Cochrane
Multiple Sclerosis and Rare Diseases of the Central Nervous System

Trusted evidence.
Informed decisions.
Better health.

REPORT

2024-2025

SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA
Azienda Unità Sanitaria Locale di Bologna

Istituto delle Scienze Neurologiche
Istituto di Ricovero e Cura a Carattere Scientifico

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Cochrane
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Cochrane is a global, independent, non-profit network of health researchers and professionals, patients and carers who work together to produce and promote trusted, high-quality health information that improves health and healthcare worldwide.

This is primarily achieved by the preparation, maintenance and dissemination of systematic reviews of the scientific literature regarding the effects of health care interventions. Twenty-nine Review Groups produce and update Cochrane Reviews.

The members of these groups have come together because they share an interest in generating high-quality, reliable, up-to-date evidence-based reviews regarding the diagnosis, prevention and treatment of a particular condition or groups of conditions.

The Cochrane Multiple Sclerosis and Rare Diseases of the Central Nervous System coordinates the preparation and production of systematic reviews that aim to cover all aspects of the diagnosis, prevention and treatment of multiple sclerosis and of the rehabilitation and palliative care of persons with the multiple sclerosis and other demyelinating inflammatory conditions of the central nervous system.

The Editorial Base of the review group is based in the Unit of Epidemiology and Statistics at the IRCCS Institute of Neurological Sciences of Bologna, in Bologna, Italy.

Knowledge Translation

This year, we focused our efforts on the development of Knowledge Translation (KT) resources. Cochrane defines KT as the process of supporting the use of health evidence from our high quality, trusted Cochrane Reviews by those who need it to make health decisions.

To support this mission, we produced a wide array of materials in various formats, aiming to enhance the accessibility of evidence-based content and promote engagement with high-quality research methodology. This initiative was made possible in part by the contributions of 18 active volunteers, primarily students from diverse backgrounds and from all around the world.

Our KT activities focused on the creation and dissemination of different materials based on the most recent reviews published by the group.

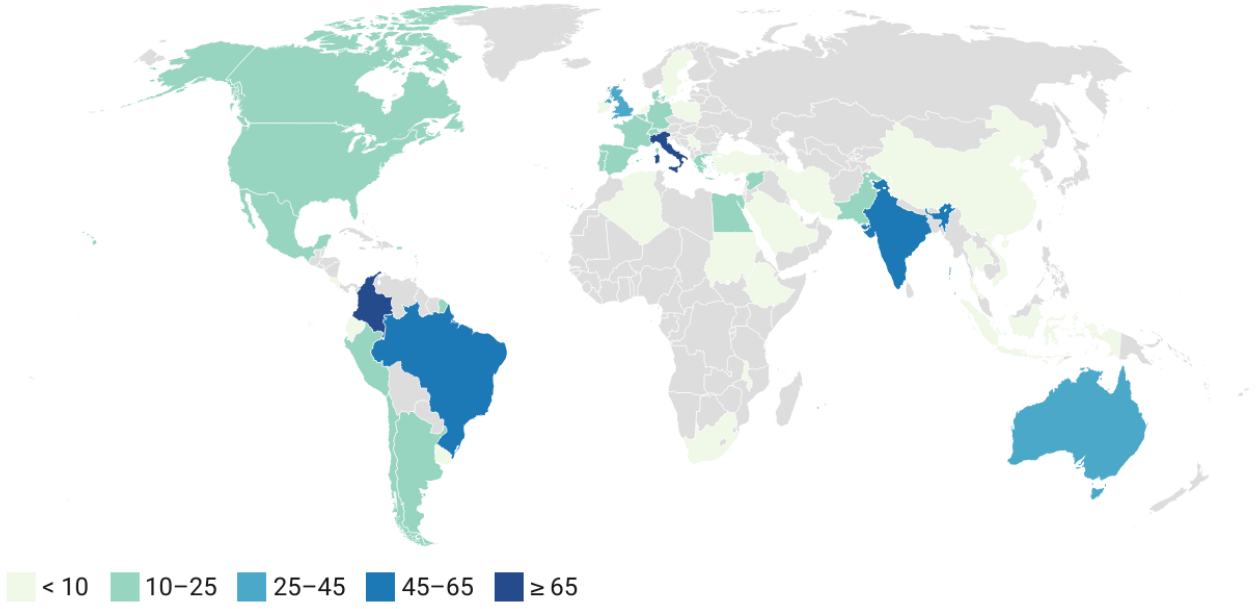
All developed resources are made available through our website, which is updated weekly, as well as through our LinkedIn and Instagram channels.

