

A collaborative initiative to improve MS research and policy across Europe

Better Outcomes with Better Data

www.eurems.eu

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The need, the challenge and the project

Multiple sclerosis (MS) is a condition of the central nervous system which affects the way in which messages or signals are carried between the brain and the rest of the body. MS affects more than 700,000 people living in Europe, two to three times as many women as men and is most often diagnosed in people aged 20-40.

MS varies in severity, from mild symptoms to a disabling condition: on average, half of those with MS lose their job within three years of diagnosis. The overall cost of MS in Europe to health and social care is estimated to be 15 billion euros per year.

The cause of MS is not known, and it cannot be cured, but there are treatments to help patients manage the condition and its symptoms.

In order to better understand, and ultimately conquer MS, more data about the condition are needed. Following the success of a pilot project, the Multiple Sclerosis Information Dividend (MS-ID), which collected clinical, socio-economic, and quality-of-life data from six countries, the European Commission provided co-funding of almost €1 million to support the development of the European Register for Multiple Sclerosis (EUREMS).

The successful data gathering method used for this project lends itself to replication in disease areas other than MS, illustrates the feasibility and importance of finding ways to access information directly from patients about their experiences and has implications for those interested in identifying better strategies to manage public health.

As explained in this document, the main efforts of the EUREMS Consortium are currently focused on the completion and dissemination of four key studies, and on ensuring that messages about the project reach the wider community to whom they are relevant.

What is EUREMS?

The European Register for Multiple Sclerosis (EUREMS) is a centralised source of information on many aspects of MS which have been gathered from other registers, such as those collected by hospitals, MS societies and research centres around Europe. EUREMS thus creates a cross-border partnership for the safe and effective storage, analysis, interpretation and dissemination of such data.

As explained in this document, the most useful core data for collection from patients and clinicians about the nature, course and treatment of MS have been agreed. It is known that services available to patients vary substantially across Europe; by collecting information about, and regularly assessing these disparities, EUREMS should help to reduce them.

Furthermore, gaining a more detailed understanding of the characteristics of patients and their MS across Europe could provide new insights into the causes and course of the condition. Long-term collection of clinical data could also provide more information about the safety and effectiveness of disease-modifying drugs (DMDs) than would be gathered from relatively short clinical trials.

EUREMS has been developed alongside, and builds on existing national databases, with the ultimate aim of providing a comprehensive resource of collected data for research and practice for all European countries, including those that do not currently have their own.

How can EUREMS be used to help conquer MS?

This report sets out significant progress in key areas of activity:

- The main project: developing a comprehensive register of MS-related data – EUREMS.
- The collection and use of such data in research – the project motto is “better outcomes with better data”
- The launch and progress of four studies that use EUREMS to explore: whether the nature of MS across Europe is changing; the possible influence of month of birth on the condition; the effectiveness of disease modifying drugs (DMDs); patients’ own measures of the effect of the condition on their quality of life.

Once data are held within EUREMS, a specific and unique agreement is made for their use by research teams and others as explained in the next section.

“ EUREMS has been developed alongside, and builds on existing national databases, with the ultimate aim of providing a comprehensive resource of collected data for research and practice for all European countries, including those that do not currently have their own.”

Who manages and participates in the EUREMS project?

The EUREMS project is an initiative of the European Multiple Sclerosis Platform (EMSP) which represents those living with MS in Europe and has a network of 39 member societies in 34 European countries. As part of the EMSP's vision of a world without MS, the platform aims to improve quality of life as well as access to treatment, care and employment. EMSP works to ensure that people with MS have a real voice in determining their own priorities.

The value of EMSP leading this project is clear in its commitment to patient advocacy at a European level, complementing the work of its national member organisations and its pivotal role in the MS-ID project, mentioned above, and the patient-centered aspects of this.

EUREMS project partners

EUREMS has 11 project partners who, between them, span the many disciplines needed to achieve a project of this scale (see appendix 1 for details). They are:

- Association of MS Societies of Croatia
- Department of Clinical and Experimental Medicine, University of Sassari, Italy
- German MS Society
- Karolinska Institutet, Medical University, Sweden
- MS Centre of Catalonia – Cemcat
- Multiple Sclerosis Society, UK
- Neurological Rehabilitation Center Quellenhof, Germany
- Polish MS Society
- Romanian MS Society
- University of Bergen, Norway
- University Medical Center Göttingen, Germany

Scientific Advisory Board

Alongside the project partners, well-known experts from the MS scientific community were identified to provide their expertise and guidance to EUREMS partners by assessing the overall quality of the project's activities and results. This Scientific Advisory Board was annually updated and consulted on the progress of the project during the annual international congress gathering the MS community, organised by the European Committee for Treatment and Research in MS (ECTRIMS).

