

## Update on the MS Registry of the German MS-Society

2023 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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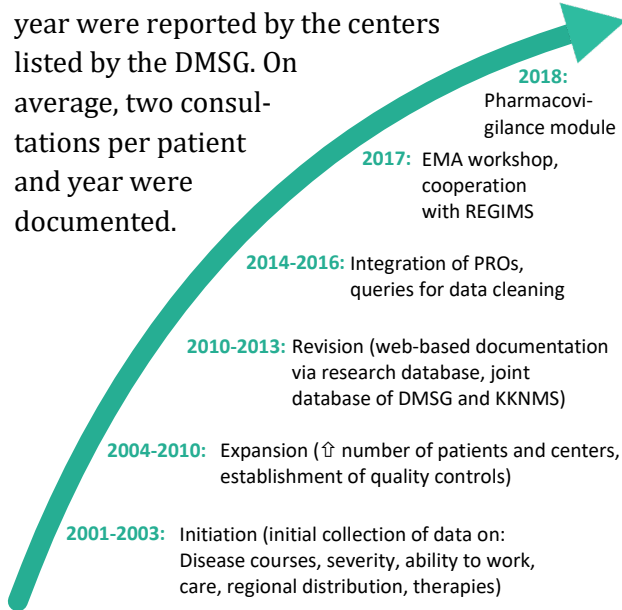
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## Introduction

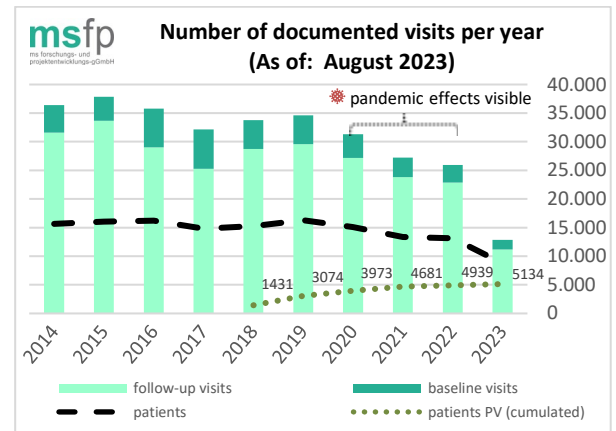
In 2001, the German Multiple Sclerosis Society (DMSG) initiated the installation of a Multiple Sclerosis Registry (MS Registry) for Germany. For this purpose, the MS Research and Project Development gGmbH (MSFP) was founded to manage the MS Registry. In 2005, the MS Registry started regular operations and has been continually developed and expanded since then. Most recently, more than 13,000 patients per year were reported by the centers listed by the DMSG. On average, two consultations per patient and year were documented.



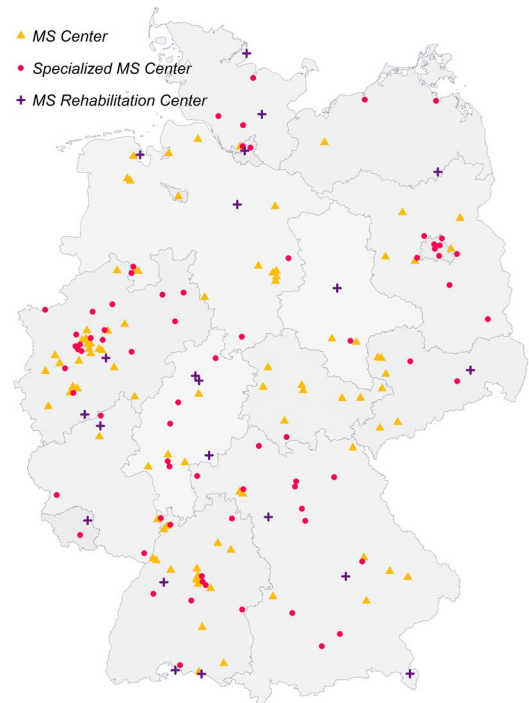
## Awards for (rehab) clinics and practices based on the guidelines of the DMSG, Bundesverband e.V.

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 71 centers as "Specialized MS Center", 92 as "MS Center", and 22 as "MS Rehabilitation Center". The geographic distribution of the centers in Germany is mostly homogen, 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](http://gadm.org).

Overview of the documenting centers awarded by the DMSG (as of 09/2023). A current list of awarded centers can be viewed at [www.dmsg.de](http://www.dmsg.de).



