

# The Italian Multiple Sclerosis and Related Disorders Register

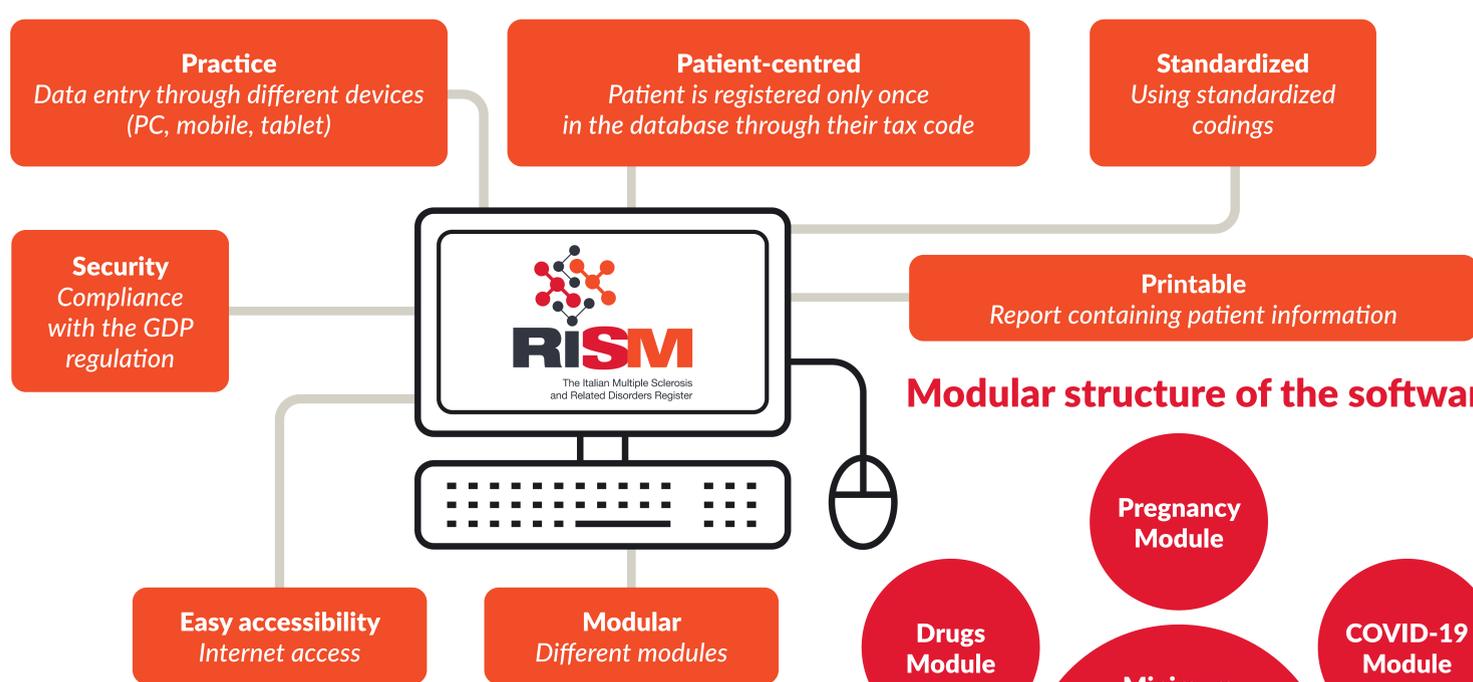
In early 2015, the Italian MS Foundation and the University of Bari, in collaboration with the network of **Italian MS clinical centers**, promoted and founded the Italian MS and Related Disorders Register (Registro Italiano SM e Patologie Correlate – **RISM**).

The RISM aims to create an organized multicenter structure to collect data of all MS patients for better defining the disease epidemiology, improving quality of care and promoting research projects in MS high-priority area. The project was in continuity with the existing Italian MS Database Network set up in 2001.