Members of the Scientific Advisory Board:

- Prof. Michel Clanet, France
- Prof. George Ebers, UK
- Prof. Gavin Giovannoni, UK
- Prof. Ralf Gold, Germany
- Dr. Eva Havrdova, Czech Republic
- Dr. Gerhard Kindler, Germany
- Prof. Xavier Montalban, Spain
- Dr. Maria Pia Somani, Italy
- Prof. Per Soelberg-Sørensen, Denmark
- Dr. Maria Trojano, Italy

The EU added value and support to the project

In 2010, the European Commission expressed its willingness to tackle more efficiently the health inequalities faced by EU citizens, e.g. the provision of health services, the design of health promotion and health protection activities, and improvements in living and working conditions.

EUREMS lays the foundation for systematic data collection and analysis. By doing so, the EUREMS project aligns with the Second Health Programme of the European Commission in terms of both priority areas and scope. The Health Programme objectives are to promote health, including the reduction of health inequalities, and to generate and disseminate health information and knowledge. It specifically included the development of the register for MS.

The European Commission granted co-funding of almost €1 million to support the development of a cross-border register for MS, within the framework of the three-year project (2011-2014).

Steering committee



EUReMS project meeting, 10th June 2014, Brussels

For full names of partner organisations see Appendix 1 (page 18)

1 Roberto Zarbo
University of Sassari
2 Elisabeth Kasilingam
EMSP
3 Peter Flachenecker
NRCQ
4 David Ellenberger
UMG-GOE

5 Christoph Thalheim
EMSP
6 Jan Hillert
Karolinska Institute
7 Alexander Stahmann
DMSG
8 Jaume Sastre-Garriga
CEM-cat

9 Cristina Marcoci
University of Sassari
10 Kjell-Morten Myhr
University of Bergen
11 Anna Glaser
Karolinska Institute
12 Diane Redfern-Tofts
UK MS Society

13 Karoline Buckow
UMG-GOE
14 Valerija Smrekar
AMSSC
15 Carola Meyer
DSMG
16 Tsveta Schyns-Liharska
EMSP

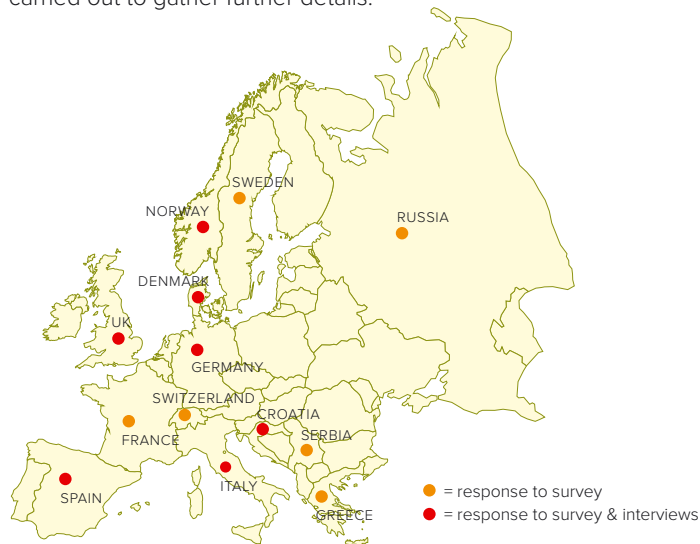
17 Danica Eškić
AMSSC
18 Betti Galanti
University of Sassari
19 Maura Pugliatti
University of Sassari

How has EUREMS been set up?

At the beginning of the project in 2011, national and regional MS registers and databases were identified through EMSP's MS Barometer, a collection of comparative MS data provided by the national MS societies, and through literature searches and professional contacts of EUREMS project partners.

Once links to the MS databases were established and a "map" of the registers obtained, more detailed information was sought on the organisation, structure, objectives and content of each of these. This was done by questionnaire, telephone interviews with the register leaders and on-site visits.

