

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

2020 Edition



**Statements according to § 35 a GmbHG:**

MS Forschungs- und  
 Projektentwicklungs-gGmbH

**Location of the Company**  
 Hannover

**Court**  
 Amtsgericht Hannover, HRB 59747

**CEO**  
 Alexander Stahmann

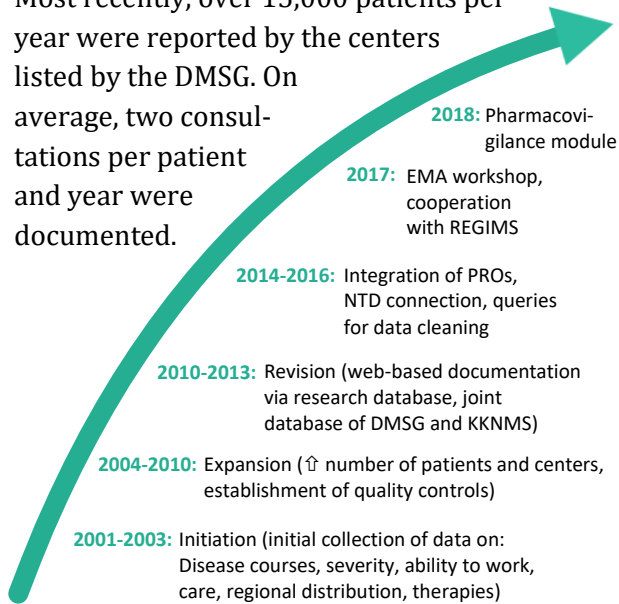
**Sole Stakeholder**  
 DMS-Stiftung, Hannover

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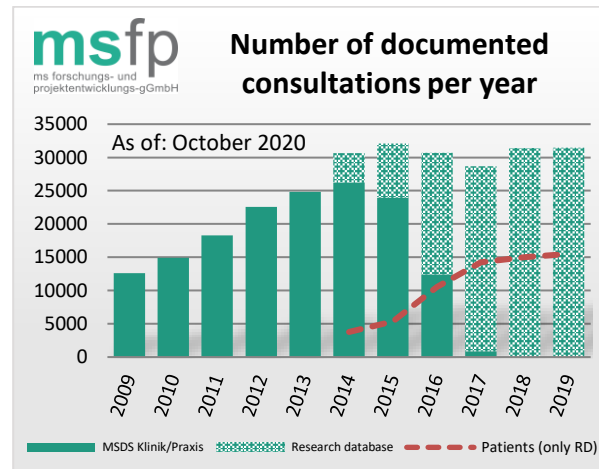
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## Introduction

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, over 15,000 patients per year were reported by the centers listed by the DMSG. On average, two consultations per patient and year were documented.



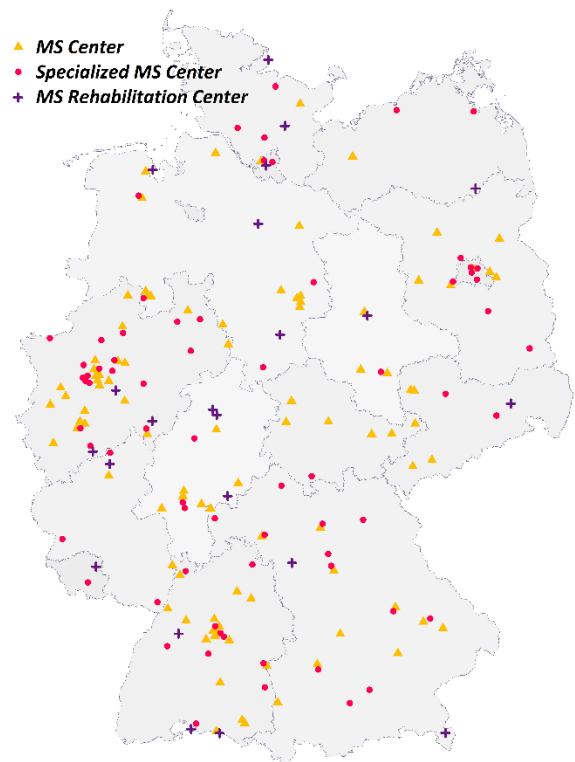
Part of these treated MS patients must be recorded in the MS Registry. MS Special Centers thus must document at least 150 data sets per year, MS Rehabilitation Centers at least 80 or 120, and MS Centers at least 80.



At the moment, the DMSG has decorated 71 centers as "Specialized MS Center", 97 as "MS Center", and 22 as "MS Rehabilitation Center". The geographic distribution of the centers in Germany is mostly homogenous, with a slight West-East and South-North gradient as well as clusters in metropolitan areas.

## 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.



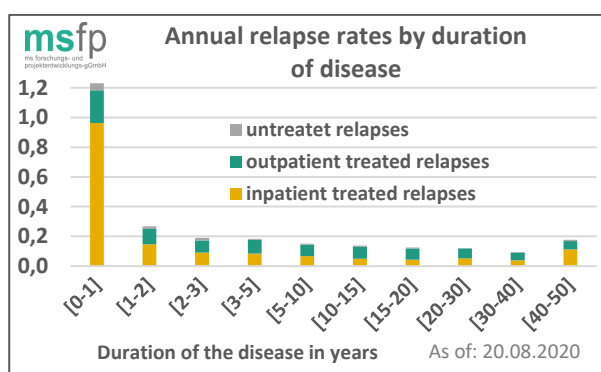
Overview of the documenting centers awarded by the DMSG (as of 10/2020). A current list of awarded centers can be viewed at [www.dmsg.de](http://www.dmsg.de).

