The Italian Multiple Sclerosis and Related Disorders Register (RISM) – Research Unit “Italian Multiple Sclerosis Foundation and University of Bari”

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Institution | Educational Institution | Not-for-profit

Institution identification

Institution ID

1000000860

Institution countries

Italy

Type of institution

Educational Institution

Not-for-profit

Institution role

Data holder

Researcher

Institution website

https://www.registroitalianosm.it/en/

ENCePP partner

No

Institution description

In 2000, the Italian collection of multiple sclerosis (MS) clinical data started at different Italian MS centres in the framework of the Italian Multiple Sclerosis Database Network. In 2014, the Italian Multiple Sclerosis Society (Associazione Italiana Sclerosi Multipla - AISM), through its Foundation (Fondazione Italiana Sclerosi Multipla - FISM), and the University of Bari (UNIBA) created a specific “Research Unit” to realize a national data source collecting demographic and clinical data on people with MS in Italy. In 2015 FISM, in collaboration with the Italian MS clinical centers and the University of Bari, promoted and funded the creation of the Italian MS Register. In 2021 the Italian MS Register has been expanded to include data on related diseases and has become therefore the "Italian Multiple Sclerosis and Related Disorders Register” (RISM). A new module has been included for the collection of information on rare forms of demyelinating diseases: Neuromyelitis Optica Spectrum Disorder (NMOSD) and pathologies associated with the presence of anti-MOG antibodies (MOGAD). The governance of RISM includes an Executive Committee (chaired by FISM and the University of Bari) with the administrative and organizational role and a Scientific Committee (including clinicians, methodologists, and representatives of both MS centers and of the Italian Neurological Society) which oversees the scientific initiatives, promotes specific strategic projects, and approves requests of access to centralized data for further research projects. The Technical Operational and Coordinating Structure, based at FISM in Genoa, operates on behalf of RISM and manages both administrative and technical-operational aspects of the project.

Institution details

Experience with collecting data directly from individual patients or respondents:

No

Interest in carrying out research that is funded by pharmaceutical companies:

No

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