

Evaluation of the quality of the care pathway for patients with multiple sclerosis in France

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Title: Evaluation of the quality of the care pathway for patients with multiple sclerosis in France: results of an original study of a cohort of 700 patients

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Evaluation of the quality of the care pathway for patients with multiple sclerosis in France: results of an original study of a cohort of 700 patients

Abstract

Introduction: Evaluating the quality of the care pathway for patients with chronic diseases, such as multiple sclerosis (MS) is an important issue. Process indicators are a recognized method for evaluating professional practices. However, these tools have been little developed in the field of MS, and few data are available. The aim of this study was to describe, retrospectively, with validated indicators, the quality of the care pathway in a population-based cohort of 700 patients with the first manifestations of the disease occurring between January 1, 2000 and December 31, 2001 and during the first 10 years of disease.

Method: This assessment was based on 48 indicators specific to MS. The information required for the calculation of each indicator was collected from the source files of the 700 patients of the cohort.

Results: Data for the 10 years of follow-up were collected for 80% of the patients. In total, 36 indicators were calculated. These results reveal that there is room for improvement, particularly in terms of the initial assessment, access to ophthalmological evaluation, employment, obtaining an evaluation of the need for rehabilitation, and access to such care.

Conclusion: The results of this survey provide access to unprecedented new data in France, that professionals and patients can appropriate to improve the targeting of actions, to improve the quality of care further for patients with MS in France. We propose to continue this process by submitting, for discussion, a targeted list of updated indicators relating to changes in guidelines, and in issues concerning the quality of patient management.

Keywords: multiple sclerosis; quality of health care; health services; clinical pathways

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1. Introduction

Health professionals and patients are continually trying to improve the quality of care pathways, particularly for chronic diseases. This is a complex process, involving multiple determinants linked to the patients themselves, current knowledge, professional practices, the interaction between patients and professionals and the organization and funding of healthcare systems.

In France, the follow-up of patients with MS involves multiple medical specialties (neurology, ophthalmology, physical and rehabilitation medicine, radiology, general practice etc.) and many other healthcare professionals (state-registered nurses, psychologists, physiotherapists, occupational therapists, social workers, etc.) working at hospitals and in private practice. The coordination of all these actors is an important issue for improving the quality of patient management [1,2]. Over the last few years, initiatives, such as the regional MS care networks in France, have been established for this purpose. Generally, when assessing the quality of their practices and the organization of care, professionals should use tools that have been validated scientifically and methodologically. However, there have been few initiatives aiming to develop such tools, which remain rare or not very specific to MS.

The available recognized tools include quality indicators, which have been used for health assessment purposes for nearly 30 years in France [3]. According to the US National Library of Medicine, quality indicators are “norms, criteria, standards, and other direct qualitative and quantitative measures used in determining the quality of health care [4]. According to the Donabedian reference model, process indicators are the most widely used, particularly for the evaluation of practices in the domain of health [5]. They measure the quality of implementation for care activities relative to professional guidelines. Outcome indicators are widely used in the context of clinical research. The links between process indicators and outcome indicators are now recognized and these two approaches are complementary for assessments of the quality of care [6].

In the field of MS, the American Academy of Neurology (ANN) published a list of indicators in 2015 [7]. These 13 indicators were chosen from a list of 76 indicators initially proposed by Cheng et al. in a study performed in 2010 [8]. The AAN stressed that these new tools should be adopted not only by healthcare professionals, but by the entire healthcare system, to improve organization and practices. To date, only one study, published in 2016, provides "real life" results for four of these indicators, essentially on the basis of information reported by the patients themselves [9] (Table 1). In England and Wales, the National Institute for health and Care Excellence (NICE) published six key guidelines in 2003 for identifying indicators for improving the quality of care for patients with MS, in particular access to rehabilitation care and social services [10]. The adoption of these guidelines was assessed

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during three national audits carried out in 2006, 2008, and 2011, again based on data declared by the care structures (hospitals, primary care centers), the patients themselves, and the overseeing authorities [11]. There is currently no standardized national approach of this type in France, although the data collected for the Observatoire Français de la Sclérose En Plaques (OFSEP) cohort and some of the studies arising from it represent a step in this direction [12]. The transposition of indicators from other healthcare systems raises questions about their pertinence. Indeed, the organization of care pathways for chronic diseases, such as MS, depends on both hospitals and private practitioners, and on the conditions governing the funding of care. It therefore remains quite country-specific.

Since 2011, in partnership with healthcare professionals, patients, and their natural caregivers, our group has been involved in a research program aiming to develop tools for the evaluation of practices and organization, to improve the quality of care for these patients in France. The tools concerned include a set of 48 dedicated quality indicators for the care pathways of patients with MS in France, which has been validated by a group of professionals representing teams with recognized expertise in the management of these patients [13]. Through the mobilization of more than 1,000 patients and caregivers, we have also developed the first two questionnaires for assessing the experiences of these patients and their caregivers in terms of their management throughout the care pathway [14].

The testing of quality indicators with real-life data is an important step for confirming their relevance in terms of the organization and practices of professionals, but also that of the available information systems. This approach also makes it possible to discuss the conditions for collecting the necessary data and adjust certain choices if necessary, before the generalization of their use.

The aim of the present study was to test the relevance of quality indicators in MS care on a population-based cohort of almost 700 patients from three French regions. Secondary objectives were to assess the availability of necessary data for said indicators, and to identify areas for improvement in the quality of the care pathways for MS patients in France

2. Methods

2.1 Study population

Our sample of patients was assembled from three population-based cohorts from three French regions (Brittany, Pays de la Loire, and Lorraine) with a total population of over seven million inhabitants.