40 MS registers received the questionnaire; it was completed by 23 of these, and in 18 cases more detailed interviews were carried out to gather further details.



This survey concluded that MS databases and registers differ significantly in terms of:

- Their objectives/purpose and structure
- Data collection methods (e.g. hospital-based or surveying a wider population)
- Their documentation (e.g. paper-based, electronic, submitted by neurologists or by patients) and coverage
- The extent and nature of involvement of national MS societies in the data collection or analysis process
- Quality control mechanisms and governance

The information gathered allowed further mapping of content and data and for the design of specific data-pooling templates.

Despite these differences, many of the registers cover at least some of the four key areas of interest to EUREMS: epidemiology (the study of how often diseases occur in different groups of people), long-term treatment outcome, health-care issues and quality of life.

It was also of note that outcome measures from doctors are used in all registers, while data from the patient perspective (in particular, health-related quality of life) were collected by only six registers, with standardised quality of life measures used in only four of these.

For this reason, one of the main conclusions at this stage of establishing EUREMS is the recognition that "patient-reported measures are underrepresented in the existing registers, but need to be considered as part of a common (minimum) data set."

Therefore, a "core data set" with 14 items, including date of birth, age at diagnosis, treatment received, quality of life and employment status has now been established.

The results of this survey were presented at the 2013 Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), held in Copenhagen, Denmark. They were later published in the Multiple Sclerosis Journal in April 2014.



EUREMS Meeting held at ECTRIMS 2013, in Copenhagen, Denmark

Practical, technical and legal aspects of EUREMS

Data that are gathered within EUREMS are taken from local and national MS registers across Europe, and managed by and stored at the Medical Centre of the University Göttingen, Germany (UMG-GOE). All data providers retain full ownership of contributed data, including the right to withdraw it. EUREMS holds ownership of compiled data.

Software tools for processing EUREMS data have been developed using the secuTrial database system at the UMG-GOE, which also holds Standard Operating Procedures (SOPs) specifying the way in which the database is used and managed. The EUREMS database has been fully operational since May 2013 and follows national regulations and UMG-GOE policy.

After completion of the four studies, and with the agreement of these studies' Working Groups, EUREMS data will be archived at UMG-GOE according to national data regulations for a 10 year period. EUREMS is thus maintained by UMG-GOE and will be updated by EMSP for two additional years after the end of the first phase of the project.

Researchers and policymakers who wish to participate in the EUREMS studies' platform can apply to the EMSP Secretariat in Brussels, on the basis of access agreements and regulations developed by the EUREMS Steering Committee.

What stage has EUREMS reached?

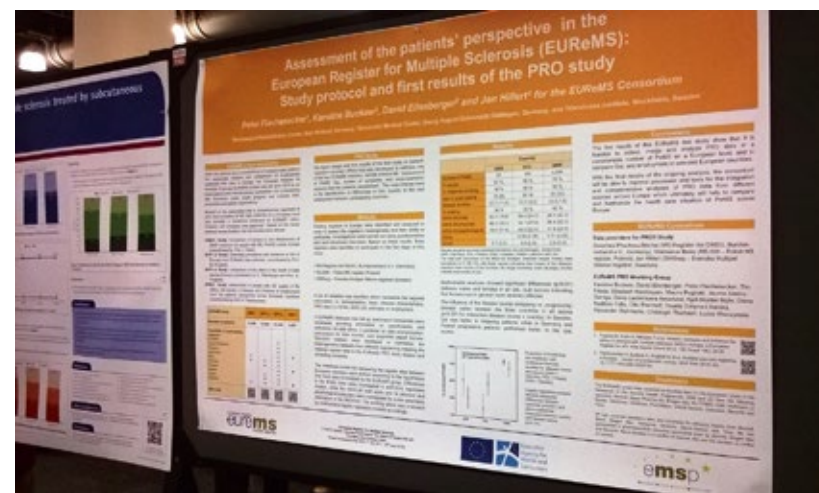
Key deliverables

In December 2011, the EUREMS Consensus Statement, presenting the mission, vision and overall strategy, was adopted by the EUREMS Consortium. Since then, the key data that need to be collected within EUREMS, of interest to scientists and those with MS, have been identified and included in "a core data set". The EUREMS charter has been developed to enable the partners and data providers involved in the project to give their informed consent. From the 18 registers participating in the initial survey, work was carried out with 13 to harmonise and standardise pooled data according to an agreed protocol.