Social Media

Over the past year, we have closely tracked the growth of engagement across Cochrane MS's social media platforms as a means of assessing the impact of our dissemination strategy.

A key performance metric was the increase in user interaction with published content, primarily measured through LinkedIn analytics. The objective was to achieve a 10% growth in followers.

Since its launch on December 1, 2023, the LinkedIn page Cochrane Review Group MS and Rare Diseases of the CNS reached 1334 new followers by July 2025. This reflects a sustained monthly growth rate of approximately 10%, with an average of three new followers per day over the course of the year (July 2024-July 2025). From a sample of our LinkedIn followers (N=674, 51%), we can see that the page is followed mostly by people from High-Income (N=324) and Upper-Middle-Income (N=179) Countries, with a minority from Lower-Middle-Income (N=116) and Low-Income (N=9) Countries. The top three countries by number of followers are Italy (89), Colombia (71), and India (48).



Geographical distribution of LinkedIn followers (N=674) on July 3rd, 2025. Countries: Algeria (5), Argentina (17), Australia (29), Belgium (19), Brazil (47), Canada (13), Chile (13), China (5), Colombia (71), Costa Rica (2), Denmark (14), Ecuador (4), Egypt (21), Ethiopia (3), France (11), Germany (19), Greece (15), India (48), Indonesia (9), Iran (7), Ireland (6), Italy (89), Malawi (3), Mexico (15), Netherlands (4), Pakistan (20), Peru (11), Poland (2), Portugal (22), Saudi Arabia (2), Serbia (3), South Africa (3), Spain (15), Sudan (3), Sweden (6), Switzerland (13), Syria (10), Thailand (9), Turkey (3), United Kingdom (29), Uruguay (3), USA (20), Vietnam (3).

Since its creation on November 15th, 2023, the Instagram page has reached a total of 228 followers.

Blogshots

Blogshots are concise visual summaries derived from Cochrane systematic reviews, designed for online dissemination to rapidly share relevant, evidence-based health information.

By creating and translating blogshots, we aim to broaden the reach of Cochrane content and engage a more diverse audience, supporting the wider uptake as an informant of evidence in healthcare decision-making.

This year, 54 blogshots were produced based on 19 Cochrane reviews and translated into nine languages: English, Italian, French, German, Portuguese, Malay, Spanish, Traditional Chinese, and Simplified Chinese.

Visual Abstract

A visual abstract is a concise, graphic summary of a scientific study, designed to highlight key elements at a glance, including the research context, clinical question, main findings, and

conclusions. It serves as an accessible communication tool for healthcare professionals, patients, and the general public alike.

In recent years, visual abstracts have gained attention among international scientific journals. Many academic publications now include them alongside full articles and share them on social media to broaden the reach and visibility of research findings.

Over the past year, we produced two visual abstracts based on the following Cochrane reviews: "Immunomodulators and immunosuppressants for relapsing-remitting multiple sclerosis: a network meta-analysis" and "Immunomodulators and immunosuppressants for progressive multiple sclerosis: a network meta-analysis".

Visual Abstract created by Agnes Zanotto, volunteer of our Review Group.

Review Snapshot

Our Review Snapshots aim to make complex medical research accessible and engaging for everyone. Each snapshot presents key findings from recent systematic reviews and meta-

analyses as concise, easy-to-understand summaries. By focusing on the most relevant outcomes and implications for clinical practice, the Review Snapshots provide valuable insights into current research trends and advancements in healthcare, offering a quick and informative way to stay updated.

At the end of each snapshot, it is possible to find some more info about the terms and methodology used in that review.

Review Snapshots are available for eleven reviews in three languages (English, Italian, French).

Podcast

Our review group has developed podcast (now called Audio Summaries) for four Cochrane Reviews, translated in six languages.

Patient & Public Resources

Our review group has a long-term commitment to involving patient and public in our research. One way to do so is developing understandable contents that could introduces them to Evidence Based Medicine, as well as the most used terms of MS research. All these resources are written in a familiar and plain languages, to empower patients and the public with a deeper understanding to engage with healthcare information more confidently.

