

msregister

Update on the MS Registry of the German MS-Society

2024 Edition



Statements according to § 35 a GmbHG:

MS Forschungs- und
Projektentwicklungs-gGmbH

Location of the Company
Hannover

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Amtsgericht Hannover, HRB 59747

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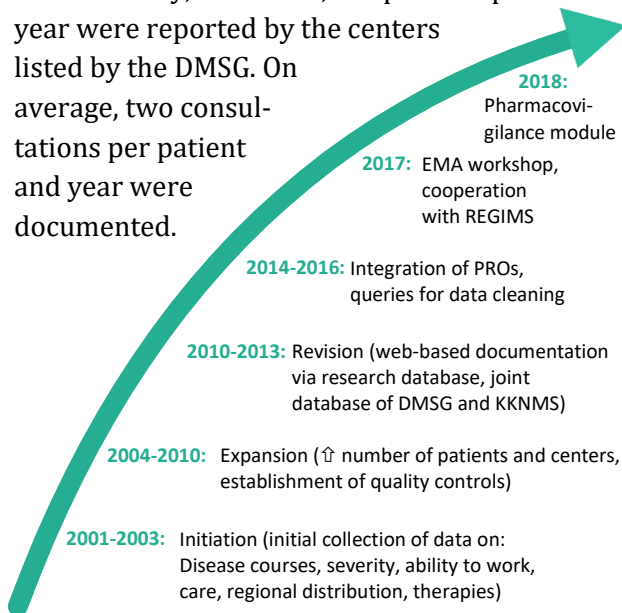
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Introduction

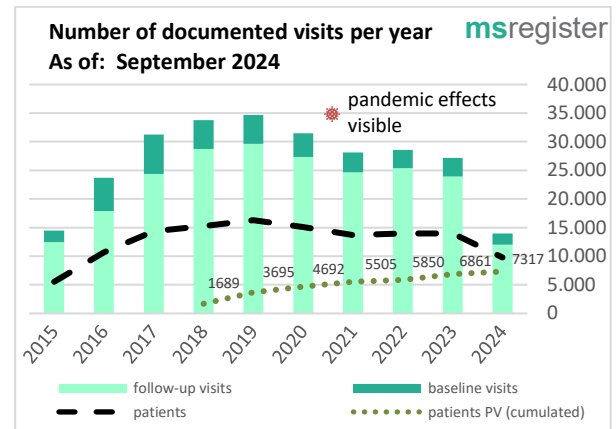
In 2001, the German Multiple Sclerosis Society (DMSG) initiated the installation of a Multiple Sclerosis Registry (MS Registry) for Germany. For this purpose, the MS Research and Project Development gGmbH (MSFP) was founded to manage the MS Registry. In 2005, the MS Registry started regular operations and has been continually developed and expanded since then. Most recently, almost 14,000 patients per year were reported by the centers listed by the DMSG. On average, two consultations per patient and year were documented.



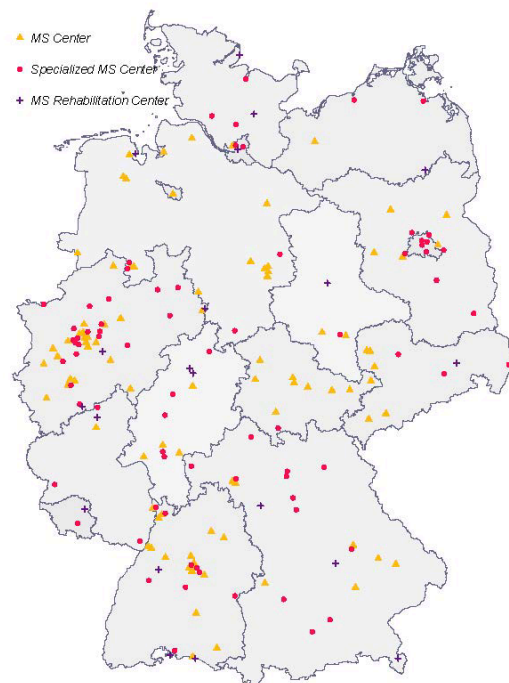
Awards for (rehab) clinics and practices based on the guidelines of the DMSG, Bundesverband e.V.

