

# RETHINKINGMS

Methodology





# ACKNOWLEDGEMENTS

## About RETHINKING MS

RETHINKING MS is a research-driven project offering tangible policy changes to improve the lives of people living with MS across Europe, building on the 2017 Value of Treatment report from the European Brain Council. The RETHINKING MS series includes:

- *RETHINKING MS in Europe* – an analysis of unmet MS care and support needs across Europe, and sustainable policy recommendations to address them
- *RETHINKING MS in Denmark, Italy, Romania and Spain* – a series of reports providing an in-depth analysis of policy, care and support available for people with MS in each country.
- *RETHINKING MS: a policy assessment tool* – a resource showing how national priorities can be achieved in each country to have a real impact on the lives of people with MS.

## Funding disclaimer

The project is funded by Biogen, Celgene, Merck, Novartis and Sanofi. This project is supported by an Expert Advisory Group who have full editorial control and provide their time for free. Outputs aim to accurately represent a consensus from the Expert Advisory Group and are developed jointly between the European Brain Council and The Health Policy Partnership. All outputs are non-promotional and not specific to any particular treatment or therapy.

## About the European Brain Council

The European Brain Council (EBC) is a non-profit organisation that aims to improve the lives of those living with brain disorders by advancing the understanding of the healthy and diseased brain through bringing together science and society.

## About The Health Policy Partnership

The Health Policy Partnership (HPP) is an independent research consultancy, working with partners across the health spectrum to drive the policy and system changes that will improve people's health.

For more information on RETHINKING MS, please visit:

**[www.braincouncil.eu/RethinkingMS](http://www.braincouncil.eu/RethinkingMS)**



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# ABOUT RETHINKING MS

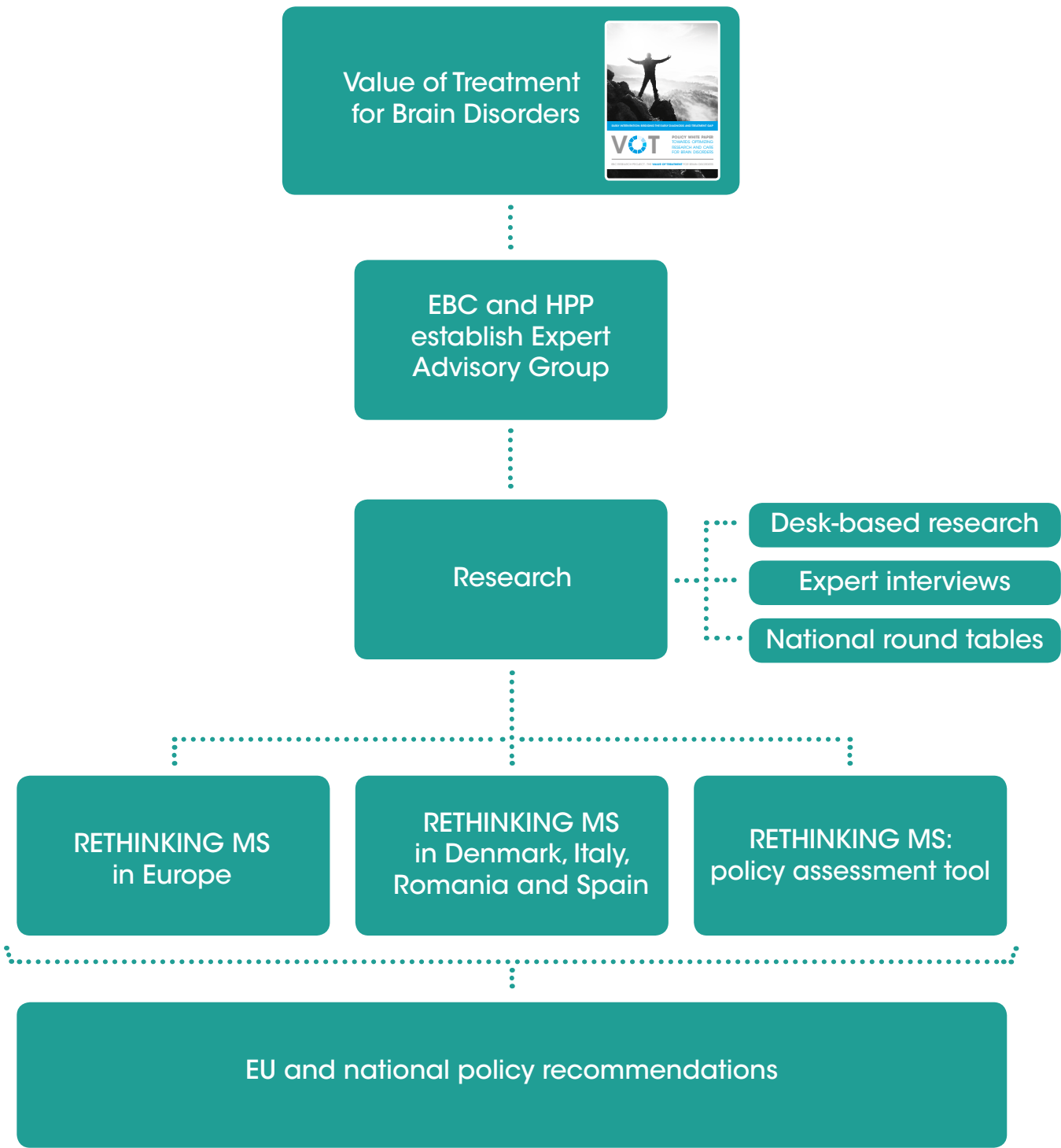
The European Brain Council (EBC) has developed a project on multiple sclerosis (MS), RETHINKING MS, in collaboration with The Health Policy Partnership (HPP). With this project, we aimed to create greater visibility for the unmet needs experienced by people with MS, with a particular focus on: timely diagnosis and personalised treatment; interdisciplinary and coordinated care; and adaptable support in daily life, including rehabilitation and social protection.