Unlocking Healthcare Insights

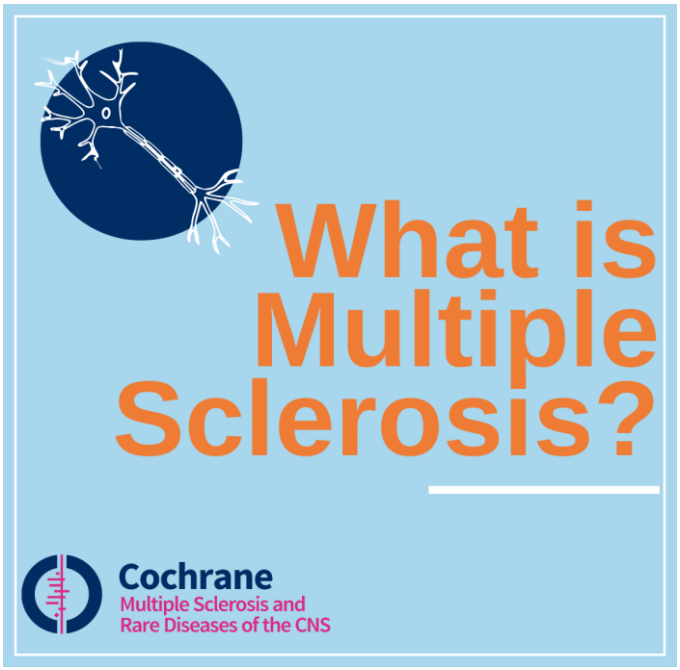
This series is made by informational cards about eight topics: Bias in Evidence Synthesis, Core Outcome Set (COS), Evidence Based Medicine (EBM), Evidence-Synthesis Protocol, Network Meta-analysis, Patient-Reported Outcomes, Randomized Controlled Trials (RCTs), Research Priority Setting.

Glossary

The Glossary is a list of terms most commonly used in our reviews, explained in plain language.

MS Awareness

A collection of slides designed to provide essential information on various aspects of MS, ranging from MS symptoms, types, to available therapies. Additionally, the slides address lifestyle tips, symptom management strategies, and the latest research advancements.



First page of our first collection of MS Awareness slides "What is Multiple Sclerosis?"

Events

- **Reproductive Health for Women with Multiple Sclerosis: Global Voices**

In occasion of World MS Day 2025, on 30th May, we have organized a global online conversation featuring women with MS, healthcare professionals, researchers and advocates from around the world to talk openly about reproductive health. The event, with 120 person registered from all around the world, was chaired by Claudia De Santis, IRCCS Istituto delle Scienze Neurologiche di Bologna and Cochrane MS and Rare Diseases of the CNS, and hosted: Riley Bove - University of California, San Francisco (UCSF) and Weill Institute for Neurosciences (USA); Shanthi Viswanathan - Kuala Lumpur Hospital, Department of Neurology (Malaysia); Jennifer McDonell - MS Canada (Canada); Gaby Mammone - person with lived experience and MS Canada (Canada); Elisa Baldin - IRCCS Istituto delle Scienze Neurologiche di Bologna and Cochrane MS and Rare Diseases of the CNS (Italy).

Flyer of the event "Reproductive Health for Women with Multiple Sclerosis: Global Voices".

- **The Role of Systematic Reviews in the Health Decision-Making Ecosystem**

In collaboration with the University of Padua (UNIPD), deliver a seminar aimed at promoting awareness of the role of systematic reviews within the health decision-making ecosystem, presenting a real-world case scenario in which collaboration among researchers, patients, and institutions led to the inclusion of essential multiple sclerosis medications in the WHO Essential Medicines List.

The seminar took place in a hybrid format on 29 April 2025 and was led by Francesco Nonino, Joint Coordinating Editor, and Elisa Baldin, Editor, respectively, of Cochrane Multiple Sclerosis and Rare Diseases of the CNS.

