmark clinical care

Standards alone, however, cannot drive systemic change at a national level. Consequently, the MSBH Steering Committee developed a clinical Quality Improvement (QI) tool designed to enable MS centres and neurology practices to measure and benchmark their local services against the international consensus standards (Hobart et al., 2022). The tool allows clinics to input patient data, evaluate the timing of key events in the MS care pathway, and identify operational bottlenecks (Hobart et al., 2022).

During 2021, the QI tool was piloted across 17 MS centres in 14 countries, resulting in real-world impacts (Hobart et al., 2022). Engaging with the audit tool catalysed direct behavioural and structural changes; >84% of participating centres initiated tangible service modifications, such as streamlining referral processes, enhancing clinical documentation, and improving multidisciplinary communication (Hobart et al., 2022).

The success of this pilot underscores a principle of healthcare auditing: the simple act of standardised measurement prompts clinical teams to self-correct and optimise their workflows. For some countries, adopting this approach in individual MS centres or neurology units could greatly improve the quality of care relative to their current baseline. The level of development of national audits varies widely across the globe. In Serbia, for example, national audits exist only for the field of radiotherapy and nuclear medicine. However, the formation of the first MS Care Unit in Serbia is expected shortly, and establishing a national audit system for MS at the same time would create meaningful synergies. However, for these localised successes to translate into national policy shifts and large-scale financial investment, the localised QI tool must be widely adopted and eventually evolve into a mandatory, centralised national audit infrastructure.

Table 1
Expert consensus on standards for timely MS care.

Section	Core	Achievable	Aspirational	Standard
Referral and diagnosis	**Reporting first symptoms**			
	4 wks	10 days	5 days	Anyone experiencing for the first time symptoms that might be related to MS should report them to a healthcare professional within [] of noticing them
	4 wks	10 days	5 days	Anyone who reports symptoms that might be related to MS to a healthcare professional should be referred to a neurologist within []
	4 wks	2 wks	5 days	An initial MRI scan should be performed within [] of first referral to a neurologist for diagnosis (if not performed earlier)
	2 mths	4 wks	7 days	The MS team should complete a diagnostic workup for MS within [] of referral to a neurologist
	4 wks	10 days	5 days	The results from a diagnostic workup for MS should be discussed within [] of completion, during an appointment with the patient
	2 mths	4 wks	2 wks	An accurate diagnosis of (uncomplicated) MS should be made and communicated to the patient within [] of their referral to a neurologist
	30 mins	45 mins	1 h	Following MS diagnosis, patients should be offered an initial appointment of at least [] to discuss the implications of the diagnosis
Priorities following diagnosis	**Diagnosis**			
	4 wks	2 wks	7 days	The MS team should discuss the aims of treatment with each patient within [] of MS diagnosis
	6 wks	3 wks	7 days	The MS team should discuss the pros and cons of early treatment with a DMT with each patient within [] of diagnosis
	6 wks	3 wks	7 days	The MS team should assess within [] of an MS diagnosis whether the patient is eligible for treatment with a suitable DMT
	3 mths	4 wks	10 days	The importance of a brain-healthy lifestyle should be discussed with each patient with MS within [] of diagnosis
	6 mths	3 mths	4 wks	Patients with MS who need additional support to make lifestyle modifications, beyond that offered by the MS team, should be referred to appropriate services within [] of diagnosis
	6 mths	—	—	Cognitive screening should be offered to all patients with MS within [] of diagnosis
Routine monitoring and support	1 yr	6 mths	—	The MS team should perform a follow-up clinical evaluation of each patient at least once every []
	1 yr	6 mths	6 mths	The MS team should review with each patient at least once every [] the aims of their treatment for MS
	1 yr	6 mths	—	The MS team should review at least once every [] whether each patient with MS who is not receiving a DMT is eligible for one, based on applicable guidelines
	1 yr	6 mths	6 mths	The MS team should review with each patient at least once every [] their currently prescribed DMT and consider alternatives if appropriate
	1 yr	6 mths	—	The MS team should engage patients with MS in an active, documented discussion about living a brain-healthy lifestyle at least once every []
	1 yr	6 mths	6 mths	All patients with MS should have a check-up with an appropriate healthcare professional to screen for and/or manage comorbidities at least once every []
	2 yrs	1 yr	1 yr	All patients with MS should be offered an MRI scan at least once every []
Treatment decisions	**Patient becomes eligible for DMT**			
	2 mths	3 wks	10 days	A DMT should be offered to a patient with MS within [] of their becoming eligible for one
	Patient decides to start DMT			
	4 wks	2 wks	7 days	Treatment with a DMT should commence within [] of a patient with MS agreeing this approach with their neurologist
	—*	4 wks	2 wks	If a patient's response to their current DMT is judged to be suboptimal, an appropriate, alternative DMT should be offered within []
New symptoms	**New or worsening symptoms**			
	2 wks	7 days	3 days	Patients with MS should report new or worsened symptoms to their MS team within [] of experiencing these symptoms
	Reporting new or worsening symptoms			
	3 days	2 days	1 day	The MS team should respond within [] to a patient with MS reporting an acute deterioration of symptoms

(*continued on next page*)

Table 1 (*continued*)

Section	Core	Achievable	Aspirational	Standard
	7 days	3 days	2 days	Patients with MS who experience an acute deterioration of symptoms should be seen by the relevant member of their MS team within [] of reporting these symptoms
Additional statements	▪ Aspirational standard: Regular cognitive screening should be offered to all patients with MS ▪ Core standard: The MS team should give all patients the opportunity to participate in informed, shared decision-making about their care ▪ Achievable standard: The MS team should regularly enter patient data into an MS database ▪ Core standard: Neurologists should use the latest accepted diagnostic criteria when diagnosing MS			

Reproduced from Hobart et al. International consensus on quality standards for brain health-focused care in multiple sclerosis. Mult Scler 2018; doi:10.1177/1,352,458,518,809,326.
Standards were agreed by at least 75% of the Delphi Consensus Panel. Core, achievable and aspirational grading reflects minimum, good and high standards of MS care, respectively.
* Time frame of 3 months was agreed by the Delphi Panel after completion of the Delphi process.
DMT, disease-modifying therapy; MRI, magnetic resonance imaging; MS, multiple sclerosis.

1.3. Transformative power of national clinical audits: exemplars

The development of both stroke and cancer care in the United Kingdom illustrates how national clinical audits can fundamentally restructure service provision, alter governmental health policy, and unlock targeted financial investment. Moving from retrospective, localised service evaluations to continuous, prospective national data collection provides the evidence healthcare commissioners require to justify resource allocation. If audit metrics are published, they also provide transparency and quality data to patients and other stakeholders, which can help drive change. No MS centre or country wants to be at the bottom of a league table.

