msfp
ms forschungs- und
projektentwicklungs-gGmbH

Update on the MS Registry of the DMSG, Bundesverband e.V.

2019

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 15,000 patients per year were reported by the centers listed by the DMSG. There was an average of two consultations per patient and year.

2017: EMA workshop, cooperation with REGIMS

2014-2016: Integration of PROs, NTD connection, 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: sub-types, 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", "MS Special Center", and "MS Rehabilitation Center", awarded by the DMSG. They are awarded to university clinics, acute care clinics, rehabilitation clinics, MS outpatient clinics, and neurological practices if they meet the specified criteria. Adherence has to be confirmed every two years. The criteria catalog developed by independent MS experts focuses on a treatment based on guidelines by neurologists and professionals specialized in MS, as well as disabled accessible equipment of the facility. Depending on the center type, a minimum number of MS patients must be treated yearly in the centers.
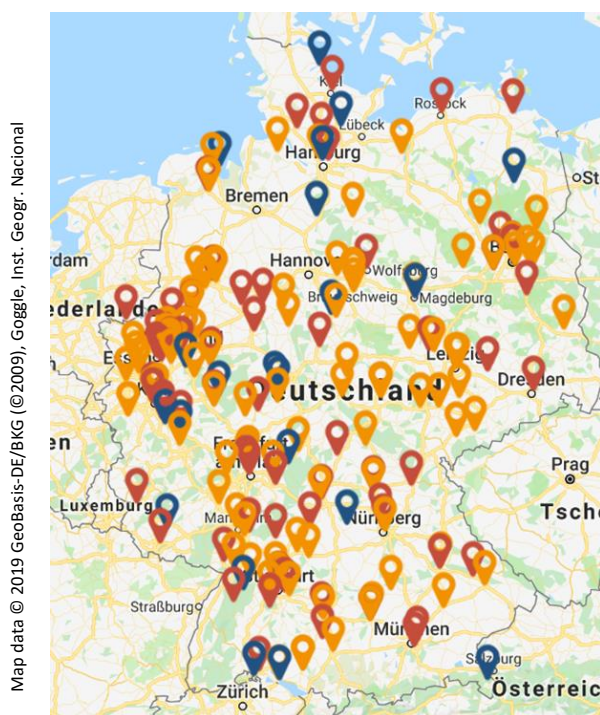
Part of these treated MS patients must be recorded in the MS Register. MS Special Centers thus must document at least 150, MS Rehabilitation Centers at least 80 or 120, and MS Centers at least 80 data sets per year.
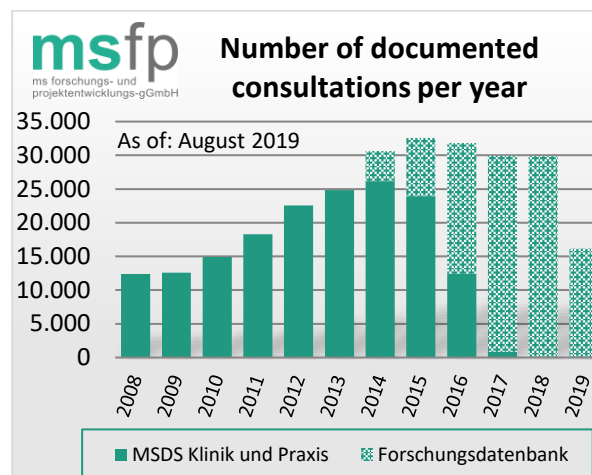
At the moment, the DMSG has decorated 67 centers as "Specialized MS Center", 99 as "MS Center", and 20 as "MS Rehabilitation Center". The geographic distribution of the centers in Germany is mostly homogen, with a slight West-East and South-North gradient and clusters in metropolitan areas.


