

The evolution of the Italian Multiple Sclerosis and Related Disorders Register - RISM ID 949

A 2015-2025 journey under the lens of data quality

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RISM

Registro Italiano Sclerosi Multipla e Patologie Correlate

RISM is a nationwide database established in 2015, built upon the Italian MS Database Network, promoted by Italian Multiple Sclerosis Foundation

RISM marks its 10th year of activity thanks to key strategic aspects of its governance and data quality assurance

The **web-based tool RISM-App** allows the standardized collection of demographics, clinical, and epidemiological data

A **network of 23 trained research assistants** improves data collection and quality at the local level

MAIN STRATEGIES TO IMPROVE DATA STANDARDIZATION, QUALITY, AND COMPLETENESS

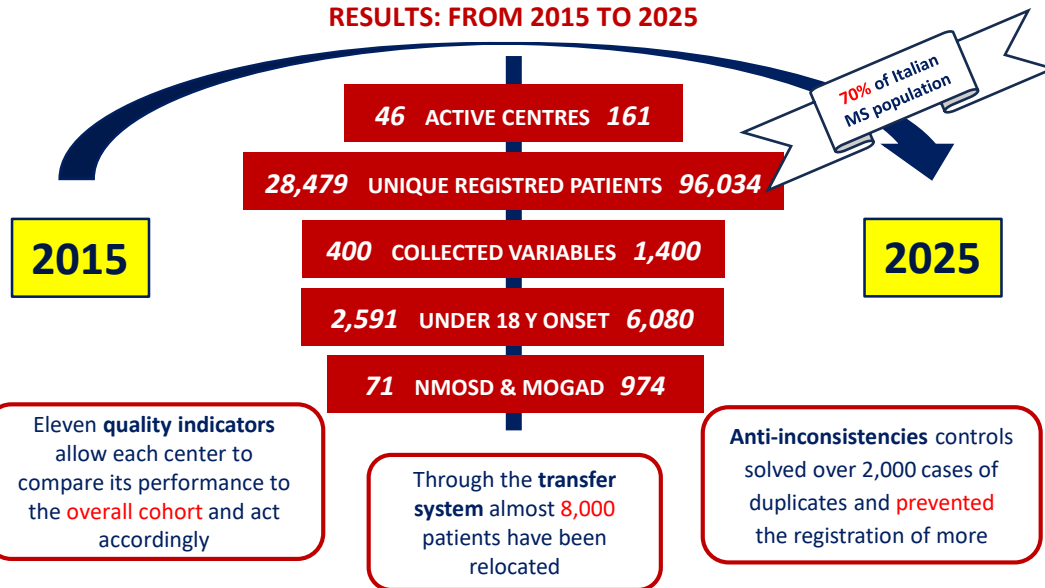
Continuous data monitoring

- Regular communications to centers
- Six-monthly quality and descriptive indicators
- data verification requests (e.g., missings or inconsistencies)
- Training on standardized data collection
- Centre-specific queries system

Dedicated tools within the RISM-App

- A patient transfer system ensures unique clinical histories
- Clinical risk assessment tool allows the management of drug prescriptions
- Anti-duplication tool prevents the creation of new inconsistencies
- Dedicated modules allow specific data collection

RESULTS: FROM 2015 TO 2025



FORWARD THE FUTURE

During its ten years of activity, RISM - <https://registroitalianosm.it> - has expanded in terms of centers, patients and variables collected, improving over time data quality, consistency and reliability

To date, RISM is the **largest Multiple Sclerosis register in Europe** and contributes to gather high-quality data for real-world observational studies, healthcare planning, cost evaluation, treatment effectiveness and post-authorization safety studies

RISM is part of the **Big MS Data Network**, <https://bigmsdata.org>, from 2024 to 2027 as network coordinator



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