



# Italian MS Register



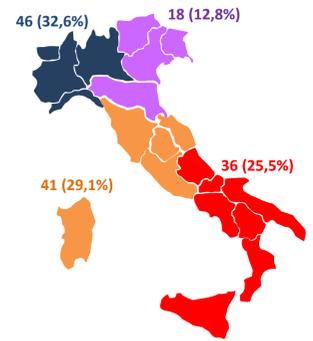
## NETWORK OF MS CLINICAL CENTERS INVOLVED IN THE PROJECT



**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



## 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.**

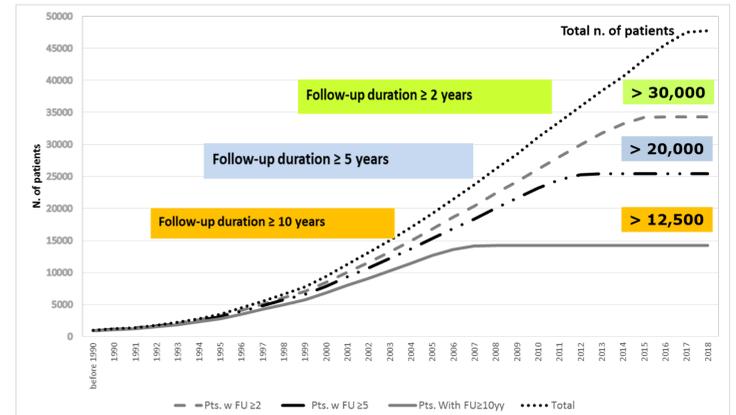
## SAMPLE

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 ( $\geq 2.0$ , 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



## CHARACTERISTICS OF 55,000 MS PEOPLE WITH MS ENROLLED

Neurological Evaluations – EDSS	
Visits recorded, 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 recorded, n	314,994
MRI for patient, mean (SD)	6.5 (7.1)
MRI for patient, median (IQR)	4 (1-10)

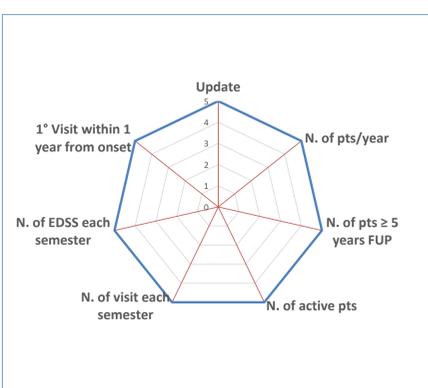
Relapse	
Relapse recorded, n	160,419
Relapse symptoms, n	143,364
Steroid treatment of relapse, n	72,343
Completeness of recovery, n	59,289
Treatments	
prescription drugs, n	201,954

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 (blue 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  $\geq 5$  years** means sample size by center with prospective clinical follow-up  $\geq 5$  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\_1°visit\_within\_1° yr** from onset means first visit within 2 year of the disease onset.