## Current results from the MS Registry of the DMSG

In October 2020, the proportion of women with MS compared to earlier analyses remained nearly unchanged at 71.3%. The mean age was 47.1 ( $\pm 12.4$ ) years, while the mean age at the disease onset was 33.2 ( $\pm 10.7$ ) years. On average, it takes 1.7 ( $\pm 4.0$ ) years from symptom onset to MS diagnosis. 74.8% of the documented MS patients have relapsing-remitting MS (RRMS), 15.4% secondary progressive MS (SPMS) and 6.6% primary progressive MS (PPMS). 1.8% had a clinically isolated syndrome (CIS) and 1.5% could not be clearly classified. The mean EDSS score (a measure of the degree of disability) was 3.0.

Baseline data				
disease course	Age (years)	MS duration (years)	EDSS value (median)	Female
<b>Total data (n = 31,440)</b>	47.1 $\pm$ 12.4	13.6 $\pm$ 10.1	3	71.3%
<b>RRMS (n = 23,508)</b>	44.4 $\pm$ 11.5	12.0 $\pm$ 8.9	2	73.1%
<b>SPMS (n = 4,830)</b>	56.8 $\pm$ 9.8	23.4 $\pm$ 10.3	6	69.2%
<b>PPMS (n = 2,060)</b>	57.3 $\pm$ 10.4	14.5 $\pm$ 10.1	5.5	56.5%
<b>CIS (n = 566)</b>	41.0 $\pm$ 12.0	4.0 $\pm$ 6.2	1.5	68.4%

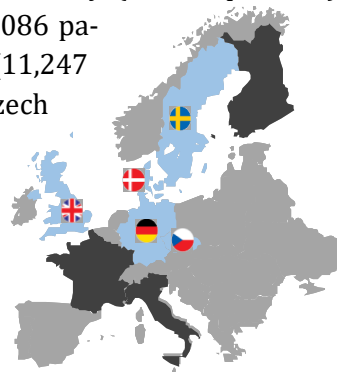
The following analysis, which is also shown as graphic of the quarter\* on the [DMSG website](https://www.dmsg.de), provides an overview of the frequency and therapy of relapses in patients with a relapsing form of MS.



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

The diagram shows that the frequency of relapses in patients with relapsing MS forms decreases with increasing disease duration. In the first year of the disease, relapses usually occur as a so-called first symptom and often mark the beginning of the MS disease. In the course of the disease, the mean of annual relapses decreases from 0.25 in the second year after disease onset to 0.10 in the third decade. The average number of relapses per person and year is 0.16 across sexes. Depending on the disease severity there can be significant differences between individual MS courses. For example, there are patients who suffer from six relapses per year, while 87% of MS patients were relapse-free in the same period.

At the joint congress of ACTRIMS andECTRIMS (American and European Committee for Treatment and Research in Multiple Sclerosis), the MS Registry was represented as part of the SPMS research collaboration network (RCN) with three virtual contributions. While Lars Forsberg presented the results of the validation of three different methods for the classification of MS patients into relapsing or secondary progressive forms, Jan Hillert focused on the characteristics of patients with SPMS misclassified as RRMS. Data from MS registries in Denmark (10,255 patients), Germany (23,185 patients), United Kingdom (5,086 patients), Sweden (11,247 patients), and the Czech Republic (11,336 patients) were used for the RCN studies. Using the decision tree classifier of the Karolinska Institute, a total of 8,372 RRMS patients were reclassified to SPMS in the five registries, increasing the overall proportion of SPMS patients from 17% to 31%. The overall proportion of clinically determined SPMS patients on disease-modifying therapy (DMT) was 36%, but varied widely between the registries. The overall proportion of newly assigned SPMS patients on DMT was significantly higher at 69%.



The conclusion of the study is that SPMS patients on DMT are often clinically misclassified as RRMS patients. This raises questions about the use of the time from MS onset to the conversion of relapsing to secondary progressive MS form as a measure of the efficacy of DMTs and argues for the use of objective categorization methods when analyzing MS patient populations.

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 is also possible to integrate so-called patient-reported outcomes (PRO), for instance for quality of life data that are self-documented by the patients via app or web.

## 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 the European Medicine Agency (EMA), in as many MS data registries and cohorts as possible in order to enable the use of registries for questions of safety and efficiency of MS therapies in the future. Since the beginning of the Corona pandemic, the MS Registry has participated in the [Global Data Sharing Initiative](#) of MSDA and the MS International Federation on COVID-19. Initial results presented at

the joint ACTRIMS/ECTRIMS Congress in September 2020 suggest that anti-CD20 agents (eg, Rituximab and Ocrelizumab) may be associated with more severe COVID-19 courses.

## 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. med. F. Paul**  
**Dr. med. D. Pöhlau**  
**Prof. Dr. med. O. Rienhoff**  
**PD 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 2020, Biogen, BristolMeyerSquibb, Merck, Novartis, Roche and Sanofi participated with uniform contributions. For more information, please visit our [website](#).

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