1.3.1. The Sentinel Stroke National Audit Programme (SSNAP)

The evolution of stroke care offers a compelling vision for the future of MS care. Historically, stroke care was characterised by fragmented services, highly variable access to specialist physicians, and poor long-term functional outcomes. The introduction of the retrospective National Sentinel Stroke Audit (NSSA) in 1998, which later evolved into the continuous, web-based Sentinel Stroke National Audit Programme (SSNAP), catalysed a systematic overhaul of stroke services (Cloud et al., 2013). Over seven rounds, the NSSA collected data revealing severe regional disparities in the quality of care, often referred to as a 'postcode lottery' (Cloud et al., 2013). These data informed two highly critical National Audit Office (NAO) reports in 2005 and 2010, which highlighted the systemic failure of emergency access to specialist stroke units in the UK (Cloud et al., 2013). The ensuing political and public pressure led to the National Stroke Strategy for England in 2007, which mandated radical service improvements and the centralisation of acute stroke care within hyper-acute stroke units (HASUs), fundamentally redesigning stroke services (Cloud et al., 2013).

Importantly, the transition to SSNAP elevated the audit from an intermittent evaluation to a continuous operational management tool that tracks the stroke pathway from the first 72 h of care through to community rehabilitation (Cloud et al., 2013). Furthermore, SSNAP data were instrumental in securing investment for community-based services. By analysing the continuous prospective data, commissioners could map the exact relationship between the provision of early

Table 2
National audits versus disease registers.

2a - key differences

Dimension	National (mandatory) audit	Disease register
Primary purpose	Measure and improve the quality of care against defined standards; drive accountability.	Describe disease occurrence, natural history and outcomes; support epidemiological and clinical research.
Core question	"Are we delivering the standard of care we should be?"	"Who has this disease, and what happens to them?"
Case ascertainment	Aims for complete capture of an eligible population; mandatory participation forces near-total coverage.	Variable; often relies on voluntary enrolment or consent, so frequently incomplete unless population-based.
Denominator	Explicit and defined – the whole eligible population – enabling calculation of true rates.	Often the numerator only; without a known denominator, rates cannot be calculated reliably.
Benchmarking	Built in – units and providers compared against standards and against each other, with feedback loops.	Not the primary function; comparisons are possible but not the design intent.
Participation	Compulsory (statutory or contractual), which reduces selection effects.	Usually voluntary, which introduces selection bias.
Standards reference	Measured against explicit, agreed clinical standards or guidelines.	Typically descriptive; no inherent standard against which performance is measured.
Accountability mechanism	Strong – public reporting, commissioning levers and professional accountability.	Weak or absent – primarily a research and surveillance tool.
Data scope	Often focused on care-process and outcome measures relevant to the standards.	Often broader and deeper – clinical detail, biosamples and long-term natural history.
Time orientation	Recurrent, cyclical measurement to track improvement over time.	Continuous, longitudinal accumulation of data.

2b - pros and cons

National (mandatory) audit	**Disease register**
Advantages	
• Complete or near-complete case ascertainment removes selection bias. • A defined denominator allows valid rates and fair benchmarking. • Mandatory participation closes the gap that undermines voluntary systems. • Direct line to quality improvement and accountability through feedback and public reporting. • Captures underperforming units that voluntary systems tend to miss.	• Rich, deep, longitudinal data ideal for natural history, prognosis and pharmacoepidemiology. • Supports biobanking and data linkage. • Flexible for research questions beyond care quality. • Generally lower-friction to establish than a statutory audit. • International comparability when harmonised.
Limitations	
• Narrower data depth, often confined to auditable standards. • Resource- and governance-intensive to establish and sustain. • Can incentivise "gaming" or tick-box behaviour. • Measures against current standards, so it is less suited to discovery. • A statutory mandate requires political and system will to set up and maintain.	• Incomplete ascertainment unless population-based, which biases results. • Missing or uncertain denominators undermine rate estimation. • Voluntary participation produces selection bias (engaged patients, specialist centres and treated patients are over-represented).

(*continued on next page*)

Table 2 (*continued*)

2b - pros and cons	
National (mandatory) audit Advantages	**Disease register**
	• Weak accountability function. • Cannot reliably identify underperforming services, because the units and patients that opt out are exactly those most likely to differ.

supported discharge (ESD) multidisciplinary teams and improved functional outcomes, using a 17-item consensus score to evaluate ESD core components (Fisher et al., 2019). SSNAP data showed that variable ESD adoption was associated with variable patient recovery. This prompted the inclusion of ESD expansion in the NHS Long Term Plan, which explicitly mandated increased investment in community healthcare services (Fisher et al., 2020).

1.3.2. National cancer audits

The National Cancer Audit Collaborating Centre (NATCAN) utilises clinical audits to drive similar systemic transformations across oncology. The National Lung Cancer Audit (NLCA) is particularly notable for its success in shifting the diagnostic curve. Historically, lung cancer was characterised by late-stage diagnosis and correspondingly poor survival rates ("The National Cancer Plan for England: delivering world class cancer care (accessible version)," n.d.). By continuously auditing the time from referral to treatment and the stage at diagnosis, the NLCA established clear improvement goals, such as increasing the proportion of patients receiving curative-intent treatment and reducing emergency presentations (Conibear et al., 2022; "The National Cancer Plan for England: delivering world class cancer care (accessible version)," n.d.). As a direct result of audit-driven policies, the proportion of people diagnosed at stages 1 or 2 increased from 35.5% in 2023 to 40% in England in 2024, leading to a significant increase in surgical resections (sitecore, n.d.). The audit also accurately tracks improvements in survival, documenting that the median survival for patients in England diagnosed in early 2023 reached 358 days, a significant leap from 267 days in 2021 (Dawson, 2025). Crucially, the NLCA not only celebrates successes but also highlights ongoing failures to mandate further policy change; for example, 88% of patients with early-stage disease waited longer than the recommended 49 days from referral to surgery (sitecore, n.d.).

Similarly, the National Prostate Cancer Audit (NPCA) has been instrumental in identifying socioeconomic and ethnic disparities in care, revealing that black men with high-risk disease were substantially less likely than white men to receive curative radical treatment (Fitzjohn et al., 2026). This demographic data serves as a powerful ethical and economic mandate. Health economic modelling derived from audit data projected that implementing a risk-stratified 10% diagnostic stage shift would generate a net initial cost saving of £1.72 million per annual cohort, averting hundreds of metastatic cases, each estimated to cost the NHS between £63,284 and £216,118 per year (Fitzjohn et al., 2026).