Participation in the MS Registry of the DMSG, Bundesverband e. V. is a prerequisite for receiving the certificate "MS Center", "Specialized MS Center", and "MS Rehabilitation Center", awarded by the DMSG. The certificates are awarded to university clinics, acute care clinics, rehabilitation clinics, MS outpatient clinics, and neurological practices if they meet the specified criteria. Adherence must be confirmed every two years. The criteria catalog developed by independent MS experts focuses on a guideline-based treatment by neurologists and professionals specialized in MS, as well as on disabled accessible equipment of the facility. Depending on the center type, a minimum number of MS patients must be treated per year in the centers.

Part of these treated MS patients must be recorded in the MS Registry. MS Special Centers thus must document at least 150 data sets per year, MS Rehabilitation Centers at least 80 or 120, and MS Centers at least 80.



At the moment, the DMSG has decorated 73 centers as "Specialized MS Center", 93 as "MS Center", and 20 as "MS Rehabilitation Center". The geographic distribution of the centers in Germany is mostly homogenic, with a slight West-East and South-North gradient as well as clusters in metropolitan areas.



The map was created with R 4, based on data from gadm.org.

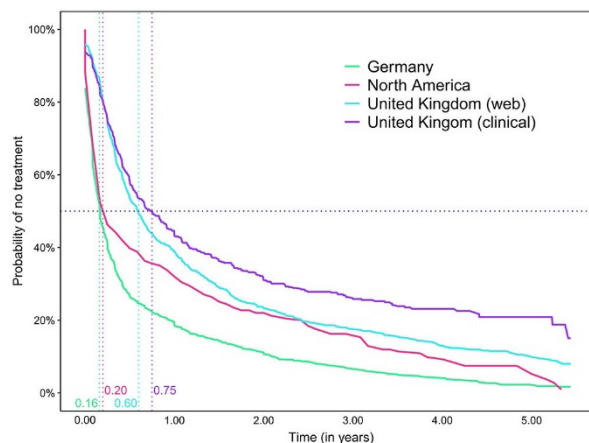
Overview of the documenting centers awarded by the DMSG (as of 09/2024). A current list of awarded centers can be viewed at <https://www.ms-wissen.de/kliniken-und-praxen>.

Current results from the MS Registry of the DMSG

In September 2024, the proportion of women with MS compared to earlier analyses remained nearly unchanged at 70.9%. The mean age was 48 (± 12.7) years, while the mean age at the disease onset was 33.3 (± 2.2) years. On average, it takes 1.5 (± 3.7) years from symptom onset to MS diagnosis. 74.2% of the documented MS patients have relapsing-remitting MS (RRMS), 16.0% secondary progressive MS (SPMS) and 7.1% primary progressive MS (PPMS). 1.5% had a clinically isolated syndrome (CIS) and 1.2% could not be clearly classified. The mean EDSS score (a measure of the degree of disability) was 3.3 (± 2.2).

Baseline data				
disease course	Age (years)	MS duration (years)	EDSS value (median)	Female
Total data (n = 41,486)	48.0 \pm 12.7	14.5 \pm 10.5	3	70.9%
RRMS (n = 30,784)	45.1 \pm 11.8	12.6 \pm 9.3	2	72.8%
SPMS (n = 6,623)	57.9 \pm 9.8	24.6 \pm 10.4	6.5	68.7%
PPMS (n = 2,926)	57.8 \pm 10.4	14.5 \pm 10.2	5.5	56.6%
CIS (n = 653)	41.5 \pm 12.0	5.2 \pm 7.1	1.5	68.2%

Once MS has been diagnosed, guidelines recommend starting immunotherapy early, to delay the progression of the disease. In the analysis "[Disease-modifying therapy initiation patterns in multiple sclerosis in three large MS populations](#)", published in *Therapeutic Advances in Neurological Disorders* in March 2024, we examined how long it takes for patients from Germany, the USA and the UK to receive their first immunotherapy after being diagnosed with MS. The study also analysed whether certain characteristics, such as age, gender or disease severity, influence the time to start treatment. The analysis showed that the time to start treatment differs between countries. In Germany, people start treatment on average around 2 months after being diagnosed with MS, while in the US it takes around 3 months and in the UK around 9 months.