- **Global Recognition of MS Drugs: from Evidence-Synthesis to Action**

To mark World MS Day 2024, May 30th, our group organized a webinar with the participation of MS International Federation (MSIF). The speakers Nick Rijke (Access to Healthcare Consultant for MSIF) and Francesco Nonino (Joint Coordinating Editor of Cochrane MS and Rare Diseases of the CNS & Director of WHO Collaborating Centre in Evidence-Based Research Synthesis and Guideline Development) broke down to 56 attendees the journey to the inclusion of rituximab, glatiramer acetate, and cladribine on the WHO Essential Medicines List, now reshaping access to MS treatments worldwide.

Flyer of the event "Global Recognition of MS Drugs: from Evidence-Synthesis to Action".

Projects & Publications

KNOWwMS

For many women living with multiple sclerosis (MS), questions about reproductive health, like pregnancy, family planning, and breastfeeding, can be especially difficult to navigate. These concerns often arise during the early reproductive years, when MS is most commonly diagnosed, and yet many women report feeling underserved or even overlooked when seeking information and support. While research on MS and reproductive health is growing, much of it remains concentrated in high-income countries. In many parts of the world, especially in resource-limited settings, women with MS continue to face significant barriers in accessing clear, reliable, and relevant information about their health.

KNOWwMS (Knowledge Gaps in Reproductive Health among Women with MS) is an international, mixed-method research project aiming to define a Core Knowledge Set, which is a clear, evidence-informed summary of what every woman with MS should know about reproductive health.

This knowledge set will be especially tailored for low- and middle-income countries, where resources and access to specialized care may be limited.

Publications

De Santis, C., Bove, R., Jacobs, D., McDonell, J., Nonino, F., Rijke, N., Saylor, D., Viswanathan, S., & Baldin, E. (2025). *Identifying knowledge gaps in reproductive health management for women with multiple sclerosis and healthcare professionals: A scoping review*. [Submitted 2025]. Multiple Sclerosis Journal.

Baldin, E., De Santis, C., Bove, R., Jacobs, D., McDonell, J., Rijke, N., Saylor, D., Schiess, N., Viswanathan Shanthakumar, S., & Nonino, F. (2024). *Identifying Knowledge Gaps in Reproductive Health Management for Women with Multiple Sclerosis and healthcare professionals: A Scoping Review protocol*. Zenodo. https://doi.org/10.5281/zenodo.13866567

De Santis C, Bove R, Jacobs D, McDonell J, Rijke N, Saylor D, Viswanathan Shanthakumar S, Francesco Nonino, Elisa Baldin. *Knowledge Gaps in Reproductive Health among Women with MS (KNOWwMS): a project protocol*. [Submitted 2025]. Multiple Sclerosis and Related Disorders.

COS-MNGIE

MNGIE (Mitochondrial Neurogastrointestinal Encephalomyopathy) is a rare autosomal recessive disorder caused by mutations in the TYMP gene, which leads to a deficiency of thymidine phosphorylase (TP). This deficiency results in the accumulation of thymidine and deoxyuridine, which disrupts the maintenance and integrity of mitochondrial DNA. The prevalence of MNGIE is unknown, and fewer than 200 cases have been reported in the medical literature.

The project Core Outcome Set in Mitochondrial Neurogastrointestinal Encephalomyopathy (COS-MNGIE) aims to develop a set of health outcomes (Core Outcome Set, or COS), relevant for clinicians and for people with MNGIE, that should be adopted as a minimum in clinical practice and in research on the efficacy, safety and value of treatments, including current and future permanent enzyme-replacement treatments.

To develop the Core Outcome Set, we adopted a multi-phase, consensus-driven methodology designed to integrate scientific evidence with the perspectives of clinicians and people with MNGIE. The project is promoted by the Mitocon patient advocacy group for people affected by mitochondrial diseases and endorsed by the European Reference Networks for Hereditary Metabolic Disorders (MetaBERN).

A final list of Core Outcomes was developed in July 2025.

Publications

Schettino, M., Baccari, F., De Santis, C., Massucci, S., Zenesini, C., Cescon, M., Hirano, M., Malagelada, C., Martí, R., Morelli, M. C., Pioli, S., Roubertie, A., Mattarozzi, K., Baldin, E., Vignatelli, L., Rinaldi, R., & Nonino, F. (2024, September 19–20). *Core Outcome Set for Liver Transplant in Mitochondrial Neurogastrointestinal Encephalomyopathy (MNGIE): The COLT-MNGIE Project* – Protocol [Conference presentation]. SISMEC 2024, Modena, Italy.