1.3.3. Mechanisms of audit-driven policy change and investment

Analysis of the SSNAP and NATCAN models reveals several distinct, interconnected mechanisms by which national clinical audits catalyse policy change and targeted financial investment. Arguably, these mechanisms are directly transferable to the objectives of the MSBH initiative.

First, audits expose unwarranted variation and establish continuous benchmarking. Healthcare is usually delivered locally; without centralised data collection, individual clinics operate in isolated silos. A national audit aggregates all data, allowing clinical directors and healthcare commissioners to see how a specific unit performs relative to the national average or international consensus standards. In the context of MS, there are wide variations in the time required to administer MRIs, perform lumbar punctures, or initiate high-efficacy DMTs (Kuri et al., 2024). By publicly reporting these variations, audits invoke a powerful peer-pressure mechanism, whereby healthcare and hospital executives invest in underperforming departments to avoid reputational damage and regulatory intervention.

Second, audits provide the necessary health economic data for strategic commissioning. In modern healthcare systems, commissioners allocate finite budgets based on proven return on investment (Future-proofing neurology services: What emerging treatments mean for people, services, and policy in England, n.d.). Clinical audits link clinical interventions to operational efficiency and downstream healthcare utilisation costs. Commissioners value data that is perceived as rational and persuasive (Jager et al., 2023). Importantly, the economic value of audit data operates across different time horizons and levels of decision-making. Local and regional commissioners are often most responsive to short-term, directly measurable outcomes such as reduced emergency admissions, fewer hospital bed days, lower outpatient burden, and reduced non-elective healthcare utilisation. In contrast, national policymakers and health system leaders must also consider the longer-term benefits of preventing disability progression, preserving independence, maintaining workforce participation, and reducing long-term social care dependency. A national MS audit is uniquely positioned to generate evidence across both levels, supporting immediate service investment decisions while also informing broader health and economic policy.

Third, audits create a feedback loop that supports clinical leadership and the redesign of clinical pathways. The data collection process itself requires standardising electronic medical records and defining precise 'time zero' parameters for diagnostic latency (Ezer et al., 2017). As seen in the NLCA, defining these metrics allows multidisciplinary teams to adopt 'two-stop pathways' or 'carousel clinics' that consolidate specialist appointments, drastically cutting the time to diagnosis for complex multi-system disorders (Ezer et al., 2017). This continuous feedback loop ensures that policy changes are actively monitored, tested, and refined based on real-world outcomes.

Some would argue that using stroke and lung cancer to illustrate the benefits of audits in improving care and outcomes is inappropriate because these conditions are easily measurable in a short timeframe, with hard, often binary outcomes, and delays in care can be disastrous. This is not a reason to be pessimistic about improving MS care and outcomes. Many MS-related metrics can be measured in an audit and used as indicators of appropriate MS care as defined by international consensus (Table 1). We are also at a point where not everyone agrees that timely access to MS care is equally important, which is why national audits are so relevant. Showing that variation in MS care leads to different outcomes is the kind of evidence a national audit can provide, driving adoption of best practices and improving outcomes.

1.4. Current advancements in MS auditing and service evaluation

MS care in most countries does not yet involve continuous, mandatory, prospective auditing as seen in stroke or oncology, but significant strides have been made through targeted national registries and large-scale service evaluations.

Disease registers and national clinical audits may use similar data-capture tools and produce similar outputs, but they are usually designed for different purposes; this distinction matters. A register is a structured data collection about people with a given disease; a national audit is an accountability mechanism that compares care actually delivered against agreed standards, with feedback loops to drive improvement (England, n.d.).

A register can substitute for a mandatory audit only when it captures essentially all eligible patients covered by the healthcare provider; at

that point, it effectively becomes population-based and acquires the accountability power of an audit (Wenk et al., 2026). Below that threshold, selection bias and the absence of a denominator mean a register cannot perform the benchmarking-against-standards function of a mandatory audit. High-ascertainment examples like Sweden's Riks-stroke (England, n.d.; Sultani et al., 2024), the Danish clinical-quality registries (Simoni et al., 2026), the Czech National MS Register (Stastna et al., 2024) and the Australian Stroke Clinical Registry (AuSCR) (Morrison et al., 2026) blur this line because they are run with audit-like completeness. We have included a supplementary table of known MS registers (Supplementary material).

1.4.1. The Norwegian MS registry and biobank

The Norwegian Multiple Sclerosis Registry demonstrates how national data collection validates clinical policy and accelerates therapeutic interventions. By systematically tracking the MS population, the registry documented a 10-fold increase in reported MS prevalence between 1961 and 2014, largely attributable to prolonged survival, improved treatments, and the progressive adoption of more sensitive diagnostic criteria (Grytten et al., 2015).

More importantly, the Norwegian registry has been utilised to actively track the MSBH quality goal of ensuring that 75% of patients receive treatment within 49 days of referral (Hobart et al., 2019). By embedding this specific metric into the registry, Norway observed a dramatic reduction in the time from referral to diagnosis and treatment initiation, demonstrating that optimising patient follow-up can significantly improve clinical efficiency. Furthermore, the registry's comprehensive tracking of DMT efficacy provides real-world evidence of drug performance. For example, audit data identified a marked difference in the risk of early MRI disease activity between therapies (Rød et al., 2025). Regulatory bodies could use such real-world evidence to evaluate the cost-effectiveness and systemic implementation of novel therapies.

1.4.2. The Italian MS registry

The Italian Multiple Sclerosis and Related Disorders Register (RISM) (Trojano et al., 2019) was established to create a multicentre national structure collecting demographic and clinical data. It aims to improve quality of care, reduce variation across centres, and support research and policy decisions. Its formal data monitoring roadmap focuses on completeness, consistency, and quality assurance, demonstrating that national registry infrastructure outside national health-based systems can evolve into a national audit (Mosconi et al., 2023; Trojano et al., 2019).

1.4.3. Data-gathering initiatives in resource-limited settings

While national MS audit infrastructure remains scarce in resource-limited settings, targeted registry and survey initiatives demonstrate feasibility and potential impact. A Latin American MS network conducted surveys of 1469 patients across 12 countries and reported that private-sector pwMS have significantly greater access to imaging and DMTs than public-sector pwMS (Carnero Contentti et al., 2021). In Africa, a continent-wide survey of neurologists from 27 countries found that the most widely available DMT was rituximab (available in 81% of countries), followed by interferons (48%), with other DMTs largely unavailable and unaffordable (Shalash et al., 2026). In India, national surveys documented that only 40% of clinicians use the McDonald criteria, with misdiagnosis occurring in the majority of paediatric MS patients at disease onset and treatment delays of up to 8 years (Yeh et al., 2025). Therefore, even in the absence of comprehensive audit infrastructure, targeted data collection can quantify inequities essential for policy reform and investment decisions.