Once this first data pooling exercise was complete, four test studies were launched, each involving researchers across Europe. The aim of these studies is both to test usability of the database, and to address EUREMS' objectives related to analysis of specific topics of interest and concern.

The four EUREMS studies

The studies are nearing completion and their results will be reported in scientific publications, on the EUREMS website and other fora. Poster presentations on studies 1 and 4 were made during the Joint Congress of America's and Europe's Committees for Treatment and Research in Multiple Sclerosis (ACTRIMS-ECTRIMS) in Boston, USA, in September 2014.



EUREMS poster exhibited at ACTRIMS-ECTRIMS 2014, in Boston, USA

Study 1

Change over time and place (EPI-1-d)

Study 1 aims to find out the extent to which MS may be changing over time and place by asking:

- How many new MS cases are diagnosed per year in Europe, and of what sex and age are those affected?
- Are there differences in the frequency of MS/MS diagnoses across the different countries studied?
- Has the frequency of MS increased over the last twenty years?
- Has any such increase occurred equally in men and women?
- What is the age at which MS begins in men and women?
- Has the age at which MS starts changed over time?
- How long is the current delay between the start of MS and its diagnosis?
- Has this delay changed over time?

“

Comparing data from different countries will be of great benefit to MS patients. EUREMS is important because it facilitates the data analysis of the MS registers throughout Europe, so it goes beyond the national borders. It is a comprehensive analysis.

It is also important because we can share information with our partners. There is a personal side to this as well: you learn about your partners, what are their experiences and what are their problems, and you learn to trust each other.

By working together we can find technical and organisational solutions. The comparisons of different regions and different countries will in the end be a benefit for the patients – because all data collections that have been done before always covered only specific regions and had certain restrictions. It will be a great benefit.”

Karoline Buckow (co-lead, Study 1),
IT Professional, Department of Information Technology
Medical University Centre, Göttingen, Germany

Study 2

Effect of month of birth (EPI-1-s)

Study 2 aims to find out more about any possible effect of month of birth on MS rates across Europe by testing whether:

- The risk of MS is greatest among those born in May, lowest among those born in November;
- The trend for increased and decreased risk relative to month of birth is similar across different countries/sub-areas;
- The effect of the minimum and maximum relative risk according to month of birth is stronger in some regions of Europe than others.

MS databases and registers participating in the four EUREMS studies, 2011-2014

	NAME	COUNTRY	DMD1	EP11-D	EP11-S	PRO1
1	MS register of Croatia	Croatia			+	
2	IMPULS MS Register	Czech Republic			+	
3	The Danish MS Registry	Denmark			(+)	
4	Tampere University Hospital Register	Finland		+	+	
5	Multiple Sklerose Register der DMSG	Germany	+		+	+
6	Italian MS Database Network	Italy	+	+	+	
7	MS register of Liguria and Tuscany	Italy Liguria & Tuscany			+	
8	Norwegian MS-Registry and Bio bank	Norway		+	+	
9	Polish MS register (REJSM)	Poland			+	+
10	MS Register of Serbia	Serbia		+	+	
11	Catalonian MS Register	Spain		+	+	
12	Svenska Multipel Skleros registret (SMSreg)	Sweden	+	+	+	+
13	UK MS Register	UK		+	+	+

Study 3 Disease modifying drugs (DMD-1)





Study 3 aims to compare the access to and effectiveness of disease-modifying drugs (DMDs) across Europe, and assess whether the effectiveness of these treatments varies across different European countries. It will ask:

- If the use of DMDs is influenced by factors such as age, sex, age of onset of MS, age at diagnosis, disease course, age at first treatment, level of disability when treatment starts
- Does the influence of these factors differ between countries?

The study also aims to assess:

- The effect of DMDs over the long-term
- The effect of different types of DMDs
- Whether early treatment leads to better outcomes
- The extent to which the impact of treatment is influenced by the factors listed above, and whether this varies between countries.