For inclusion, patients had to meet the following criteria: patient residing in one of these three regions at the onset of the first symptoms, with the first manifestations of the disease occurring between

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January 1, 2000 and December 31, 2001, patient at least 18 years old at symptom onset and not refusing access to their personal data. The putative incident cases had to meet McDonald'scriteria 2010 to be considered true incident cases of MS [15].

Patients from the Brittany and Pays de la Loire cohorts (regions with over 5 million inhabitants) were identified by the incidence survey carried out between 2000 and 2001 in these two regions [15]. This survey included 275 patients from the Brittany region (4 *départements*, a French administrative area equivalent to a county) and 120 from the two counties concerned for the Pays de la Loire region.

For the Lorraine cohort (more than 2 million inhabitants in 4 counties), patients were identified from the population based Lorraine MS registry (ReLSEP). This registry holds accreditation from the national registries committee and its data are held at the Clinical Epidemiology Center of Nancy University Hospital [16]. In total, 332 patients met the inclusion criteria for our study. The incidence of MS in this region is known to be higher than that in the regions of western France [17].

2.2 Development of the indicators

The indicator development method has been described elsewhere [13]. In brief, the 48 indicators were selected by a group of experts made up of professionals representing several hospital and private neurology and rehabilitation-reeducation teams from the three regions. Each of the indicators was defined on the basis of existing guidelines in the field. The selection method was based on the search for a consensus according to an approach developed by the Research and Development Corporation (Rand / UCLA Appropriateness Method), checking the agreement of each expert with the guidelines and the agreement between experts [18]. This approach includes an individual and anonymized rating phase, followed by face-to-face discussions. The indicators cover the following areas: access to care during follow-up and according to disease progression, management by imaging (MRI), overall management/management of relapses, management of maintenance treatment (immunomodulators and immunosuppressants), and the management of rehabilitation and reeducation.

2.3 Data collection

Data for the 48 indicators were collected retrospectively for a period of 10 years of disease from the onset of the first symptoms. The data were collected between 2012 and 2013. In addition to the data required for calculation of all the indicators, the sociodemographic characteristics of the patients and other items of health information were included, such as the occurrence of pregnancy or a

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concomitant pathological condition. All data were collected from the medical records of the patients stored in both hospitals and private practice offices, on paper or in electronic form. We also used data from the EDMUS database and the Lorraine MS registry [19]. Data collection was partially automated (for data from the EDMUS database and the Lorraine MS registry), but mostly performed by clinical research assistants and the principal investigator of the study extracting information directly from each patient file.

2.4 Data analysis

All the available data were described with the usual descriptive statistics: frequencies and percentages for qualitative variables and means, standard deviations, medians, and interquartile range for quantitative variables. Missing data were not replaced, being, by their nature, an indicator of the non-traceability of information. Calculations of the time taken to reach an Expanded Disability Status Scale (EDSS) score ≥ 3 and for a secondarily progressive form to appear were calculated according to the nonparametric Kaplan-Meier method. The results are expressed as the median time to the occurrence of these events since the start of follow-up for the included patients.

Each indicator was then calculated according to the definition validated by the experts[13]. The form of MS was determined if necessary.

Analyses were performed with SAS® software version 9.4.

This study was approved by the Ethics Committee Ouest V in November 2010 (reference 10/36-778), and by the French national data protection authority (CNIL, authorization no. 911029).

3. Results

In total, 699 of the 727 patients identified were included in our study, and 28 (3.8%) were excluded because they were under the age of 18 years when symptoms first occurred or because they refused to allow access to their health data.

3.1 Principal characteristics of the patients and their disease

These characteristics are described in Table 2. In general, they were similar to those described for the OFSEP cohort [20].

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In addition, socioprofessional category at disease onset was identified for 457 (65.4%) patients, 268 (58.6%) of whom were employees and middle managers, 40 (8.8%) of whom were manual laborers, and 32 (7%) of whom were senior managers. Another fraction of the study population (95 patient, or 20.8%) had no professional activity at the time (students, retired, unemployed, or on disability benefits). During the 10 years of follow-up, 174 patients (almost 4 in 10 of the patients with professional activities at disease onset) had to change their professional activity due to the disease.

The main concomitant pathological conditions identified during the 10 years of follow-up were psychiatric disorders (especially depression) for 29 patients, cardiovascular conditions (stroke, coronary artery disease, arrhythmias, etc.) for 33, cancers (e.g. lung, digestive tract and gynecological cancers, digestive, gynecological) for 30, and other chronic diseases (diabetes, thyroid conditions, etc.) for 18.

The traceability of information concerning height and weight was low, at 5.2% (36/699) for weight and 7.6% (53/699) or height, over the entire duration of the study.

In terms of disability levels, EDSS score was indicated at least once in the source files for 87.5% of the patients included without a clinically isolated syndrome (CIS) and with at least 10 years of follow-up (436/498). EDSS score was indicated once during the first five years of follow-up and once again during the second five years for 68.8% (300/436) of these patients. EDSS score was ≥ 3 from the start of follow-up in 64 of these 300 patients (see Table 3). The Kaplan-Meier median time taken to reach an EDSS score of 3 was 8.78 years (95% CI: 8.15 - 10.94 years) for the other 236 patients, and 3.82 years (95% CI: 0.20 - 6.33 years) for the 10 patients presenting a progressive form from onset.