1.4.4. Health economic auditing

In the United Kingdom, the MS Trust pioneered the Generating Evidence in MS Services (GEMSS) program to address the chronic underfunding and highly variable caseloads of MS Specialist Nurses (MSSNs) (Evidence for MS specialist services: Findings from the GEMSS MS specialist nurse project, n.d.; MS Trust, 2016). As MS treatment pathways have become increasingly complex with the advent of high-efficacy DMTs, the clinical demand on MSSNs has increased. However, without concrete data demonstrating their clinical and economic value, specialist nursing posts were frequently left vacant or defunded by hospital trusts seeking short-term savings (Ruscoe et al., 2026).

The GEMSS program served as a targeted, prospective service evaluation, equipping MSSN teams with tools to collect robust data on their caseloads, activities, and patient outcomes, using sophisticated workload analysis tools such as the Cassandra Matrix (Ruscoe et al., 2026). The audit revealed the complexity of modern MS caseloads, noting that patients with relapsing-remitting MS (RRMS) receiving DMTs accounted for approximately 42% of a specialist nurse's caseload and required significantly more face-to-face contacts than newly diagnosed patients (Mynors and Bowen, 2014). The data were transformative, underpinning the creation of strong business cases for service investment (MS Trust, 2019).

By proving that MSSNs increase the overall capacity of specialist neurologists and minimise expensive emergency admissions, the GEMSS audit facilitated targeted, evidence-based investment in nursing infrastructure. NHS commissioners now view MSSNs as a critical cost-saving mechanism rather than an administrative burden (Evidence for MS specialist services: Findings from the GEMSS MS specialist nurse project, n.d.; Metcalfe and Owen, 2023; MS Trust, 2019). However, meaningful clinical audits are typically self-funded and have less influence on health care development than their important findings demonstrate are required (Hobart et al., 2022).

1.5. Risks associated with mandatory MS audits

A mandatory audit, which legally requires individuals with MS to be recorded in a government or state-backed database, carries distinct ethical, social, and practical risks compared to voluntary, patient-centred registries (such as the UK MS Register) (Chingarande, 2025; Ford, 2006; Hurwitz, 2011; "UK MS Register," n.d.). Mandatory registration strips patients of the right to opt out, to decline data collection, or to control how their personal health information is initially captured (Chingarande, 2025). Once information is logged into a state mandate, patients often lose unfettered access to inspect, modify, or delete their records if errors occur (Chingarande, 2025). Centralised state or national databases are high-value targets for cyberattacks, leaks, or accidental disclosures of sensitive neurological histories. Without strict, independent guardianship committees, sensitive data can drift to commercial entities, insurance underwriters, or third-party marketing groups (Chingarande, 2025). People with MS frequently report anxiety and actual discrimination regarding employment and disclosure. A mandatory state list raises concerns that employers, licensing bodies, or insurers could gain access to a progressive neurological diagnosis (Chingarande, 2025; Hurwitz, 2011). Fear of being officially "labelled" in a permanent government file can potentially lead individuals to delay seeking care, hide symptoms, or socially isolate themselves (Chingarande, 2025). As with mandatory reporting frameworks for other chronic conditions, forcing disclosure can make patients less candid with neurologists about sensitive symptoms (such as cognitive, bladder, or mobility changes) for fear of losing privileges or facing driving restrictions. When people feel coerced rather than supported, they may disengage from healthcare systems or seek alternative care outside traditional tracking networks (Chingarande, 2025; Hurwitz, 2011). Healthcare systems might use the information to make inappropriate policy decisions aimed at cost savings, for example, by implementing criteria for stopping treatment even though patients may still benefit. The misuse of audit data can be prevented by designing the audit to avoid misaligned objectives and data misuse.

To mitigate the risks of a mandatory MS audit, governments, researchers, and registry operators should build rigid legal, technical, and governance frameworks directly into the system's design. The registry should collect only the minimum data necessary to meet public health goals, avoiding overly sensitive or redundant personal history. The system must strip direct identifying information (such as names or national ID numbers) and replace it with artificial identifiers or codes (pseudonymisation). The "key" that links the code back to the actual patient must be held securely by a completely independent third party (such as a trusted medical privacy ombudsman), entirely separate from the main research database. Only authorised researchers or public health officials should access the data, and only on a strict need-to-know basis. Data must be encrypted both at rest (in storage) and in transit (when being transferred). The system must use immutable logs to track exactly who accessed which data and when, enabling immediate detection and legal prosecution of data misuse. An independent board, including patient advocates, neurologists, ethicists, and data privacy experts, must govern the database. Explicit statutory bans must prevent the sale or sharing of data with private health insurance providers, employers, or commercial marketing firms. Patients should have an easy way to view their own recorded data, report inaccuracies, and see exactly which research projects have utilised their de-identified information. Codified legal protections (similar to the Genetic Information Nondiscrimination Act in the US or GDPR protections in Europe) must explicitly forbid employers or insurers from using registry data to deny jobs, promotions, or coverage. Strict legal firewalls must prevent law enforcement or government agencies outside of health ministries from accessing the database for non-medical reasons. Public health bodies must run transparent campaigns co-designed with MS charities to explain why the data is being collected and how it directly benefits MS research and resource allocation. Clinicians must ensure that patients understand that while registration is a legal administrative requirement, the quality and delivery of their personal medical treatment remain entirely unaffected.

1.6. Future directions

Despite the localised successes described earlier, MS data collection remains highly fragmented. To achieve the systemic, nationwide transformation witnessed in stroke and cancer care, the MS community must transition from episodic service evaluations to a continuous, prospective, mandatory national clinical audit (Wenk et al., 2026). The MSBH policy recommendations and the QI tool provide a valuable architectural framework for this transition (Hobart et al., 2019). They do not need to be used in isolation. Fig. 1

1.6.1. Scaling the MS brain health QI tool

The future of MS quality improvement relies on the widespread, systematic integration of the MSBH QI tool into routine clinical practice. Transitioning from an Excel-based pilot to a sophisticated, web-based continuous reporting system would enable MS centres globally to track their performance against consensus timeframes in real time (Hobart et al., 2019). A successful transition from local service benchmarking to a mandatory, continuous national MS audit requires several important structural prerequisites. These include agreement on a minimum standardised dataset across services, interoperability between electronic health record systems, clear governance ownership at national and regional levels, and strong clinician engagement to ensure accurate and sustainable data capture. In addition, dedicated funding mechanisms are needed to support audit infrastructure without increasing administrative burden on frontline teams, while robust data protection and regulatory frameworks must ensure secure handling of patient information and compliance with national legislation. Addressing these foundational requirements is essential if the MSBH QI tool is to evolve from a local quality improvement resource into a scalable national audit system. Complementary German work has derived a