Stemming from the 2017 Value of Treatment report, RETHINKING MS featured a sequence of research which led to a suite of reports. The *RETHINKING MS in Europe* policy report provides a pan-European policy analysis of unmet needs in MS and how best to address them. Four country profiles – *RETHINKING MS in Denmark, Italy, Romania and Spain* – take an in-depth look at the different MS-related policy, health and social care landscapes across Europe. These countries were selected in consultation with our Expert Advisory Group (EAG) to represent a broad range of national contexts from across the continent. *RETHINKING MS: a policy assessment tool* is the final resource of the project, intended as a starting point for the development of national MS policies, with the ultimate aim to build them into relevant national plans.

The interdisciplinary EAG was established in spring 2018 to help guide the RETHINKING MS project. The group featured 16 experts including neurologists, nurses, clinical psychologists, rehabilitation specialists, academic researchers and patient advocacy representatives from around Europe. They were consulted at key milestones of the development of *RETHINKING MS in Europe*. Country leads were nominated from the EAG to provide additional support for the country profiles of Denmark, Italy, Romania and Spain, and were instrumental in the development of the policy priorities for the policy assessment tool. *Figure 1* outlines the approach to research for the development of RETHINKING MS.

EBC and HPP are extremely grateful for the time and expertise that the EAG dedicated to the project.

**Figure 1.** Approach to the RETHINKING MS project



The research to inform the RETHINKING MS series fell into three categories:

1. Desk research
2. Expert interviews
3. National round tables

Each are described in the sections below.

## Desk research

Desk research comprised scientific and grey literature reviews, supported by stakeholder recommendations, snowballing and web searches.

### Scientific literature

A search string was developed and used to run a search on PubMed, Embase and Medline. The concepts incorporated in the string were “multiple sclerosis”, “treatment, rehabilitation or social inclusion” and “needs”. These concepts were expanded, and the resulting search strings investigated on the databases. For the four country briefs, the process was mirrored including an “AND” term of the country name. For the country briefs, these searches were carried out in English and the national language.

### Grey literature

The research team mapped potential sources for grey literature. Intergovernmental agencies and international networks were included at European level, while national governments and regulatory bodies, national patient associations and national scientific societies and registries were mapped and investigated for the four country briefs.

### Stakeholder recommendations, snowballing and web searches

Further scientific and grey literature was identified following the indications of the EAG. Reference lists of included papers were examined in order to identify further relevant literature. Finally, searches were carried out on generalist and specific web search engines to identify further suitable documentation.

## Expert interviews

The research team invited the EAG and other interdisciplinary experts from across Europe to participate in semi-structured interviews. The questions were broad, spanning diagnosis, treatment and support in daily life, allowing for follow-on questions based on the expertise of participants.

A total of 22 telephone interviews were undertaken and 5 additional experts provided written responses to questions. Insights came from 12 European countries – Bulgaria, Croatia, Denmark, Germany, Greece, Hungary, Italy, Latvia, Poland, Romania, Spain and the UK – encompassing people with MS, patient advocates, specialist neurologists, specialist nurses, pharmacists, rehabilitation specialists and social workers.

## National round tables

Round-table meetings were organised to discuss the findings of the developing country profiles and identify priorities for policy change in each country. Round-table events were organised in the capital cities of Italy, Romania and Spain. No round table was organised in Denmark; instead, the country lead from Denmark, an MS specialist neurologist, provided input into the prioritisation exercise in consultation with other leading MS experts and advocates in Denmark.


For each round table, EBC and HPP worked closely with the country leads to gather 15–20 regional and national health decision-makers, and representatives from patient advocacy groups, neurology, nursing, rehabilitation, physiotherapy, occupational therapy, social care, general practice and other specialties. Meeting reports were developed after each round table, and the findings were integrated into that country's specific output.



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