Countries and patients participating in EUReMS

EUReMS study	DMD1	EPI1 -d	EPI1 -s	PRO1
Number of patients	15.788	13.004	61.848	4507
Countries of participating registers				
Croatia			■	
Czech Republic			■	
Finland		■	■	
Germany	■		■	■
Italy	■	■	■	
Norway			■	
Poland			■	■
Serbia		■	■	
Spain		■	■	
Sweden	■	■	■	■
QR-Code				

Study 4 Patients' perspectives (PRO-1)

Study 4 assesses patients' own perspectives on their quality of life, the impact of MS on this and on their ability to work. There is evidence that quality of life of patients with MS differs across European countries and that the use of DMDs also varies by country. These factors may be related, and in turn linked to geographic variation in the employment status of people with MS across Europe and the impact and influence of this on quality of life.

This study will further explore these beliefs, to see whether:

- Quality of life of MS patients differs between European countries (depending on the level of health-care available), and whether factors specific to certain groups of people and/or disease characteristics account for any difference
- The employment status of MS patients differs between countries in Europe, and whether demographic factors and/or disease characteristics account for any difference
- The data provided by the MS Barometer accurately reflects the true picture of health and care in different European countries.

“

The main goal for EUReMS is to have a data collection on a European level – we already have MS registers in Germany, UK, Norway or Sweden but this information is not combined. We have to combine it and compare the data. The MS Barometer shows that there is a huge disparity across Europe – but this is only an estimate coming from the national MS societies. But EUReMS is a tool to collect data directly from the patients and to have a more scientific approach.”

Peter Flachenecker (Co-lead study 4),
Neurologist, Medical Director of the
Quellenhof Neurological Rehabilitation Centre
in Bad Wildbad, Germany

Where next for EUREMS?

The first phase of EUREMS under the current Health Programme is now complete. The EUREMS study platform has been successfully established and validated, including testing and validation of the EUREMS Charter, the legal agreements, collaborations and methodology development.

EMSP will now build on the knowledge, experience and momentum achieved between 2011 and 2014 to encourage a growing number of MS registers across Europe to adopt EUREMS protocols of data pooling and analysis. This will address the post-2014 aim of using the newly created data infrastructure in collaboration with existing and emerging registers, eventually creating a pan-European data pool to better assess the situation of people with MS.

All EUREMS stakeholders are committed to ensuring that the knowledge and momentum gained during the first three years of the project are sustained and that the project continues to grow and develop for the benefit of all concerned, and, in particular, for the tens of thousands of people affected by MS in Europe and beyond. There is also enthusiasm within the EUREMS team to promote the concept of databases of this sort among those working in disease areas other than MS, where a similar approach to data collection, handling and analysis could reap rewards for the patient community.

To ensure future development of EUREMS beyond the current funding, the EUREMS Consortium has also been exploring opportunities for support under EU and industry programmes.

“ There is also enthusiasm within the EUREMS team to promote the concept of databases of this sort among those working in disease areas other than MS, where a similar approach to data collection, handling and analysis could reap rewards for the patient community.”

Funding and managing the next phase of EUREMS

There are several major international MS data register projects at varying stages of development and activity. During the last three years, EUREMS has made substantial progress in this field and can make a significant contribution to future developments, with a particular emphasis on keeping patient-reported outcomes and patient-centered health-care at the top of the agenda.

However, it is also clear that no single data register project can, or should try to, supplant existing projects.

The concept that would appear to have the best chance of success would be to establish a collaborative grouping of all key stakeholders, led by a Joint Coordinating Centre which would serve the combined purposes of:

- 1 Bringing together and coordinating the contributing MS data register programmes
- 2 Designing, formulating and leading a combined expression of interest/full proposal for funding under an anticipated call under the Innovative Medicines Initiative (IMI) expected to come late 2014
- 3 Managing and coordinating the (combined) joint programme in the event of a successful application
- 4 Maximising the pooled expertise, data and health intelligence housed in current and future European and international MS data registers

EMSP is not equipped to coordinate the next stage of EUREMS alone, but is exploring the possibility of acting as an independent broker for a joint IMI bid bringing together groups and individuals with interest in the pooling of MS patient data on a European or even global level.

The potential for competitiveness among existing registers suggests it may not always be easy to steer the project. However, it seems desirable to make a joint project application, for work led by committed and experienced people from the patient and scientific communities, helped by a wider Steering Committee of the MS players currently involved in EUREMS and other key stakeholders. This would allow future work to significantly improve the lives of those affected by MS, as well as contribute to the understanding that can help to create a world free of the condition.