🟠 MS Center
🔴 Specialized MS Center
🔵 MS Rehabilitation Center

Current results from the MS Registry of the DMSG

In August 2019, the percentage of women with MS compared to earlier analyses remained nearly unchanged at 71.7%. The average age was 46.3 (± 12.2) years, while the average age at the onset of disease was 33.6 (± 10.8) years. On average, it takes 2.0 (± 4.3) years until MS is diagnosed. 73.3% of the documented MS patients have relapsing-remitting MS (RRMS), 16.0% secondary progressive MS (SPMS), and 6.5% primary progressive MS (PPMS). 2.0% had a clinically isolated syndrome (CIS) and 2.2% could not be clearly classified. The severity of the disability (EDSS score) was averagely 3.0.

| Baseline data				
disease course	Age (years)	MS duration (years)	EDSS value (median)	Female
Total data (n = 22,848)	46.3 ± 12.2	15.3 ± 10.0	3	71.7%
RRMS (n = 17,153)	43.5 ± 11.3	13.5 ± 8.8	2.5	73.5%
SPMS (n = 3,737)	55,4 ± 9.9	24.5 ± 10.3	6	69.0%
PPMS (n = 1,510)	56.8 ± 10,1	15.6 ± 15.6	5	57.8%
CIS (n = 448)	40.4 ± 11.9	6.5 ± 5.9	1.5	69.0%

The following analysis, which is also shown as graph of the month* on the DMSG website, provides an overview of the utilization of the different types of care:
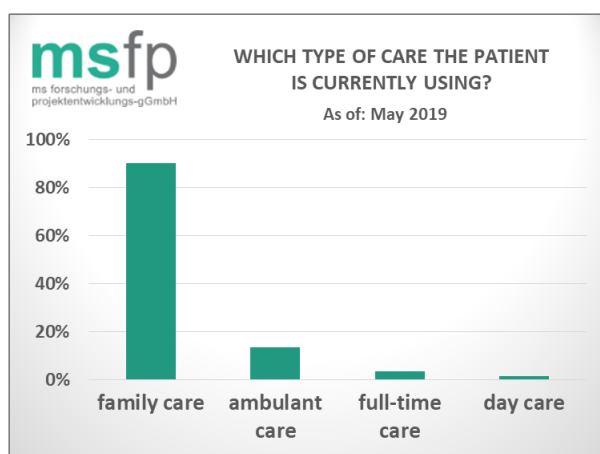
*Since January 2018, the website of the German MS Society at www.dmsg.de monthly presents analyses from the MS Registry on various topics .

At the time of last notification for the MS Registry a total of 30.1% of the registered MS patients received one or more of the provided types of care. The majority (90.2%) of people with MS who were in need of care was looked after by family members, 13.3% received ambulant care and 3.4% received full-time care. Day care was used by 1.4%. Compared to the total population of Germany, where 76.0% of those people that are in need of care (within the meaning of the German care insurance law SGB XI) are cared for at home (Statistisches Bundesamt, 2017), MS patients are more often cared for by family members.

At the congress of the EAN (European Academy of Neurology) 2019 in Oslo, the MS Registry was represented with a lecture on the „Variation in time to first DMT among people with MS in the United States, United Kingdom and Germany". The following graph shows the time to first disease-modifying therapy in the three MS registries that were involved in the analysis.
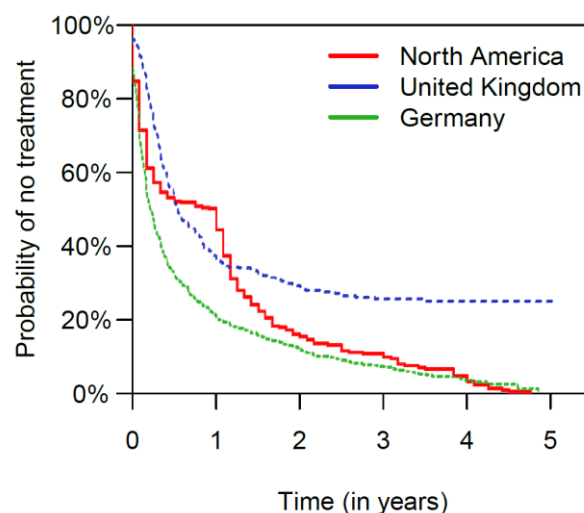
Within the participants who started a DMT (N = 2,132, 75.0%), the median time to first DMT was shortest in Germany at 2 months, followed by Great Britain (4 months) and North America (6 months). Time to first DMT in cross-country analysis was shorter for mild disease severity than in moderate disease. In addition, in all countries a markedly delayed initiation of therapy was noted among over-60-year-old patients.

All published publications on the MS Registry can be downloaded on our website www.msregister.de.

MS Register 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 is based 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 patients document themselves 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 the implementation of 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. Another key priority formulated by the initiative is the existence of a federated IT independent data ecosystem that supports re-use and request-based pooling of data when necessary and tackles the challenges of data sharing.

Scientific advisory group

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

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