MS patients who were diagnosed after 2017 started treatment more quickly than those who were diagnosed before 2017. MS patients also waited longer before receiving an initial therapy with higher efficacy. The fact that the time to start treatment varies by country could indicate that there are barriers to accessing treatment, particularly in the UK. However, since 2017, the time to start treatment has decreased in all investigated countries. Further studies are needed to analyze how time to treatment initiation affects the long-term course and whether initial treatment with higher efficacy makes a difference.

The following analysis, which appeared as a graph of the quarter* in the DMSG-journal *aktiv!* Nr. 282 1/2024, examines the various forms of bladder dysfunction and their treatment.

The results show that 35.7% of the analyzed MS patients are affected by bladder dysfunction. The most common single symptom of bladder dysfunction in female and male MS patients is the imperative urge to urinate (10.7% and 9.9% respectively). While incontinence occurs significantly more frequently in female patients (female: 7.2%; male: 5.1%; $p < 0.002$), male patients show significantly more frequent bladder emptying disorder (female: 6.3%; male: 8.3%; $p < 0.001$). Two or more types of bladder dysfunction are documented in 5.5% of male and 5.9% of female patients. In a third of all cases of reported bladder dysfunction, these remain untreated (33.3%), regardless of the type of dysfunction. In the case of imperative urination and other bladder dysfunctions, even more than a third remain untreated (47.6% and 33.9%).

Bladder dysfunction is recorded more frequently with longer disease duration, which means that people with MS who have been affected for a longer period of time may experience increased problems with their bladder function. This can be attributed to the progressive damage to the nervous system, in particular the impairment of the nerves responsible for controlling bladder function.

Overall, the analysis of the German MS registry data shows that bladder dysfunction occurs in over 10% of cases right from the beginning and with increasing frequency as the disease progresses. Depending on the type of bladder dysfunction, the proportion of patients in whom the disorder(s) is/are not treated remains very high at 20-48%, even in comparison with earlier analyses.

* Since January 2020, the website of the German MS Society at www.dmsg.de quarterly presents analyses from the MS Registry on various topics.

All MS Registry publications can be downloaded at https://www.msregister.de/en/_ms-registry/publications.

MS Registry documentation

Since 2014, there has been a web-based, platform- and device-independent research database for the documentation of MS Registry data. The research database relies on established tools and the concepts of the TMF e. V. for collaborative research. It also integrates so-called patient-reported outcomes (PRO), for instance for quality of life data that are self-documented by the patients.

Quality & data management

Using implemented value range and plausibility controls, the research database recognizes and reports incorrect information already at the time of data entry. In addition, downstream quality control in combination with query management ensures data quality.

International cooperation

The MS Registry collaborates with the UK MS Registry and the American NARCOMS Registry as well as the partners of the Research Collaboration Network in SPMS.

Scientific advisory group

The MS Registry receives support for content and methodology from the scientific advisory group. It is composed of:

Prof. Dr. med. K. Berger
Prof. Dr. med. P. Flachenecker
Prof. Dr. sc. hum. T. Friede
Prof. Dr. med. K. Hellwig
Prof. Dr. med. C. Kleinschnitz
Prof. Dr. rer. nat. D. Krefting
Prof. Dr. med. F. Paul
Dr. med. D. Pöhlau
Prof. Dr. med. C. Warnke
Prof. Dr. med. U. K. Zettl

Supporters of the MS Registry

The MS Registry of the DMSG has been financed since 2001 by the DMS Foundation and the DMSG, Bundesverband e. V. The MSFP receives project funding from the Innovation Fund of the G-BA and the German Pension Insurance (DRV Bund), among others. Since 2018, companies from the pharmaceutical industry have also been supporting the MS Registry as part of a multistakeholder funding. This primarily supports the establishment and operation of the recording of adverse events. In 2024, BristolMyersSquibb, Merck, Novartis, Roche and TG Therapeutics / Neuraxpharm participated with uniform contributions. For more information, please visit our [website](#).

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