Cognitive Impairment in Multiple Sclerosis

Cognitive impairment (is a prevalent and disabling symptom in people with MS, affecting various cognitive domains and contributing to reduced quality of life. However, the definitions of CI and the screening tools used in research and clinical settings vary widely. In order to summarize the definitions of cognitive impairment and the screening tests employed in clinical practice, the review group is currently undergoing an overview of reviews (umbrella review) of studies assessing cognitive impairment in people with MS.

The project is developed in collaboration with the International Multiple Sclerosis Cognition Society (IMSCOGS) and funded by European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS).

Elisa Baldin presented the project entitled “Cognitive Impairment in Multiple Sclerosis: An IMSCOGS Overview of Systematic Reviews Protocol” during an ePoster session at the 11th European Academy of Neurology (EAN) Congress, held in Helsinki from June 21 to 24, 2025.

Publications

Hancock, L. M., Nonino, F., Baldin, E., Schettino, M., De Santis, C., Bassi, M. C., Langdon, D., Morrow, S. A., Young, C. A., & Schoonheim, M. (2025). *Cognitive Impairment in Multiple Sclerosis: an IMSCOG Overview of Systematic Reviews Protocol*. Zenodo. https://doi.org/10.5281/zenodo.14872533

Baldin, E., Schettino, M., De Santis, C., Bassi, M., Langdon, D., Morrow, S., Hancock, L., Schoonheim, M., Young, C., & Nonino, F. (2025, June 21–24). *Cognitive impairment in multiple sclerosis: An IMSCOGS overview of systematic reviews protocol* [Conference presentation]. 11th European Academy of Neurology (EAN) Congress, Helsinki, Finland.

DMTs in low-resource settings

During the last year, our review group has published on the Cochrane Library a series of reviews that provided the evidence base to inform recommendations developed by two international working groups, coordinated by MSIF, on disease-modifying therapies (DMTs) for both relapsing-remitting and progressive forms of multiple sclerosis, focusing on the availability in low-resource settings.

Publications

Gonzalez-Lorenzo M, Ridley B, Minozzi S, Del Giovane C, Peryer G, Piggott T, Foschi M, Filippini G, Tramacere I, Baldin E, Nonino F. *Immunomodulators and immunosuppressants for relapsing-remitting multiple sclerosis: a network meta-analysis*. Cochrane Database Syst Rev. 2024 Jan 4;1(1):CD011381. doi: 10.1002/14651858.CD011381.pub3. PMID: 38174776; PMCID: PMC10765473.

Ridley B, Nonino F, Baldin E, Casetta I, Iuliano G, Filippini G. *Azathioprine for people with multiple sclerosis.* Cochrane Database of Systematic Reviews 2024, Issue 12. Art. No.: CD015005. DOI: 10.1002/14651858.CD015005.pub2.

Ridley B, Minozzi SM, Gonzalez-Lorenzo M, Del Giovane C, Piggott T, Filippini G, Peryer G, Foschi M, Tramacere I, Baldin E, Nonino F. *Immunomodulators and immunosuppressants for progressive multiple sclerosis: a network meta-analysis.* Cochrane Database of Systematic Reviews 2024, Issue 9. Art. No.: CD015443. DOI: 10.1002/14651858.CD015443.pub2.

Saylor D, Rijke N, McDonell J, Laurson-Doube J, Avasarala J, Baldin E, Banerjee TK, Bogdanovic I, Bove R, Chawla DK, Costello K, Del Giovane C, Abkari NE, Filippini G, Foschi M, Gonzalez-Lorenzo M, Helme A, Jacobs D, Kalincik T, Mantel-Teeuwisse A, Minozzi S, Navas C, Nonino F, Ojo OO, Ozcan B, Pasi E, Peryer G, Prato Chichiraldi A, Ridley B, Sokhi DS, Traboulsee A, Tramacere I, Tye JS, Vecchi S, Viswanathan S, Xie F, Zeineddine M, Schunemann H, Piggott T. *Recommendations for essential medicines for multiple sclerosis in low-resource settings.* Mult Scler. 2025 Apr;31(4):464-473. doi: 10.1177/13524585241308134. Epub 2024 Dec 31. PMID: 40167177.

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