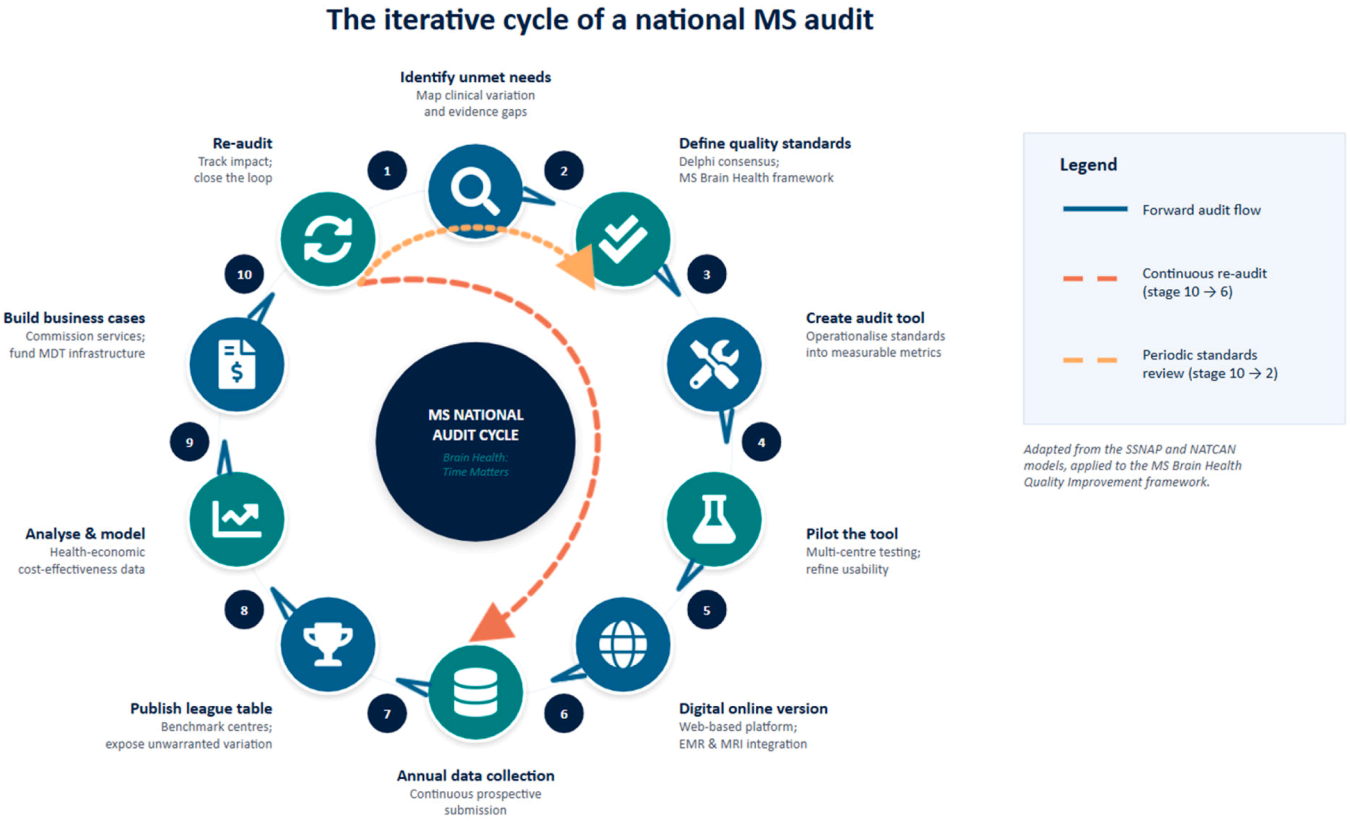


Fig. 1. Iterative cycle of a national audit.

consensus set of 24 quality indicators for the MS disease monitoring pathway through a two-round Delphi process with MS specialists, offering a granular, monitoring-focused dataset that could inform the minimum standardised dataset underpinning a national audit (Voigt et al., 2024b). In low- and middle-income countries, implementing continuous national MS audits will likely require a different approach than UK or European models. Given the limited access to technology and lack of dedicated funding, initial efforts may need to focus on simplified datasets, a small number of sentinel MS centres, and periodic rather than real-time data collection. A gradual strategy, starting in specialised MS centres and using the QI tool to establish local performance metrics, could progressively expand to regional networks as infrastructure develops. In addition, prioritising a dataset that captures unmet basic needs would yield immediately actionable data without waiting for comprehensive infrastructure.

If national health systems mandate the use of the QI tool—much like NHS England requires data submission to NATCAN and SSNAP in its standard service specifications—the resulting data ecosystem would, in our opinion, be revolutionary. It would immediately expose the precise operational bottlenecks preventing clinics from meeting the 49-day diagnosis-to-treatment standard, shifting the focus from subjective clinical complaints to objective resource allocation (Hobart et al., 2019).

The feasibility and success of a continuous national audit depend heavily on minimising the administrative burden on clinical staff. Modern MS audits can leverage automated health informatics to ensure continuous data streaming. The integration of automated MRI quantification tools and patient-reported outcome applications directly into electronic medical records allows healthcare systems to maintain continuous auditing without paralysing clinical workflows, ensuring that subtle shifts in population health or therapeutic efficacy are detected in real time.

1.6.2. Aligning audit with commissioning

For the MSBH QI tool to successfully unlock large-scale investment, its metrics must align seamlessly with the financial and policy structures of modern healthcare systems. In England, the transition of commissioning responsibilities to Integrated Care Boards (ICBs) means that funding decisions for specialist neuroscience centres are managed at a regional level, where MS services must constantly compete with other disease areas for finite, non-ringfenced resources (Future-proofing neurology services: What emerging treatments mean for people, services, and policy in England, n.d.).

A national MS audit empowers clinical directors to engage in outcome-based commissioning (Fisher et al., 2019). Through initiatives like the Neurology Transformation Programme, which has developed a national data dashboard for ICBs to monitor the delivery of MS care and DMT utilisation, clinical leaders can present live evidence of service gaps ("Written questions and answers - Written questions, answers and statements - UK Parliament," n.d.). Recent approvals by NHS England of "take at home" therapies, such as oral cladribine, significantly reduce the need for hospital infusion chairs ("Groundbreaking MS treatment to benefit thousands," n.d.). An audit tracking the uptake of such therapies can demonstrate the subsequent freeing of clinical capacity, boosting overall NHS productivity and unequivocally proving the value of investing in high-efficacy, low-burden treatment paradigms ("Groundbreaking MS treatment to benefit thousands," n.d.).

