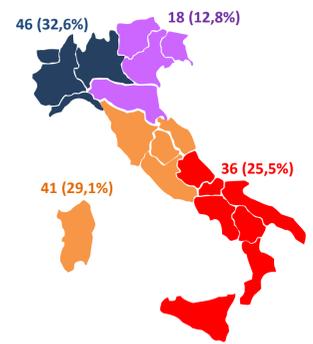# Italian MS Register

NETWORK OF MS CLINICAL CENTERS INVOLVED IN THE PROJECT

Total Centers involved: 141
- 🟢 Active Centers (113)
- 🔴 Pending approval Centers (28)

The medical care to MS patients in Italy is mainly delivered by 236 qualified MS centers, of these, **141 (60%) declared the willingness to participate**.

Geographic distribution of the Centers involved

46 (32,6%)   18 (12,8%)
41 (29,1%)   36 (25,5%)

RESEARCH ASSISTANTS NETWORK

In order to increase the quality of the data collected, a group of research assistants has been ad hoc trained for the project with the objective to foster the collection of good quality data in the Italian MS centers.
15 Research Assistants are working in 13 Regions and supporting over 90 MS Clinical Centers.
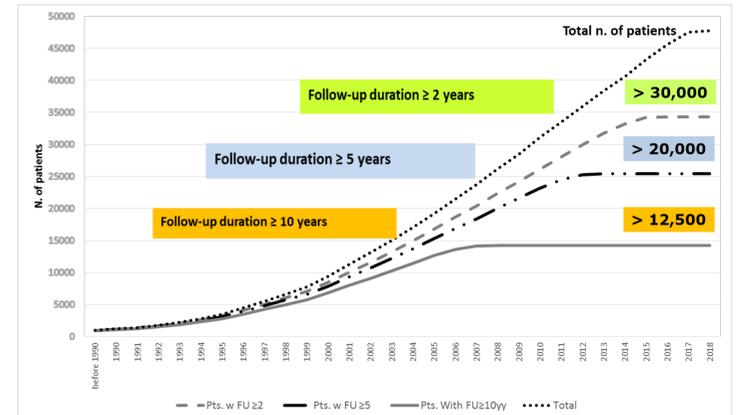
SAMPLE

The database included the clinical history of approximately **55,000** patients.

The increasing temporal trends of the total cohort and sub-cohorts with different follow-up duration (≥ 2.0, 5.0, and 10 years) are reported in graph.

More than 10,000 patients have a follow up duration over 10 years.

Temporal trend, N. of patients with at least 2, 5, and 10 years of follow-up

Total n. of patients
Follow-up duration ≥ 2 years > 30,000
Follow-up duration ≥ 5 years > 20,000
Follow-up duration ≥ 10 years > 12,500

N. of patients

Pts. w FU ≥2   Pts. w FU ≥5   Pts. With FU≥10yy   Total

CHARACTERISTICS OF 55,000 MS PEOPLE WITH MS ENROLLED

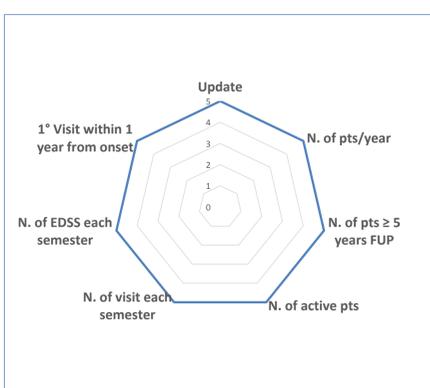| Neurological Evaluations – EDSS	
Visits recoded, n	644,309
EDSS evaluation for patient, mean (SD)	11.8 (13.7)
EDSS evaluation for patient, median (IQR)	7 (2-16)
Neurological Evaluations – MRI	
MRI recoded, n	314,994
MRI for patient, mean (SD)	6.5 (7.1)
MRI for patient, median (IQR)	4 (1-10)

Relapse	
Relapse recoded, n	160,419
Relapse symptoms, n	143,364
Steroid treatment of relapse, n	72,343
Completeness of recovery, n	59,289
Treatments	
prescription drugs, n	201,954

Disability indicators	
Expanded Disability Status Score (EDSS), n	570,640
Functional System Score (FSS), n	349,064
9-Hole Peg Test (9-HPT), n	47,790
Timed 25-Foot Walk (T25-FW), n	47,908
Paced Auditory Serial Addition Test (PASAT3), n	48,801
Paraclinical tests	
Evoked potentials, n	28,613
Cerebrospinal fluid, n	26,660

MONITORING DATA QUALITY

A set of 7 performance indicators has been identified and adopted with the aim to improve the quality, completeness of the survey, timeliness, generalization, and representativeness of the collected data. Score between 1 and 5 (1=worst performance; 5=best performance; 0=not applicable).

Every 6 months, each participating center receives a report where data and performance indicators of its own center (red line) are benchmarked with the whole sample (blu line): in this way, each center can assess the most critical performances and the level of improvement with time.

Score_UPDATE means adherence to periodic central database update; **Score_N._Pts_year** means sample size by center; **Score:_Pts_with FUP ≥ 5 years** means sample size by center with prospective clinical follow-up ≥5 years; **Score:_active Pts** means patients in active status, i.e., at least one visit and/or contact with the center in the last 2 years; **Score:_VISIT every 6 months** means semi-annual visit rates; **Score:_EDSS every 6 months** means semi-annual EDSS assessment rates; **Score:_I°visit_within_I° yr** from onset means first visit within 2 year of the disease onset.

All Centers   Center XXX