msregister

Update on the MS Registry of the German MS-Society

2025 Edition

Statements according to § 35 a GmbHG:

MS Forschungs- und Projektentwicklungs-gGmbH

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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, over 14,000 patients per year were reported by the centers listed by the DMSG. On average, two consultations per patient and year were documented.

2018: Pharmacovigilance module

2017: EMA workshop, cooperation with REGIMS

2014-2016: Integration of PROs, queries for data cleaning

2010-2013: Revision (web-based documentation via research database, joint database of DMSG and KKNMS)

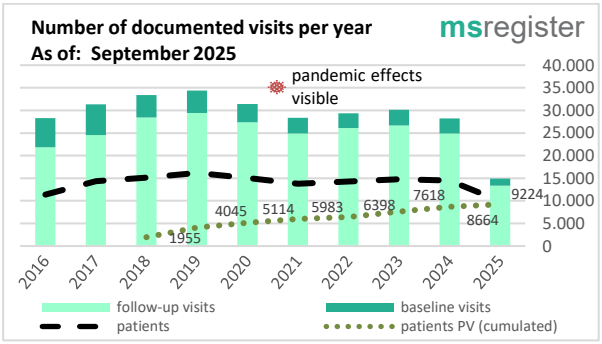
2004-2010: Expansion (⇧ number of patients and centers, establishment of quality controls)

2001-2003: Initiation (initial collection of data on: Disease courses, severity, ability to work, care, regional distribution, therapies)

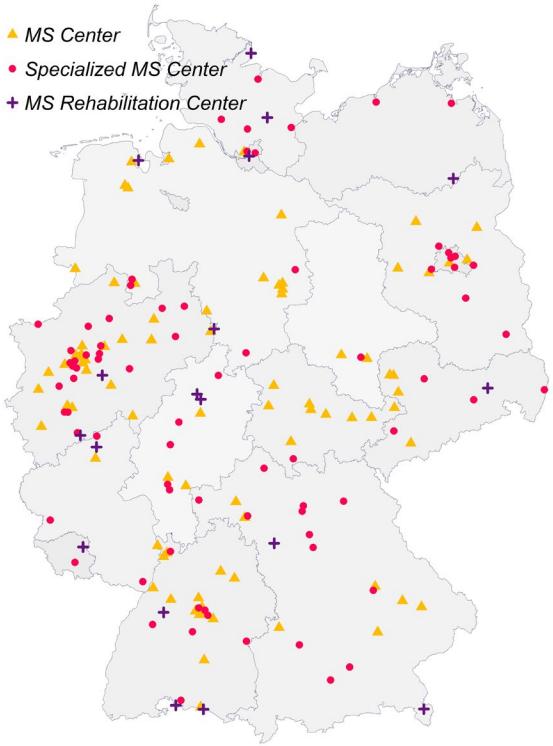
Awards for (rehab) clinics and practices based on the guidelines of the DMSG, Bundesverband e.V.

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 75 centers as "Specialized MS Center", 85 as "MS Center", and 18 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.

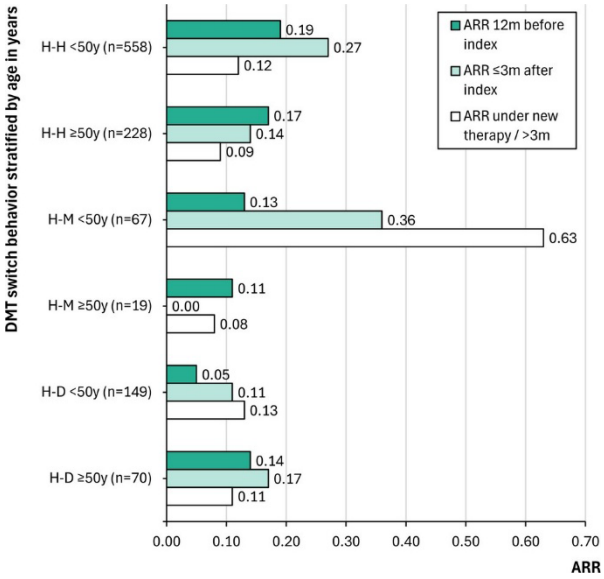
Overview of the documenting centers awarded by the DMSG (as of 09/2025). A current list of awarded centers can be viewed at https://www.ms-wissen.de/kliniken-und-praxen.

Current results from the MS Registry of the DMSG

In September 2025, the proportion of women with MS compared to earlier analyses remained nearly unchanged at 71.2%. The mean age was 48.3 (± 12.7) years, while the mean age at the disease onset was 33.3 (±10.8) years. On average, it takes 1.5 (± 3.7) years from symptom onset to MS diagnosis. 74.4% of the documented MS patients have relapsing-remitting MS (RRMS), 15.8% secondary progressive MS (SPMS) and 7.2% primary progressive MS (PPMS). 1.4% had a clinically isolated syndrome (CIS) and 1.2% could not be clearly classified. The mean EDSS score was 3.3 (± 2.2).