2. Conclusion

In many parts of the world, the management of MS stands at a critical inflexion point. The advent of highly effective DMTs, combined with a deeper understanding of the biological imperative to intervene early to preserve neurological reserve, provides the medical capacity to drastically alter the disease trajectory. However, in nearly every country, clinical potential is routinely squandered by systemic inefficiencies, diagnostic delays, and inequitable access to specialist multidisciplinary teams.

The historical precedent set by the Sentinel Stroke National Audit Programme and the National Lung Cancer Audit in the UK establishes a reproducible methodology for systemic healthcare reform. Continuous, prospective clinical audits do not merely measure care; they actively transform it. By exposing unwarranted variations, highlighting demographic inequalities, and generating compelling health economic data, audits compel policymakers to redesign care pathways and force commissioners to invest in critical infrastructure. The *MS Brain Health: Time Matters* policy recommendations, consensus standards, and the associated QI tool offer an internationally validated framework to replicate this success in MS (Butzkueven et al., 2025; Hobart et al., 2022, 2019). Aligning with the MSCUs and content-focused approaches could further strengthen this potential (Sörensen et al., 2026).

Contributorship

Gavin Giovannoni conceived of and wrote the first draft of the paper. Paola Zaratin, Sara Samadzadeh, Jelena Drulovic, Emma Gray, Ruth Stross, Anne Helme, Saúl Reyes, Tjalf Ziemssen, Ruth Bentley and Jeremy Hobart contributed to critical revision and approved the final version. Gavin Giovannoni is responsible for the overall content as guarantor.

Funding

N/A.

Ethical approval information

N/A.

Data sharing statement

N/A.

Artificial intelligence

The infographic was created using Gemini Notebook, using the draft article as source material.

CRediT authorship contribution statement

Gavin Giovannoni: Writing – review & editing, Writing – original draft, Visualization, Conceptualization. **Paola Zaratin:** Writing – review & editing. **Sara Samadzadeh:** Writing – review & editing. **Jelena Drulovic:** Writing – review & editing. **Laura Thomas:** Writing – review & editing. **Ruth Stross:** Writing – review & editing. **Anne Helme:** Writing – review & editing. **Saúl Reyes:** Writing – review & editing. **Tjalf Ziemssen:** Writing – review & editing. **Jeremy Hobart:** Writing – review & editing.

Declaration of competing interest

Gavin Giovannoni has received compensation for serving as a consultant, speaker or research support from Astoria Biologica, Aurinia Pharmaceuticals, Biogen, BMS, BioNTech, GlaxoSmithKline, Janssens/J&J, Kiniksa, Merck KGaA/EMD Serono, Moderna, Novartis, Pfizer, Sandoz, Sanofi, Roche/Genentech, UCB, Vir Biotechnology, Viracta and Zenas BioPharma.

Paola Zaratin declares no personal conflicts of interest relevant to this work.

Sara Samadzadeh declares no personal conflicts of interest relevant to this work.

Jelena Drulovic declares no personal conflicts of interest relevant to this work.

Laura Thomas declares no personal conflicts of interest relevant to this work.

Ruth Stross, RGN, director of services and healthcare professional lead, MS Trust. MS Trust receives funding from a range of healthcare companies including Biogen, Merck, Novartis, Roche, Sandoz, Sanofi, Juvise and Neuraxpharm. RS declares no personal conflicts of interest relevant to this work

Anne Helme is employed by the Multiple Sclerosis International Federation (MSIF). MSIF receives funding from a range of sources, including healthcare companies. Current and recent funders include Biogen, Bristol Myers Squibb, Coloplast, F. Hoffmann-La Roche, Merck, Novartis, Sandoz, Sanofi Genzyme, and Viatris. AH declares no personal conflicts of interest relevant to this work.

Saúl Reyes declares no personal conflicts of interest relevant to this work.

Tjalf Ziemssen reports scientific advisory board and/or consulting for Biogen, Roche, Novartis, BMS, Sanofi and Merck; compensation for serving on speaker's bureaus for Roche, Neuraxpharm, Novartis, Merck, Novo Nordisk, Sanofi, BMS, TEVA and Biogen; and research support from Biogen, Novartis, Merck, TEVA and Sanofi.

Jeremy Hobart declares no personal conflicts of interest relevant to this work.

Acknowledgements

We would like to acknowledge writing and editing support from Ruth Bentley. We would also like to acknowledge Oxford Pharmagenesis and Oxford Policy Health Forum for supporting the 'MS Brain Health: Time Matters' policy initiative for over a decade, which includes the work on the International quality standard and the quality improvement tool. The 'MS Brain Health: Time Matters' and the Quality Improvement tool have now been taken over by the MS International Federation (MSIF) and the MSBase Foundation, respectively.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.msard.2026.108033.

References

Butzkueven, H., Arkelsten, S., Comi, G., Costello, K., Devlin, M., Drulovic, J., Gray, E., Haartsen, J., Helme, A., Hlavácová, J., Kasilingam, E., Liu, Y., Mathew, T., Reyes, S., de Sèze, J., Williams, M.J., Giovannoni, G., 2025. Brain health - time matters: multiple sclerosis, neuromyelitis optica spectrum disorder (NMOSD), myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) and related conditions. 2024 report. Mult. Scler. Relat. Disord. 101, 106456.

Carnero Contentti, E., Giachello, S., Correale, J., 2021. Barriers to access and utilization of multiple sclerosis care services in a large cohort of Latin American patients. Mult. Scler. 27, 117–129.

Chingarande, G.R., 2025. The ethics of informed consent for data registries: moving beyond moral minimalism to the high ground. BioEthics 39, 709–715.

Cloud, G., Hoffman, A., Rudd, A., Intercollegiate Stroke Working Party, 2013. National sentinel stroke audit 1998-2011. Clin. Med. (Lond) 13, 444–448.

Conibear, J., Nossiter, J., Foster, C., West, D., Cromwell, D., Navani, N., 2022. The national lung cancer audit: the impact of COVID-19. Clin. Oncol. (R. Coll. Radiol) 34, 701–707.

Dawson, S., 2025. National Lung Cancer Audit (NLCA) State of the Nation report [WWW Document]. HQIP. URL https://www.hqip.org.uk/resource/nlca-2023/(accessed 4.29.26).