3.2 Available and interpretable data for calculating a large majority of the quality indicators (see Tables 3 and 4)

The indicators were calculated for the entire study population, regardless of the form of the disease, provided they were considered relevant for patient management. We were able to collect the necessary data for calculation of the indicators during the first 10 years of disease for more than 80% of the patients in the cohort (587/699). The other 112 patients were followed up less completely, and for a mean duration of 5.4 years (standard deviation 3.1). The reasons for this partial follow-up were the patient moving to another region without indicating his or her new medical team for 28 patients, death for 13 patients, and loss-to-follow-up for the other 71 patients (10.2%).

With the available data, we were able to calculate 36 of the 48 indicators.

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Data were missing for the other 12 indicators, due, in particular, to a lack of traceability in the source files. This lack of traceability concerned both dates (for the indicators "distribution of patients according to their level of disability after follow-up", "Time to ophthalmology consultation after the first detection of a visual disorder (including retrobulbar optic neuritis)", "percentage of physical and rehabilitation medicine consultations during which a pain evaluation was performed", "percentage of patients for whom the indications and contraindications for mitoxantrone use were respected at treatment onset") and clinical data, including, in particular, the EDSS score after a relapse, which was missing for more than 90% of cases (for the indicators "percentage of relapses after which the EDSS score was ≥ 2 and followed by physiotherapy sessions", "time to first rehabilitation management for patients with an EDSS score ≥ 3 after a relapse").

We were also confronted with the problem of data that were too imprecise and too heterogeneous to define the criteria for referral to a specialist center for the indicator "percentage of patients having access to a specialist MS center", or the disorders to be identified for the indicator "percentage of patients screened for cognitive and/or psychological disorders during follow-up". Finally, there were almost no data in the source files for the indicator "Percentage of mitoxantrone-treated patients for whom the blood cell count-monitoring guidelines had been followed".

3.2.1 Access to care during follow-up and according to disease progression

The results for the indicators calculated in this domain are presented in Table 4.

The etiological assessment (inflammatory test, brain MRI, cerebro-spinal fluid) based on the initial symptoms was performed during the 12th month after the first neurological consultation for a minority of patients (82/699 or 11.7%). Data about inflammatory test were available only for 200 patients due to lack of traceability in the source files. This assessment complied with guidelines for three quarters of the patients concerned, versus less than one quarter for the other patients.

One third of the patients presenting an initial form of the remitting type (*N* = 489) were able to consult a neurologist within 30 days of the appearance of the first symptoms, but one third did not see a neurologist until more than one year later (Figure 1). During follow-up, the patients had a mean of 14.8 (SD = 12.2) consultations with a neurologist, with 1.52 consultations per year (95% CI: 1.49-1.55), for all forms combined.

We found that 227 of 409 patients (55.5%) were able to see an ophthalmologist after the identification of a visual disorder by a neurologist or physiotherapist or rehabilitation specialist. The median time

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between the first detection of visual disturbances and consultation with an ophthalmologist was 1.1 months (0,1-15), regardless of the type of disorder.

3.2.2 Management by imaging (MRI)

The four indicators of this domain could be calculated, and the results are presented in Table 4. However, we were unable to analyze the indicator relating to respect for MRI sequences for the patients from Lorraine, due to a lack of data.

Comparing the timing of the first brain MRI scan and the first consultation with a neurologist (see Fig. 1), we found that:

- The majority of patients had their first MRI scan before their first consultation (396 or 56.6%). The median time to the examination was similar for patients undergoing MRI before and after the first consultation (taking into account a time limit of 12 months after a first consultation with no other consultation in the intervening period): 24 days (0 – 64 days) and 28 days (8 - 79.5), respectively.
- The sequences for this diagnostic brain MRI scan were respected (for the 467 patients for whom data were collected) in 62.1% (117/191) of patients undergoing scans after first consultation with a neurologist, versus 37.1% (87/234) if the scan was performed before this consultation.

Most patients had a first spinal cord MRI scan before the first consultation with a neurologist (180/264 or 68%). The median time to the examination was 15 days (0 - 50.5 days).

The mean number of brain MRI scans over the 10-year period of the study was 0.5 (SD 2.1) patient-years, and the median number of scans was 0.3.

A brain MRI was performed before the initiation of immunosuppressive treatment for 55.3% (120/217) of the patients concerned if a period of six months, rather than three months was taken into account.

3.3.3 Management of relapses

The three indicators of this domain could be calculated for patients from Brittany and Pays de la Loire, for whom the results are presented in Table 4. No data were accessible for the patients from Lorraine. Time to initiation of corticosteroid therapy depends on the time to consultation with a neurologist to confirm the relapse. A soon as patients have access to the neurologist this treatment is quickly initiated

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(median 0 days; IR).

3.3.4 Management of immunomodulatory treatment

The five indicators of this domain were calculated, and the results are presented in Table 4.

Immunomodulatory maintenance treatment was proposed to 83.4% (408/489) of patients presenting an initial remittent form, and was administered to 378 of these patients (77%). The median time to the first administration of immunomodulatory treatment was 14.4 months (0-124 months) after the first consultation with a neurologist (see Table 4), 11.5 months (3.7 - 35.2 months) after MS diagnosis, and 28.5 months (12.9 - 53.7 months) after the onset of the first symptoms. The indications and contraindications for the initiation of this treatment were observed in 70% of cases. The mean duration of treatment was 55.3 months (SD: 37.1 months; median 54.0 months) for all immunomodulators considered together.

In addition, 28 patients with a progressive form at disease onset received immunomodulatory treatment for a mean duration of 36.3 months (25.5 - 64.0 months).

3.3.5 Management of immunosuppression

It was possible to calculate eight of the 10 indicators of this domain, and the results are presented in Table 4.