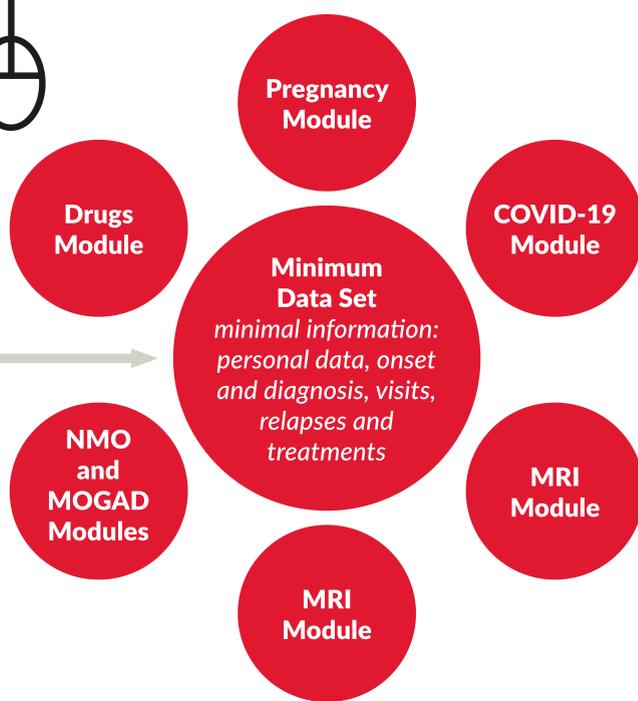
## DEDICATED SOFTWARE

The RISM runs on modular web-based software in an exclusive way. The software access happens through the reserved area of the website of the project (<https://www.registroitalianosm.it/>).

### Characteristics of the software

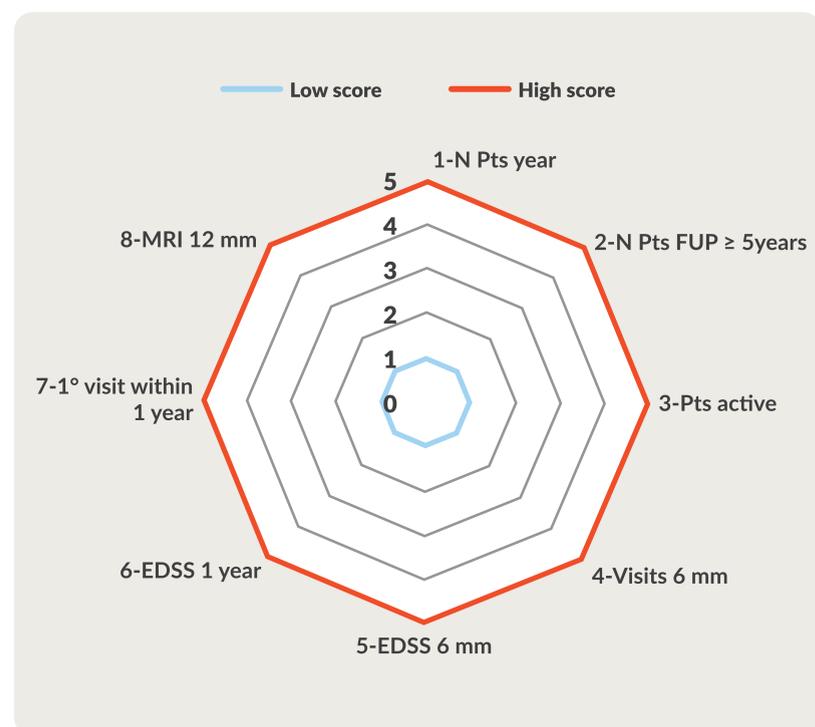


### Modular structure of the software



## DATA MONITORING

Several tools for quality control data have been implemented in order to increase the generalizability of the results. An innovative set of 8 performance indicators has been developed with the aim to improve the quality, completeness, timeliness, generalization, and representativeness of the collected data.



For each examined indicator or domain, each participating center was awarded with a score of 5 for the best performance, while lower scores of 4 to 1 were attributed for progressively lower performance. Every 6 months, each participating center receives a report where data and performance indicators of its own center are bench-marked with the whole sample: in this way, each center can assess the most critical performances and the level of improvement with time.

- 1 - N Pts year: number of patients/year
- 2 - N Pts FUP  $\geq$  5years: % of patients with follow-up longer than 5 years
- 3 - Pts active: At least 1 visit in the last 2 years
- 4 - Visits 6 mm: At least 1 visit every 6 months/FU
- 5 - EDSS 6 mm: At least 1 EDSS evaluation every 6 months/FU
- 6 - EDSS 1 year: At least 1 EDSS evaluation every 12 months/FU
- 7 - 1° visit within 1 year: first visit within 12 months of disease onset
- 8 - MRI 12 mm: MRI (brain and spinal cord) every 12 months



Network of the Italian MS Clinical Centers



Technical Methodological Structure



AISM. INSIEME, UNA CONQUISTA DOPO L'ALTRA



Industry Advisory Board