Appendix 1:

EUReMS project partners

Association of MS Societies of Croatia

AMSSC is a non-profit social organisation for people with MS, their families and other citizens who support the fight against multiple sclerosis – translated in measures prompting the treatment, rehabilitation, research and protection of people with MS and related diseases.

www.sdmsk.org

Department of Clinical and Experimental Medicine, University of Sassari, Italy

The Referral Centre for Diagnosis and Treatment of MS in Sardinia, insular Italy (a region with exceptionally high MS frequency) has a long-standing experience in the descriptive and analytic epidemiology of MS and other neurodegenerative diseases; projects on e-Health with special regards to medical records; multinational collaborative research in MS at European level and worldwide; data set of clinical and demographic variables on MS cases for northern Sardinia, dating back 40 years.

www.uniss.it

German MS Society

The DMSG, founded in 1952, is the official national MS society of Germany, with 16 regional branches. DMSG actively represents the interests of around 130,000 people living with MS in Germany. It initiates and finances research programmes on MS, coordinates research projects and prepares and disseminates useful information. DMSG is running a German national MS register and also participated in the MS-ID project.

www.dmsg.de

Karolinska Institutet, Medical University, Sweden

Karolinska Institutet is one of the world's leading medical universities, located in Solna, Sweden. Our mission is to contribute to the improvement of human health through research and education. Karolinska Institutet accounts for over 40% of the medical academic research conducted in Sweden and offers the country's broadest range of education in medicine and health sciences. Since 1901, the Nobel Assembly at Karolinska Institutet has selected the Nobel laureates in Physiology or Medicine.

www.ki.se

MS Centre of Catalonia – Cemcat

Fundació Institut de Recerca Hospital Universitari Vall d'Hebron (FIRHUVH) represents the MS Centre of Catalonia (CEM-Cat), a leading European Center for treatment, research and training in the field of MS. On the clinical side, it cares for more than 4,000 MS patients. It also trains MS neurologists from Europe and abroad. FIRHUVH has participated in the MS-ID project and is now part of the MS Register of Catalonia.

www.cem-cat.org

Multiple Sclerosis Society, UK

The MS Society in UK was founded 1953. Today, the Society has 38,000 members and branches in every part of the country. Its mission is to enable everyone affected by MS to live life to their full potential and secure the care and support they need, until we ultimately find a cure.

www.mssociety.org

Neurological Rehabilitation Center Quellenhof, Germany

The rehabilitation center "Quellenhof", based in the German city of Bad Wildbad, is a neurological clinic which focuses on multiple sclerosis and stroke disease. Quellenhof receives patients in the early rehabilitation phase.

www.quellenhof.de

Polish MS Society

PTSR is the national non-governmental organisation for people with MS, their families and friends. Founded in 1990, PTSR obtained a status of "public benefit" organisation in 2004. PTSR has about 6,000 members all over the country and cooperates with local organisations engaged in helping disabled people as well as associations of people living with MS in Europe and other continents. PTSR was part of the MS-ID project.

www.ptsr.org.pl

Romanian MS Society

The SSMR is a non-profit organisation representing people with MS at national level. It has developed collaborating and partnership relations with public authorities, scientists and other patients' organisations. SSMR has been part of the MS-ID project.

www.ssmromania.ro

University of Bergen, Norway

The UiB is represented by the Norwegian Multiple Sclerosis Registry and Biobank, Dept. of Neurology, Haukeland University Hospital. The Registry was established in 2001, and includes about 4,500 patients that account for around 65% of all MS patients in Norway.

www.uib.no/en/node/36362

University Medical Center Göttingen, Germany

The “University Medical Center Göttingen” represents the Georg-August-University in Germany. The aim of this integration model is the close cooperation of the medical school and university hospital in patient care, teaching and research. Since 2003, it belongs to the University Medical Center Göttingen Public Law Foundation.

www.uni-goettingen.de

Appendix 2: Reference list

Publications

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P Flachenecker, et al.,

Development and pilot phase of a European MS Register, 2010

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K-M Myhr, MD, N Grytten Torkildsen, PhD, **Survival in MS: Current Insights from International Registries and Databases**, Supplement to the International Journal of MS Care, Sept. 2012, Vol. 14 Suppl. 4, p.5-10