Echocardiography was performed in 65.6% (21/32) of cases and blood cell counts were performed in 46.9% (15/32) of cases, for patients undergoing pretreatment evaluations before the initiation of mitoxantrone treatment.

3.3.6 Management of reeducation and rehabilitation

We were able to calculate nine of the 13 indicators in this domain, and the results are Table 4.

Fewer than one in five patients (35/214) with EDSS scores remaining below 3 throughout the follow-up period attended at least one consultation or one session at a rehabilitation center.

For the 121 patients with an initially remittent form, the median time from the estimated date of the first symptoms of the disease to first contact with a rehabilitation center was 5.1 years (2.9 - 7.3 years). This time lag was only 3.4 years (2.2 - 6.3 years) for the 54 patients with an initially progressive form

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of the disease.

Outside of relapses, less than half (73/168) the patients with progressive forms (either from the outset or secondary) who reached an EDSS score ≥ 3 during the follow-up period received physiotherapy in private practice, in a majority of cases more than six months later. Similarly, less than half (73/168) received treatment at a rehabilitation structure, with only just under half these patients receiving such treatment within a period of six months.

A urodynamic assessment was performed for 145 (43%) of the 337 patients who reported urinary problems.

4. Discussion

This is the first study to provide such extensive information on the course of the care pathways in a population-based cohort of almost 700 patients followed for 10 years after the appearance of the first symptoms of the disease in France. The collection of data from patient records provided results for 36 of the 48 indicators tested, and it was possible to collect for the 10 years of follow-up for more than 80% of the patients in the cohort

Access to care and, particularly, to a certain number of medical specialties, has an indirect but real impact on the quality of care and the progression of MS symptoms and disease [21,22].

Our results concerning neurological follow-up are similar to those of other published studies, in France and other countries at the same period of time [23-26]. The frequency of follow-up visits conforms to the guidelines for annual follow-up, but access to the first consultation with a neurologist could be earlier for some patients. Strengthening information and raising the awareness of patients, and, above all, of front-line healthcare professionals, particularly general practitioners, to get this first neurological consultation done therefore remains an important issue, particularly in light of the guidelines for early treatment. The general practitioner is the healthcare professional most frequently consulted by patients with MS [22]. Access to ophthalmic expertise is difficult to obtain for a sizeable proportion of patients. This difficulty has been raised by the patients themselves in other studies [24,26]. In France, this difficulty results primarily from the shortage of ophthalmologists in many areas, particularly those outside the most highly urbanized zones, and from the continual increase in demand for consultations as the general population ages. Given that the first symptoms of MS are often visual and the demographic outlook remains pessimistic for the foreseeable future, maintaining easy access to a neurologist for these patients is of particular importance.

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Access to functional rehabilitation is an important issue for patients with MS. Indeed, beyond the motor consequences of disability, this area of care contributes to better overall management for fatigue, pain, and bladder and sexual problems [27]. In our study, less than half of the patients reaching an EDSS score ≥ 3 had access to such care. The results of other studies in this area, based primarily on declarative data, also highlight the underuse of such resources [28-30]. Several studies have suggested that this underuse may result from patient themselves not identifying or poorly identifying their needs in this area [30,31]. Resources are not generally lacking in France, but patient awareness and information concerning the issues and benefits in this area, and the possibilities and conditions of access, need be strengthened.

The low rate of ultrasound examinations performed on patients with urinary disorders problems may be partly due to a certain "trivialization" of symptoms and their consequences by the patients, especially in the initial phase. However, the urinary problems linked to MS and the consequences of delayed treatment are well known and are the subject of specific guidelines from academic societies [31,32]. Here too, raising awareness and informing professionals, but above all patients and those caring from them, would provide key opportunities for improvement.

For follow-up by MRI, it should be pointed out that the new criteria of McDonald et al. were published in 2001 and revised in 2005 [33,34]. These guidelines were, obviously, primarily transmitted to neurologists. Indeed, in our study, 61.7% of MRI scans performed after the first consultation with a neurologist met the criteria in terms of sequences, whereas this rate was only 27.8% if the examination was performed before the first consultation with a neurologist. However, accessibility to such exam was not so easy and annual follow-up by brain imaging was not yet the rule during the study period considered here.

Concerning the overall management of relapses, the results of the three indicators were largely satisfactory, particularly the access to a neurologist, which was almost systematic (93% of relapses), and the time to the appointment (median of 9 days).

The proportion of patients with an initially remittent form who received at least one maintenance treatment with an immunomodulator during the 10 years of follow-up was similar to that reported in other studies, particularly in France [35]. As also observed by the authors of this study, the time to initiation of such treatments was longer (a mean of 26.5 months after the first consultation with a neurologist) than advised in current guidelines [36].

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Concerning the initiation and monitoring of immunosuppressive treatment, few patients were treated with natalizumab at the time of the study. It is not, therefore, possible to draw any firm conclusions from the results.