Baseline data				
disease course	Age (years)	MS duration (years)	EDSS value (median)	Female
Total data (n = 47,963)	48.3 ± 12.7	14.7 ± 10.6	3	71.2%
RRMS (n = 35,683)	45.3 ± 11.9	12.9 ± 9.4	2	73.1%
SPMS (n = 7,557)	58.1 ± 9.8	24.8 ± 10.5	6.5	69.0%
PPMS (n = 3,470)	58.0 ± 10.4	14.5 ± 10.2	5.5	56.9%
CIS (n = 670)	41.6 ± 12.0	5.2 ± 6.7	1.5	69.1%

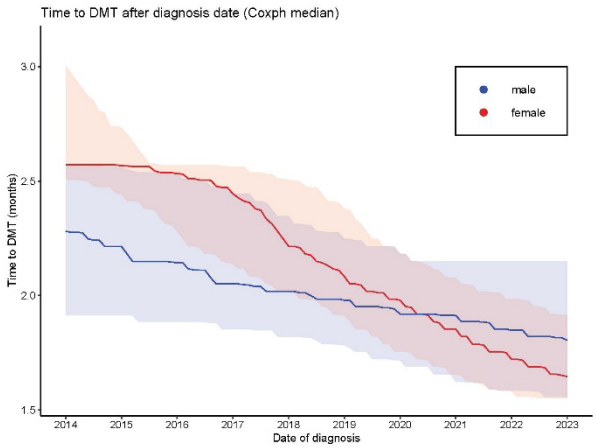
In the analysis "Age-related differences in switching highly effective disease-modifying therapy in patients with multiple sclerosis", published in *Journal of Neurology* in September 2025, we aimed at evaluating the impact of high efficacy therapies (HET) discontinuation on annualized relapse rates (ARRs) in people with MS (pwMS) aged ≥ 50 or < 50 years. To this purpose, we retrospectively analyzed data of 1,091 pwMS from the German MS Register. ARR before and 12 months after the HET washout period were compared between older and younger patients for switching from HET to HET (H–H), HET to mild/moderate efficacy therapies (H-M) or HET to discontinuation (H–D). Reasons for therapy switches were assessed for all subgroups. The analysis shows, that most treatment switchers continued with another HET (H–H n=786), while de-escalation (H-M n=86) or discontinuation (H–D n=219) occurred less frequently. The minority within each switching group were ≥ 50 years of age (H–H 29%, H-M 22%, H–D 32%).



The figure above shows, that ARR in H–H decreased after switching in both age groups, increased in H-M < 50 and remained stable in ≥ 50, and increased in H–D < 50 and remained stable in ≥ 50. Main reason for therapy switch was lack of efficacy in H–H, adverse events in H-M regardless of age, patient's choice (23%) in H–D < 50, and lack of efficacy (26%) in H–D ≥ 50. This leads to the conclusion that strategies for discontinuing medication should be individualized, considering age-related changes in disease activity, adverse events and patient's choice.

In the following analysis, which appeared as a graph of the quarter in the DMSG-journal *aktiv!* Nr. 287 2/2025, we focused on the time until diagnosis and the start of treatment. The average time to MS diagnosis in Germany has continued to decline in the last years and was most recently just under 6 months (standard deviation: ±1 month). A multivariate analysis of various influencing factors showed that the following factors (in descending order of statistical significance) tended to shorten the time to MS diagnosis: older age at onset, higher level of education, sensory problems at onset, bowel dysfunction at onset and multiple symptoms at onset. The following factors tended to prolong the time to MS diagnosis: a primary progressive course, bladder dysfunction at disease onset, motor problems at disease onset and depression at disease onset.

Analysis of the registry data also shows that the time between diagnosis and the start of treatment has fallen continuously over the last 11 years in patients with relapsing-remitting MS, especially for women, indicating improved quality of care and the application of the relevant guidelines:



All MS Registry publications can be downloaded at https://www.msregister.de/en/ms-register/veroeffentlichungen/artikel/.

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
Dr. rer. nat. M. Mai
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 German National MS Society (DMSG, Bundesverband e. V.) The MSFP receives project funding from the Innovation Fund of the G-BA, the German Pension Insurance (DRV Bund) and the German Ministry of Health among others. Since 2018, companies from the pharmaceutical industry have also been supporting the MS Registry as part of a multistakeholder funding primarily supporting the establishment and operation of the recording of adverse events. In 2025, BristolMyersSquibb, Merck, Roche and TG Therapeutics / Neuraxpharm participated with uniform contributions. For more information, please visit our website.

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