England, N.H.S., n.d. NHS England » Clinical audits and registries: A best practice guide [WWW Document]. URL https://www.england.nhs.uk/long-read/clinical-audits-registries-best-practice-guide/(accessed 4.29.26).

Evidence for MS specialist services: Findings from the GEMSS MS specialist nurse project, n.d. . MS Trust.

Ezer, N., Navasakulpong, A., Schwartzman, K., Ofiara, L., Gonzalez, A.V., 2017. Impact of rapid investigation clinic on timeliness of lung cancer diagnosis and treatment. BMC. Pulm. Med. 17, 178.

Fisher, R., Chouliara, N., Byrne, A., Lewis, S., Langhorne, P., Robinson, T., Waring, J., Geue, C., Hoffman, A., Paley, L., Rudd, A., Walker, M., 2019. What is the impact of large-scale implementation of stroke early supported Discharge? A mixed methods realist evaluation study protocol. Implement. Sci. 14, 61.

Fisher, R.J., Byrne, A., Chouliara, N., Lewis, S., Paley, L., Hoffman, A., Rudd, A., Robinson, T., Langhorne, P., Walker, M.F., 2020. Effectiveness of stroke early supported discharge: analysis from a national stroke registry. Circ. Cardiovasc. Qual. Outcomes. 13, e006395.

Fitzjohn, J.-P., Bolodeoku, J., Chinegwundoh, F., Rogers, J., Chambers, K., Anyaeche, C., Odeyemi, I., 2026. Budget impact analysis of risk-stratified prostate cancer screening in the UK using national audit data. British J. Healthcare Med. Res. 13, 63–90.

Ford, H.L., 2006. The effect of consent guidelines on a multiple sclerosis register. Mult. Scler. 12, 104–107.

Future-proofing neurology services: What emerging treatments mean for people, services, and policy in England, n.d. . Neurological Alliance.

Giovannoni, G., Butzkueven, H., Dhib-Jalbut, S., Hobart, J., Kobelt, G., Pepper, G., Sormani, M.P., Thalheim, C., Traboulsee, A., Vollmer, T., 2016. Brain health: time matters in multiple sclerosis. Mult. Scler. Relat. Disord. 9 (Suppl 1), S5–S48.

Giovannoni, G., Popescu, V., Wuerfel, J., Hellwig, K., Iacobaeus, E., Jensen, M.B., García-Domínguez, J.M., Sousa, L., De Rossi, N., Hupperts, R., Fenu, G., Bodini, B., Kuusisto, H.-M., Stankoff, B., Lycke, J., Airas, L., Granziera, C., Scalfari, A., 2022. Smouldering multiple sclerosis: the "real MS. Ther. Adv. Neurol. Disord. 15, 17562864211066751.

Groundbreaking MS treatment to benefit thousands [WWW Document], n.d. . National Health Executive. URL https://www.nationalhealthexecutive.com/articles/groundbreaking-ms-treatment-benefit-thousands (accessed 4.29.26).

Grytten, N., Torkildsen, Ø., Myhr, K.-M., 2015. Time trends in the incidence and prevalence of multiple sclerosis in Norway during eight decades. Acta Neurol. Scand. 132, 29–36.

Hobart, J., Bowen, A., Pepper, G., Crofts, H., Eberhard, L., Berger, T., Boyko, A., Boz, C., Butzkueven, H., Celius, E.G., Drulovic, J., Flores, J., Horáková, D., Lebrun-Frénay, C., Marrie, R.A., Overell, J., Piehl, F., Rasmussen, P.V., Sá, M.J., Sîrbu, C.-A., Skromne, E., Torkildsen, Ø., van Pesch, V., Vollmer, T., Zakaria, M., Ziemssen, T., Giovannoni, G., 2019. International consensus on quality standards for brain health-focused care in multiple sclerosis. Mult. Scler. 25, 1809–1818.

Hobart, J., Butzkueven, H., Haartsen, J., Ziemssen, T., Lane, T., Giovannoni, G., 2022. Timely intervention, monitoring and education MATTERS in MS (TIME MATTERS in MS): development of a globally applicable quality improvement tool. Mult. Scler. J. Exp. Transl. Clin. 8, 20552173221124023.

Hurwitz, B.J., 2011. Registry studies of long-term multiple sclerosis outcomes: description of key registries. Neurology 76, S3–S6.

Jager, A., Wong, G., Papoutsi, C., Roberts, N., 2023. The usage of data in NHS primary care commissioning: a realist review. BMC. Med. 21, 236.

Kuri, A., Henshall, D.E., Chaudhry, D., Ooi, S.Z.Y., Zhang, Q., Mathews, J., Thomson, A., Rog, D., Hobart, J., Dobson, R., Neurology and Neurosurgery Interest Group (NANSIG), 2024. Delays in Multiple Sclerosis diagnosis (DIMES): protocol for a multicentre, observational study of multiple sclerosis diagnostic pathways in the United Kingdom and Republic of Ireland. BMC. Neurol. 24, 105.

Metcalfe, G., Owen, A., 2023. Can multiple sclerosis nurses help reduce non-elective admissions? Revisiting the question 2 years on from an analysis of a service delivery audit. Br. J. Neurosci. Nurs. 19, S12–S16.

Morrison, J.L., Dalli, L.L., Kilkenny, M.F., Lannin, N.A., Paice, K., Thandar, M., Kim, J., Birhanu, M.M., Pompeani, N., Carter, H., Ghuliani, J., Gibbs, A.K., Middleton, S., Dewey, H.M., Cadilhac, D.A., 2026. Optimising data quality in a national clinical quality registry: insights from the Australian Stroke Clinical Registry. Health Inf. Manage 55, 183–192.

Mosconi, P., Guerra, T., Paletta, P., D'Ettorre, A., Ponzio, M., Battaglia, M.A., Amato, M. P., Bergamaschi, R., Capobianco, M., Comi, G., Gasperini, C., Patti, F., Pugliatti, M., Ulivelli, M., Trojano, M., Lepore, V., Italian Multiple Sclerosis and Related Disorders Register Centres Group, 2023. Data monitoring roadmap. The experience of the Italian Multiple Sclerosis and Related Disorders Register. Neurol. Sci. 44, 4001–4011.

MS Trust, 2016. MS Forward View [WWW Document]. MS Trust. URL https://mstrust.org.uk/health-professionals/programmes/ms-forward-view (accessed 6.17.26).

MS Trust, 2019. MS Trust guide to Writing a Strong Business Case. MS Trust.

Mynors, G., Bowen, A., 2014. Modelling sustainable caseloads for MS specialist nurses: report on a consensus process led by the MS Trust. Br. J. Neurosci. Nurs. 10, 274–280.