One limitation of this study was that 20% (9/48) of the indicators could not be calculated. We found that there was a strong lack of traceability for the data required for the calculation of these indicators in patient records, with data either almost entirely absent (e.g. the EDSS scores after relapses, and dates) or too imprecise (e.g. for the characterization of psychological and cognitive disorders, multidisciplinary consultations, or for the systematic assessment of fatigue). These findings are consistent with previous reports, for national evaluation campaigns, such as that of the IQSS in France, for example, which is based on retrospective studies of the data recorded in the files of patients staying in healthcare establishments [37]. Nevertheless, we believe that this source of information remains the reference for the calculation of indicators of this type. It prevents the recall bias associated with declarative patient data, especially for a period of 10 years. Keeping patient files correctly, which includes ensuring the traceability of information, is governed by very precise regulatory obligations for healthcare professionals and establishments, as indicated in the public health code in particular (decree no. 2002-637 of April 29, 2002). Aside from the indicators that we were unable to calculate, this lack of traceability is probably a wider limitation, also concerning some of the indicators for which results are presented, albeit to a lesser extent. Thus, for indicators requiring the results and date of a biological assessment, such as those for the initiation and follow-up of maintenance treatment, assessments are mostly carried out in private practice, with the results transmitted to the patient on paper. Consequently, a trace of these results is not always kept in the medical files of the patient held in hospital departments or at the offices of doctors in private practice. At the time of this study, assessments of fatigue were not based on the routine use of specific assessment scales, with a direct impact on the traceability and accuracy of this type of information. For the indicators relating to work, such as screening for difficulties integrating into the workplace, the traceability of these activities had not yet been formalized. Thus, among the messages of this study for all professionals involved in the care and management of these patients, the issue of the traceability of essential information to improve feedback to teams concerning their application of the guidelines in practice is undoubtedly the most important. The formalization of shared and standardized databases, such as that of the EDMUS network, could be helpful in this respect. Indeed, we observed that the patients followed within the framework of the MS registry in Lorraine benefited from the traceability of their EDSS score, which was clearly superior to that for other patients.

The other major limitation of this study concerned the interpretation and use of results corresponding to the period from 2000 to 2011 in the context of current practices and organization. For example, the

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time to initiation of the first immunomodulatory treatment has decreased over time, with practices evolving spontaneously with changes in the guidelines in this area. Similarly, the availability of second-line treatment has changed significantly since the end of the study period (i.e. 2010). Thus, the indications for natalizumab have expanded and the number of patients receiving this treatment has significantly increased. Furthermore, other treatments have also come onto the market. In the field of imaging, changes in knowledge and guidelines have also probably led to changes in practices, in terms of both the frequency and quality of examinations during patient follow-up. It would be useful to collect such data for patients treated after 2010, for example, for the same duration of follow-up, to confirm these observations. These findings also highlight the value of periodically collecting data for the proposed indicators, so as to obtain regular factual data confirming concrete changes in practices and organization in line with professional guidelines. Such continual changes in scientific knowledge and, therefore, guidelines, may also lead to a review of the definition of certain indicators. For example, it could be suggested that, to evaluate the quality of care, the time to the first diagnostic brain MRI should be calculated not from the onset of the first symptoms, which is independent of the practices and organization of professionals, but from the first consultation with a neurologist. Similarly, it could be suggested that the time to the initiation of maintenance treatment with immunomodulators should be calculated from the first consultation with a neurologist, who is in fact the prescriber, rather than from the onset of the first symptoms. The central issue of access to a first consultation with a neurologist would still be measured by the indicator evaluating the time between the onset of the first symptoms of the disease and this first consultation.

Based on this unique experience, the authors wish to provide the community of professionals involved in the care of these patients with an updated list of quality indicators for the evaluation of their practices and organizations. These choices were, firstly, guided by current clinical practice guidelines, to ensure the definition of indicators that are pertinent with respect to these guidelines. They were also guided by a desire for the evaluation process to be deployable beyond dedicated projects, such as this one, with support from local or national initiatives, particularly in connection with the French-speaking Society for MS and the French Observatory for Multiple Sclerosis. These indicators therefore needed to cover the major steps in the diagnosis and follow-up of patients, according to the logic of the care pathway used in our project.

At each of these stages, the proposed indicators refer to scientific data validated in the domain, in terms of appropriate diagnostic and therapeutic approaches, and issues of access to the care system and waiting times for the patients concerned. These issues remain relevant today, as demonstrated by some of the results of this study.

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These proposals are presented in Table 5 and should now be discussed by professionals. In our opinion, such discussions should also integrate the views of patients and their carers, by making use of the results of the first study of their experiences concerning the quality of care pathways, in particular [14]. Ultimately, we will be able to validate the precise definition of these indicators, together with the methods used to calculate them, and to provide teams with methodological data collection tools for the assessment of their practices and organizations on the basis of these validated indicators.

5. Conclusion:

The results of this first real-life survey illustrate the potential usefulness of tools developed and validated by the professionals themselves. They also provide access to unprecedented new data in France, for a sample of patients that can be considered representative for the follow-up period concerned. Many of these results confirm data already published or known to the professionals managing these patients. They should make it possible to improve the targeting of actions, to improve the quality of care further for patients with MS in France. Progress in our knowledge, leading to changes in the guidelines, should be taken into account when updating the tools on which these assessments are based. For this reason, we propose to continue this process by submitting, for discussion, a targeted list of updated indicators relating to changes in guidelines, and in issues concerning the quality of patient management.