P Flachenecker, et al., **Multiple sclerosis registries in Europe – results of a systematic survey**, Multiple Sclerosis Journal, published online 28 April 2014, DOI: 10.1177/1352458514528760, by SAGE

Scientific posters

T Schyns-Liharska, M Pugliatti, P Flachenecker, D Pitschnau-Michel, J Hillert, T Friede and O Rienhoff, on behalf of the EUREMS Consortium:

European Register For Multiple Sclerosis (EUREMS) – A tool to assess, compare and enhance the status of people with MS throughout the European Union, 2011

P Flachenecker, K Buckow, M Pugliatti, for the EUREMS Consortium: **Multiple sclerosis registries in Europe – results of a systematic survey**, 2013

P Flachenecker, K Buckow, D Ellenberger and J Hillert, for the EUREMS Consortium: **Assessment of the patients’ perspective in the European Register for Multiple Sclerosis (EUREMS): Study protocol and first results of the PRO study**, 2014

M Pugliatti, et al. for the EUREMS Consortium: **Prevalence and incidence of multiple sclerosis estimated in European Register for Multiple Sclerosis (EUREMS): Study protocol of the Epi-1d study**

website: www.eurems.eu



Assessment of the patients' perspective in the European Register for Multiple Sclerosis (EUReMS): Study protocol and first results of the PRO study

Peter Flachenecker¹, Karolina Bockow², David Ellenberger³ and Jan Hillert⁴ for the EUReMS Consortium

¹University Hospital Bonn, Bonn, Germany; ²University Hospital Cologne, Cologne, Germany; ³University Hospital Göttingen, Göttingen, Germany; ⁴Karolinska Institute, Stockholm, Sweden

Objectives: The main aim of the study is to assess the patients' perspective in the EUReMS PRO study. The study protocol and first results of the PRO study are presented.

Methods: The study protocol and first results of the PRO study are presented.

Results: The study protocol and first results of the PRO study are presented.

Question	Yes (%)	No (%)
Do you have a good understanding of your condition?	75	25
Do you have a good understanding of the treatment options?	65	35
Do you have a good understanding of the risks and benefits of the treatment options?	55	45
Do you have a good understanding of the costs of the treatment options?	45	55
Do you have a good understanding of the side effects of the treatment options?	35	65
Do you have a good understanding of the long-term effects of the treatment options?	25	75

Conclusions: The first results of the EUReMS PRO study show that it is feasible to collect, manage and analyse PRO data in a systematic manner in PMS on a European level, and to establish a patient-centred European consortium.

EUReMS Consortium: Data providers for PRO Study: Bernhard Flachenecker (MS Register der DMSG, Göttingen, Germany), Waldemar Kiese (MS Register, Poland), Jan Hillert (Stockholm, Sweden), Multiple Sclerosis Register, Sweden.

EUReMS PRO Working Group: Karolina Bockow, David Ellenberger, Peter Flachenecker, Tim Fricke, Elisavinda Gallegos, Maria Fogel, Jürgen Gassner, Corina Lammert, Annette, Katharina Meyer, Diana Rappin, Otto Rasmussen, David Schöne-Hornik, Alexander Schöningh, Christoph Thumler, Julia Wenzel.

References: 1. Flachenecker P, Hillert J, Bockow K, et al. (2014) Assessment of the patients' perspective in the European Register for Multiple Sclerosis (EUReMS): Study protocol and first results of the PRO study. *Acta Neurologica Scandinavica*, 130, 1-10.

Keywords: Multiple Sclerosis, Patient Perspective, PRO Study, EUReMS Consortium.

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Credits



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As an independent non-profit making organisation, the EMSP brings these partners together under a strict code of conduct which ensures independence and transparency.

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EMSP represents more than 700,000 people living with MS in Europe and has a network of 39 member societies in 34 European countries. En route to our ultimate vision of a world without MS, we aim to improve quality of life as well as access to treatment, care and employment and we work to ensure that people with MS have a real voice in determining their own priorities – www.emsp.org.

The EUReMS project (2011–2014) enables MS-data sharing at European level. It focuses on epidemiology, long-term therapy outcome, healthcare and quality of life of people with multiple sclerosis.

europa register
eurems
project of european multiple sclerosis platform

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