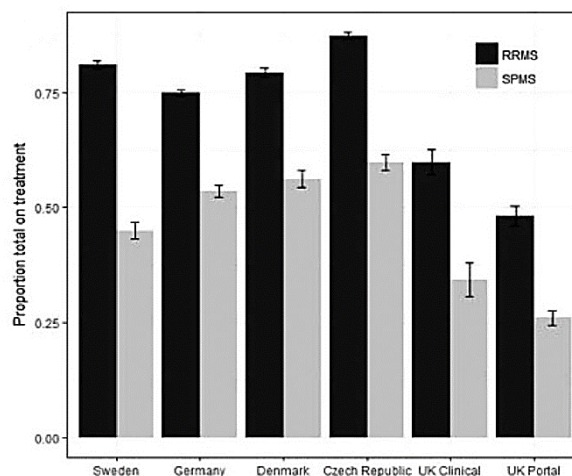
## Current results from the MS Registry of the DMSG

In August 2023, the proportion of women with MS compared to earlier analyses remained nearly unchanged at 70.8%. The mean age was 47.8 ( $\pm 12.6$ ) years, while the mean age at the disease onset was 33.2 ( $\pm 10.8$ ) years. On average, it takes 1.6 ( $\pm 3.8$ ) 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). 1.6% 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 ( $\pm 2.2$ ).

Baseline data				
disease course	Age (years)	MS duration (years)	EDSS value (median)	Female
Total data (n = 41,486)	47.8 $\pm$ 12.6	14.3 $\pm$ 10.3	3	70.8%
RRMS (n = 30,784)	44.9 $\pm$ 11.7	12.4 $\pm$ 9.2	2	72.7%
SPMS (n = 6,623)	57.6 $\pm$ 9.8	24.3 $\pm$ 10.4	6.5	68.8%
PPMS (n = 2,926)	57.6 $\pm$ 10.4	14.5 $\pm$ 10.2	5.5	56.2%
CIS (n = 653)	41.2 $\pm$ 12.1	4.7 $\pm$ 6.5	1.5	69.1%

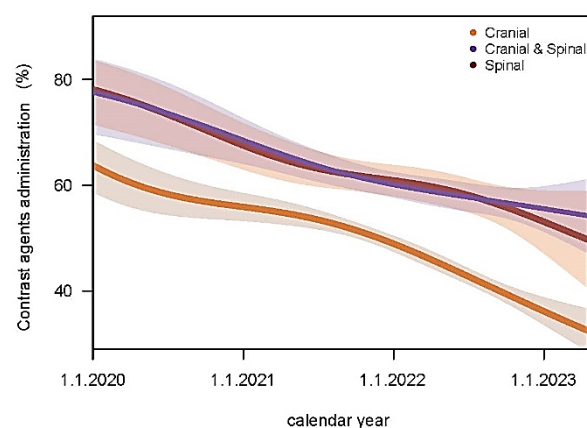
The article "[The impact of healthcare systems on the clinical diagnosis and disease-modifying treatment usage in relapse-onset multiple sclerosis: a real-world perspective in five registries across Europe](#)", published in *Therapeutic Advances in Neurological Disorders* in September 2023, explores how SPMS is diagnosed and treated in Czechia, Denmark, Germany, Sweden and the UK. Data from over 60,000 MS patients were analysed for the study. An algorithm (a sequence of actions performed on data by a computer program) was used in order to decide if the patients had RRMS or SPMS and was compared with the doctor's diagnosis or the participants self-declared response. Subsequently, it was investigated which factors influenced the prescription of course-modifying drugs (DMTs). This showed that there were differences in how DMTs were prescribed to MS patients in different countries.

More people with relapsing remitting disease were prescribed DMTs compared to those with secondary progressive.



The factors *being female, having higher disability* (measured by the EDSS) were all linked to a higher chance of receiving DMTs. This study shows that how MS is diagnosed/classified and treated can vary a lot depending on where you live. It also shows that it's important for the various healthcare systems to allow for some flexibility in uncertain cases to ensure that people get access to the right treatment.

The following analysis, which appeared as a graph of the quarter\* in the DMSG-journal *aktiv!* Nr. 279 2/2023, investigated the impact of changes to the recommendations on contrast agents administration for magnetic resonance imaging (MRI) in practice. The figure below shows the distribution of MRI visits with contrast agents administration for cranial, spinal cord and combined examinations from 2020 to 2023.



The proportion of cranial MRIs with contrast agents administration has decreased from 60.8% in 2020 to 35.2% in the first quarter of 2023, almost a halving the number of MRIs with contrast agents. The proportion of spinal cord MRIs with contrast agent administration and MRI examinations in which both cranial and spinal cord were examined decreased from 76.4% to 56.7% in the same period. Overall, the evaluation of the German MS Registry data shows a continuous trend towards a lower proportion of MRI examinations in which contrast agents were used. The observed decrease is more pronounced for purely cranial MRIs. MRIs for diagnosis confirmation are still to be conducted using contrast agents according to the guideline.

\* Since January 2020, the website of the German MS Society at [www.dmsg.de](http://www.dmsg.de) quarterly presents analyses from the MS Registry on various topics.

All published 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 participates in the EMSP initiative "Multiple Sclerosis Data Alliance" (MSDA), whose main purpose is to implement a

minimal data set and quality standards, approved by EMA, in as many MS registries and cohorts as possible. Further international collaborations include the UK MS-Registry and NARCOMS as well as the members of the RCN 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. J. Haas**

**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. O. Rienhoff**

**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 2023, Biogen, BristolMyersSquibb, Merck, Novartis and Roche participated with uniform contributions. For more information, please visit our [website](#).

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