6. Funding

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7. References

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Table 1. The AAN MS quality measurement set (2015). *Rae-Grant A, Bennett A, Sanders AE, Phipps M, Cheng E, Bever C. Quality improvement in neurology: Multiple sclerosis quality measures: Executive summary. Neurology. 2015 Nov 24;85(21):1904-8.*

1.MS diagnosis : percentage of patients who receive a new diagnosis of MS in the past 12 months fulfilled international criteria
2.Comparison MRI within 24 months of MS diagnosis : percentage of patients with MS who had an MRI with and within 24 months of diagnosis compared with a baseline MRI
3.Current MS disability scale score : percentage of patients with MS who have an MS disability scale score documented in the medical record in the past 12 months
4.Fail risk screening for patients with MS : percentage of patients with MSwho were screened for fall risk in the past 12 months
5.Bladder infections for patients with MS : percentage of patients with MS who have had a bladder infection in the past 12 months
6.Exercise and appropriate physical activity counseling for patients with MS : percentage of patients with MS who were counseled on the benefits of exercise and appropriate physical activity for patients with MS in the past 12 months
7.Fatigue outcome for patients with MS : percentage of patients with MSwhose most recent score indicates results are maintained or improved on a validated fatigue rating instrument for patients with MS in the past 12 months
8.Cognitive impairment testing for patients with MS : percentage of patients 18 years and older with MS who were tested for cognitive impairment in the past 12 months
9.Clinical depression screening for patients with MS : percentage of patients aged 12 years and older with MS who were screened for clinical depression using an age-appropriate standardized depression screening instrument for patients with MS in the past 12 months
10.Depression outcome for patient with MS : percentage of patients aged 12 years and older with MS whose most recent score indicates results are maintained or improved on a validated depression screening instrument for patients with MS in the past 12 months
11.Maintained or improved baseline quality of life for patients with MS : percentage of patients with MS whose most recent score indicates results are maintained or improved on an age-appropriate quality of life tool in the past 12 months

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Table 2. Sociodemographic data from 2000 to 2010

Sex ratio Female/male	**2.6 (504/195)**
Age at first symptoms In years, median (IQR), *N* = 699	**34.7** (27.2 - 42.9)
Time from first symptoms to diagnosis In months, median (IQR), *N* = 554	**12.4** (3.6 – 36.2)
Phenotype of the disease *N* (%), *N* = 699	**Remitting: 489** (70%) **Progressive from the outset: 94** (13.4%) **CIS: 116** (16.6%)
Number of patients with an initially remitting form progressing to the progressive form during follow-up *N* = 489	**92** (18.8%)
Time from initial diagnosis to the progression of a remitting form to a progressive form In years, median (IQR), *N* = 68	**4.4** (2.2 – 6.0)
Number of female patients who became pregnant during follow-up *N* = 504	**89** (17.6%)
Duration of follow-up In years, *N* and %, mean ± SD, *N* = 699	**10** (*N* = 584, 84%) **5.4 ± 3.1** (*N* = 112, 16%)
Annual relapse rate (95% CI) *N* = 532 (CIS excluded)	**0.42** [0.40 – 0.43]

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Table 3: Change in EDSS score during follow-up :

Nb of patients % row % column	**Remitting**	**Progressive**	**Secondarily progressive**	**Total**
EDSS < 3 throughout follow-up	**103** 98.10 53.09	**0** 0.00 0.00	**2** 1.90 3.45	**105** (35.0%)
Change in EDSS from < 3 to ≥ 3 throughout follow-up	**84** 64.12 43.30	**10** 7.63 20.83	**37** 28.24 63.79	**131** (43.7%)
EDSS ≥ 3 throughout follow-up	**7** 10.94 3.61	**38** 59.38 79.17	**19** 29.69 32.76	**64** (21.3%)
Total	**194** (64.7%)	**48** (16.0%)	**58** (19.3%)	**300**

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Table 4. Results by indicators for the MQIS cohort

List of indicators that could be calculated, by domain	Results for the MQIS cohort
Access to care during follow-up, depending on the course of the disease	
A3. Percentage of initial etiological assessments performed, *N* = 699	**88** (12.6%)
A4. Percentage of ophthalmologic examinations for patients with retrobulbar optic neuritis, *N* = 273	**107** (39.2%)
B6. Time to neurological consultation after the first symptoms suggestive of MS, median (IQR) in days and months, *N* = 688	**5.9 months** (1.8 – 26.4)
B7. Percentage of patients who had annual neurological follow-up for patients with at least 10 years or less than 10 years of follow-up from the first consultation, *N* = 582	**19.7%** (115/582)
B9. Percentage of patients with an ophthalmic consultation within 30 days of the identification of visual problems by a neurologist or rehabilitation physician, *N* = 409	**89** (21.8%)
B11. Percentage of active patients who had an "MS and work" consultation or a consultation with a social worker, *N* = 692	**42** (6.1%)
B12. Percentage of patients included in at least one clinical trial, *N* = 699	**32** (4.6%)
Management by imaging (IRM)	

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List of indicators that could be calculated, by domain	Results for the MQIS cohort
C13. Percentage of patients who had a diagnostic brain MRI scan for a clinically isolated syndrome within 3 months of the onset of symptoms, N = 699	**304** (43.5%)
C15. Percentage of patients whose diagnostic brain MRI performed within 12 months before or after the first consultation respected the T1, FLAIR, T2, double-echo, T1 sequences 5 min after the injection of a dose of gadolinium, *N* = 568	**176** (31.0%)
C16. Percentage of patients whose diagnostic brain MRI was performed within 3 months of the initiation of immunosuppressive therapy, *N* = 217	**84** (38.7%)
C17. Time to brain MRI of less than 3 months, and initiation of immunosuppressive therapy, median (IQR) in months, mean (SD), *N* = 84	**1.4** (0.8) **1.4** (0.7 – 2.0)
Management of relapses	
D18. Time to consultation with a neurologist after the onset of symptoms suggestive of a relapse; median (IQR) in days, *N* = 1,141 relapses	**9** (5 – 22)
D19. Rate of relapses confirmed by a neurologist and treated with an IV bolus of methylprednisolone (0.5, 1, 1.2, or 1.5 g for 3-5 days), *N* = 888 relapses	**826** (93.0%)
D20. Time to initiation of corticosteroid therapy by an IV bolus of methylprednisolone (0.5, 1, 1.2, or 1.5 g for 3-5 days) after a relapse confirmed by a neurologist; mean (SD), median (IQR) in days, *N* = 772	**24.6** (84.1) **9** (5 – 22)