Rød, B.E., Høgestøl, E.A., Torkildsen, Ø., Bjørnevik, K., Gran, J.M., Øverås, M.H., König, M., Myhr, K.-M., Wergeland, S., Nygaard, G.O., 2025. Comparative effectiveness of rituximab and cladribine in relapsing-remitting multiple sclerosis: a target trial emulation. Mult. Scler. 31, 975–984.

Ruscoe, L., Lowndes, C., Sheldon, K., Perrin, N., Keohane, H., Ellis, L., Smith, K., 2026. The evolution of nurse prescribing in multiple sclerosis care. Br. J. Neurosci. Nurs. 22. https://doi.org/10.12968/bjnn.2025.0075.

Shalash, A., Gams Massi, D., Ben Sassi, S., Tibar, H., Fall, M., Zewde, Y.Z., Alsiddig Ebraheem, A., Mecheri, Y., Razafimahefa, J., Dadah, S., Fernando, G.C., Kapto, O., Kisekka Musubire, A., Sheikh Mohamed, A.O., Camara, M., Nestor, N., Amer, N., Neshuku-Nampala, S.N., Marcellin, B., Sakad, F., Ngwende, G.W., Hooker, J., Jamnagerwalla, Y., Akpalu, A., Saylor, D., van Coller, R., Okubadejo, N.U., Hamid, E., Abdelaziz, A.A., Salah, N.M., 2026. Availability and affordability of therapies and services of multiple sclerosis in Africa: a continent-wide survey. Mult. Scler. 32, 315–325.

Simoni, A.H., Ahlstrøm, L.M.V., Ording, A.G., Borre, M., Johnsen, S.P., Jensen, J.W., Møller, H., 2026. Development targets in the clinical quality registries for cancer and non-cancer diseases. J. Cancer Policy. 47, 100726.

Sitecore, n.d. Response to National lung cancer audit [WWW Document]. Royal College of Surgeons. URL https://www.rcseng.ac.uk/news-and-events/media-centre/press-releases/nlca-response/(accessed 4.29.26).

Solomon, A.J., Marrie, R.A., Viswanathan, S., Correale, J., Magyari, M., Robertson, N.P., Saylor, D.R., Kaye, W., Rechtman, L., Bae, E., Shinohara, R., King, R., Laurson-Doube, J., Helme, A., 2023. Global barriers to the diagnosis of multiple sclerosis: data from the Multiple Sclerosis International Federation Atlas of MS, third edition: data from the multiple sclerosis international federation Atlas of MS, third edition. Neurology 101, e624–e635.

Sörensen, P.S., Zaratin, P.F., Battaglia, M.A., Edan, G., Samadzadeh, S., Leocani, L., Becker, J., Flores, J., Hamuy, F., Cristiano, E., Patrucco, L., Montalbán, X., Hartung, H.-P., Comi, G., Fernandez, O.F., 2026. Global overview of multiple sclerosis care units: an international cross-sectional survey. Front. Neurol. 17, 1812690.

Stastna, D., Drahota, J., Lauer, M., Mazouchova, A., Menkyova, I., Adamkova, J., Ampapa, R., Dufek, M., Grunermelova, M., Hradilek, P., Kubala Havrdova, E., Mares, J., Martinkova, A., Pavelek, Z., Peterka, M., Recmanova, E., Rockova, P., Stetkarova, I., Stourac, P., Vachova, M., Horakova, D., 2024. The Czech National MS Registry (ReMuS): data trends in multiple sclerosis patients whose first disease-modifying therapies were initiated from 2013 to 2021. Biomed. Pap. Med. Fac. Univ. Palacky. Olomouc. Czech. Repub. 168, 262–270.

Sultani, G., Hillal, A., Ramgren, B., Apostolaki-Hansson, T., Norrving, B., Wasselius, J., Ullberg, T., 2024. Diagnostic accuracy and radiological validation of intracerebral hemorrhage diagnosis in the Swedish Stroke Register (Riksstroke). Eur. J. Neurol. 31, e16413.

The National Cancer Plan for England: delivering world class cancer care (accessible version) [WWW Document], n.d. . GOV.UK. URL https://www.gov.uk/government/publications/national-cancer-plan-for-england/the-national-cancer-plan-for-england-delivering-world-class-cancer-care-accessible-version (accessed 4.29.26).

Trojano, M., Bergamaschi, R., Amato, M.P., Comi, G., Ghezzi, A., Lepore, V., Marrosu, M. G., Mosconi, P., Patti, F., Ponzio, M., Zaratin, P., Battaglia, M.A., Italian Multiple Sclerosis Register Centers Group, 2019. The Italian multiple sclerosis register. Neurol. Sci. 40, 155–165.

UK MS Register [WWW Document], n.d. . Multiple Sclerosis Society UK. URL https://www.mssociety.org.uk/research/explore-our-research/search-our-research-projects/the-uk-ms-register (accessed 10.13.26).

Voigt, I., Akgün, K., Inojosa, H., Haas, J., Temmes, H., Meuth, S.G., Giovannoni, G., Ziemssen, T., 2024a. MS brain health quality standards: a survey on the reality in clinical practice in Germany. Neurol. Res. Pract. 6, 59.

Voigt, I., Fischer, S., Proschmann, U., Konofalska, U., Richter, P., Schlieter, H., Berger, T., Meuth, S.G., Hartung, H.-P., Akgün, K., Ziemssen, T., 2024b. Consensus quality indicators for monitoring multiple sclerosis. Lancet Reg. Health Eur. 40, 100891.

Wenk, J., Inojosa, H., Voigt, I., Gilbert, S., Ziemssen, T., 2026. Are traditional registries becoming obsolete in the modern digital health ecosystem? J. Med. Internet. Res. 28, e92696.

White, S.A., Mgawadere, F., Gopalakrishnan, S., van den Broek, N., 2024. Standards-based audit to improve quality of maternal and newborn care-A stepped-wedge cluster randomised trial in Malawi. PLoS. One 19, e0310896.

Written questions and answers - Written questions, answers and statements - UK Parliament [WWW Document], n.d. URL https://questions-statements.parliament.uk/written-questions/detail/2025-07-02/64710/(accessed 4.29.26).

Yeh, E.A., Tremlett, H., Suntornlohanakul, R., Castillo-Villagran, D., Ciftci, B., Tenembaum, S., Savaransky, A., Pandit, L., Lim, M., 2025. Access to therapy for children and adolescents with multiple sclerosis: global considerations in preventing disease progression. Lancet Child Adolesc. Health 9, 673–684.