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List of indicators that could be calculated, by domain	Results for the MQIS cohort
Management of immunomodulatory treatment	
E21. Percentage of patients with relapsing-remitting MS for whom the prescription of an immunomodulatory treatment respected the indications, *N* = 377	**264/377** (70.0%)
E22. Time to initiation of a first immunomodulatory treatment after the diagnosis of relapsing-remitting MS; mean (SD), median (IQR) in months, *N* = 339	**24.1** (28.0) **11.5** (3.7 – 35.2)
E23. Percentage of patients on immunomodulatory treatment (relapsing-remitting MS) with an informative diagnosis at the start of treatment, within 12 months of diagnosis, *N* = 378	**78** (20.6%)
E24. Percentage of patients on immunomodulatory treatment (relapsing-remitting MS) who were trained in self-injections and whose skills were assessed as part of a therapeutic education program, *N* = 94	**15** (16%)
E25. Percentage of patients (relapsing-remitting MS) with regular laboratory monitoring during the initiation period of immunomodulatory treatment, *N* = 513	**178** (35.5%)
Management of immunosuppressive treatment	
F26. Percentage of patients for whom the indications for prescribing natalizumab (relapsing-remitting MS) were respected when initiating treatment, *N* = 45	**11** (24.4%)
F27. Percentage of patients who had a blood test (complete blood cell count, assay of immunoglobulin subclasses, B lymphocyte, CD4 T-cell and CD8 T-cell counts, HIV serology) in the 3 months before starting natalizumab treatment, *N* = 45	**16** (35.6%)
F28. Percentage of treatment periods with natalizumab for which an annual brain MRI was performed, from the start of treatment, N=43	**4** (9.3%)
F29. Percentage of patients for whom information concerning the potential benefits and risks of natalizumab was included in medical records, *N* = 45	**13** (28.9%)

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List of indicators that could be calculated, by domain	Results for the MQIS cohort
G31. Percentage of patients for whom information concerning the potential benefits and risks of mitoxantrone was traceble in the medical records, from 2004, *N* = 28	**12** (42.9%)
G32. Percentage of patients for whom a pretreatment assessment (echocardiography and/or blood cell count) was performed before the initiation of mitoxantrone treatment, for patients treated from 2004, *N* = 32	**14** (43.8%)
G33. Percentage of patients on mitoxantrone for whom the maximum cumulative dose administered over a period of more than 6 months was respected, for patients treated from 2004, *N* = 5 (treatment over a period of more than 5 years)	**4** (80.0%)
G35. Percentage of patients on mitoxantrone for whom cardiac monitoring recommendations were followed, for patients treated from 2004 onwards (by number of years after the end of treatment)	**1 year : 52.4%** (11/21) **2 years : 70.6%** (12/17) **3 years : 80.0%** (12/15) **4 years : 78.6%** (11/14) **5 years : 90.0%** (9/10)
Management of care and rehabilitation	
H36. Percentage of patients with an EDSS score ≥ 3, determined by two assessors, who subsequently had a consultation with a rehabilitation physician, *N* = 292	**115** (39.4%)
H37. Time to a first consultation with a rehabilitation physician after the onset of the disease, according to EDSS score; mean (SD), median (IQR) in months, *N* = 115	**18** (23.2) **9.4** (1.2 – 29.1)
H42. Percentage of patients with progressive or secondarily progressive MS with an EDSS score ≥ 3 who had access to physiotherapy within 6 months after a relapse, *N* = 168	**18** (10.7%)
H43. Percentage of patients with progressive or secondarily progressive MS with an EDSS score ≥ 3 for the first time who had access to a rehabilitation department and/or structure within 6 months of reaching this score, *N* = 168	**33** (19.6%)
H44. Percentage of patients with bladder sphincter disorders (urinary urgency, frequent urination, dysuria, urinary retention, urinary incontinence, etc.) who had an ultrasound scan of the kidneys and bladder, *N* = 337	**107** (31.8%)
H45. Time to kidney and bladder ultrasound examination after the discovery of the first bladder sphincter problems; mean (SD), median (IQR) in months, *N* = 104	**27.5** (33.6%) **19.0** (6.5 – 41.1)
H46. Percentage of patients who underwent urodynamic assessment after an ultrasound scan of the kidneys and bladder showing a post-voiding urine residue > 100 mL, *N* = 24	**13** (54.2%)
H47. Percentage of patients with known urinary disorders (i.e., confirmed by reno-bladder ultrasound showing a urinary residue post-voiding > 100 mL) and who had an annual kidney-bladder ultrasound scan, *N* = 209	**5** (2.4%)

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List of indicators that could be calculated, by domain	Results for the MQIS cohort
H48. Percentage of physiotherapy and rehabilitation visits at which fatigue was assessed, *N* = 670	**53** (7.9%)

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Table 5 : Proposal of the authors to define quality indicators

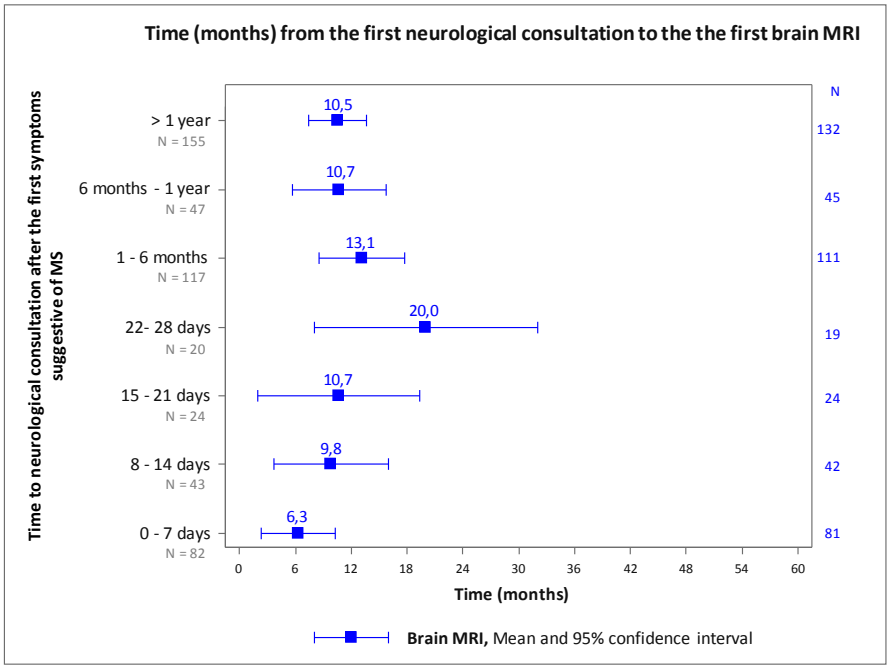
Stage of the care pathway	Proposal to define Quality indicators
Diagnosis	Time to neurological consultation after the first symptoms suggestive of MS
	Percentage of patients who had a diagnostic brain or spinal cord MRI scan for a clinically isolated syndrome, during 3 months of the onset of symptoms
	Percentage of patients who had a lumbar puncture when dissemination can not be assessed by clinical and MRI results
Follow up for patients with RR MS	
	Rate of relapses confirmed by a neurologist and needed a treatment with bolus of methylprednisolone
	Percentage of patients who had annual neurological follow-up (after a first visit with neurologist to confirm MS)
	Percentage of patients having access to an MS- specialized center (multidisciplinary clinic)
	Time to consultation with an ophthalmologist after detection of a 1st visual disorder (including retrobulbar optic neuritis)
	Percentage of patients with at least one annual brain MRI throughout follow-up
	Percentage of patients whose brain MRIs respected the sequences of the OFSEP protocol
	Time to the 1st rehabilitation management for patients with an EDSS score ≥3
	Percentage of patients with prescription of a 2nde line immunosuppressors treatment having a multidisciplinary advice
	Time to initiation of a first immunomodulatory treatment after the diagnosis
	Percentage of immunomodulator-treated patients evaluated for a patient-education program at treatment onset
Follow up for patients with PP MS	Percentage of PPMS patients with a EDSS >3 having access to an MS- specialized center (multidisciplinary clinic)
	Percentage of patients whose brain MRIs respected the sequences of the OFSEP protocol
	Time to consultation with an ophthalmologist after detection of a 1st visual disorder (including retrobulbar optic neuritis)
	Percentage of patients with progressive or secondarily progressive MS with an EDSS score ≥ 3 for the first time who had access to a rehabilitation department and/or structure
	Percentage of patient with RR MS with an EDSS score ≥ 3 acceding to rehabilitation

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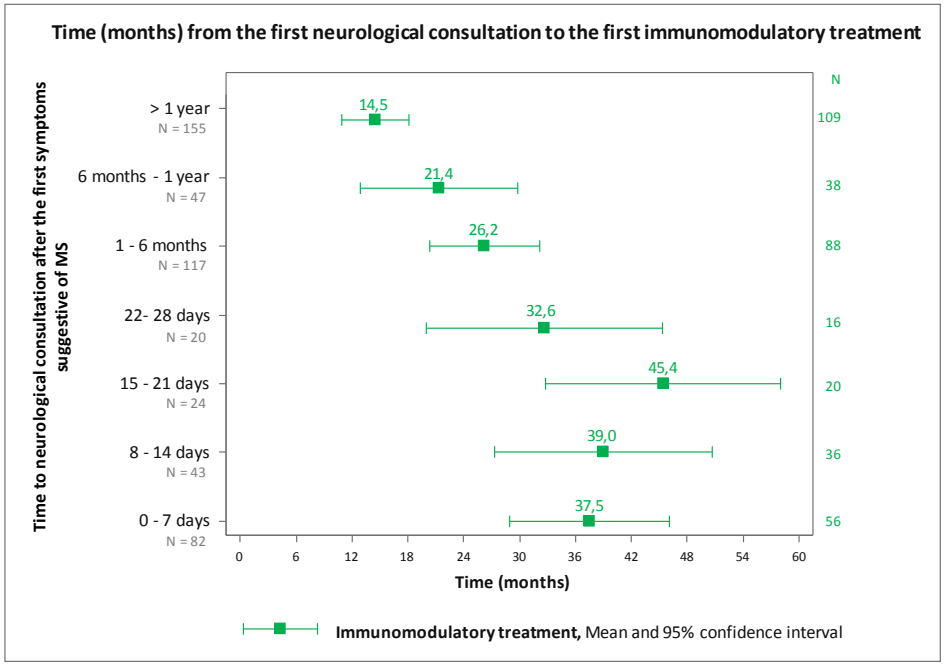
Click here to access/download;Figure;NEUROL-D-21-00204R1_Fig1.docx

Figure 1. A. Time from the first neurological examination to the first brain MRI scan. B. Time from the first neurological examination to the first treatment with a disease modifying treatment (immunomodulator)

A.



B.



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