Multiple sclerosis registries in Europe – results of a systematic survey

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Background

The EUReMS (European Register for Multiple Sclerosis) project was designed as a platform aimed to facilitate harmonized merging and collection of existing data from MS registries and databases, as well as comprehensive analyses and comparisons across European populations[1]. For this purpose, identification of MS registries and databases that are currently in use in Europe as well as a detailed knowledge of their content and structure is important.

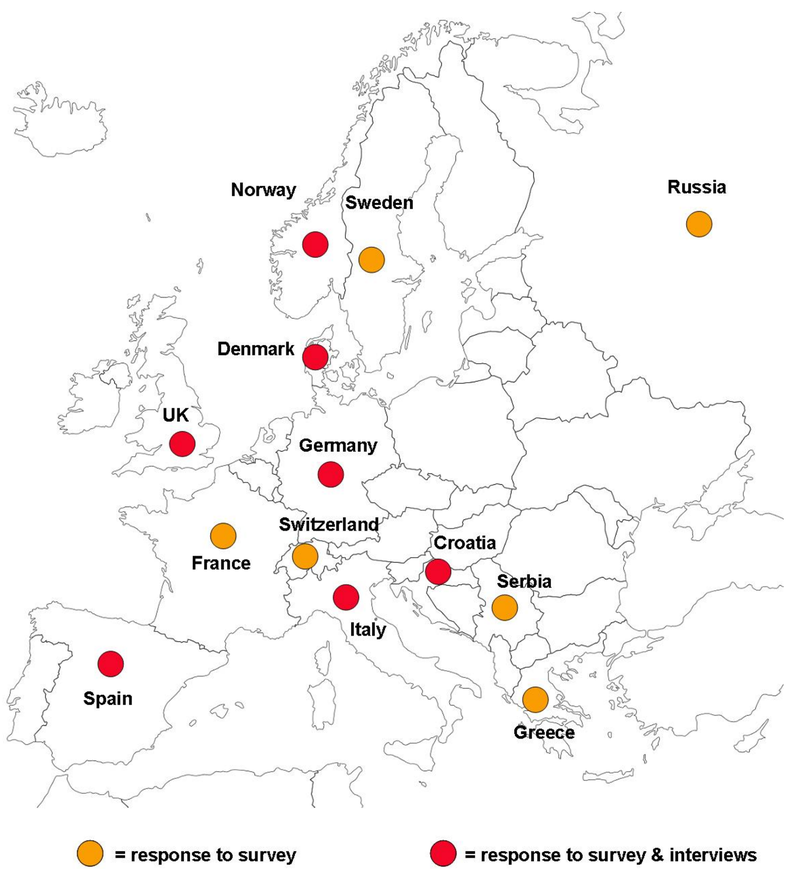
In this study, we report the results of a survey on MS registries in Europe that was performed between January and April 2012 as part of the EUReMS project.

Identification of MS registries and databases

The existing registries and databases in Europe were identified by recent reviews[2], records from the EMSP (MS Barometer)[3], PubMed search, checking of publications and abstracts, and contacting 33 national MS societies in Europe.

With this approach

- 20 registries were identified
- 13 registries responded to the standardized questionnaire
- 7 registries took part in the interviews:



Development and content of the standardized questionnaire

The standardized questionnaire was developed and circulated between members of the steering committee. After reaching consensus, it was sent to the registry leaders. The following information was obtained:

- Organizational structure
- Background/purposes of the registry
- Inclusion criteria for centers and patients
- Documentation process
- Data that are collected
- Quality control
- Governance
- Current state of the registry (updated to December 31th, 2011)

Results of the standardized questionnaire

The main purposes of the 13 registries were epidemiological research (n=10), health care research (n=9), long-term therapy research (n=8), and support/basis for clinical trials (n=8). One registry (Spain/Catalunya) was specifically designed for patients with clinically isolated syndromes (CIS).

There is large heterogeneity in organizations running the registries, duration of data collection, number of centers and patients included and follow-up:

Country	Institution	Start	# of pts	# of ctrs	follow-up
Croatia	MS society	2007	2,477	10/21	annually
Denmark	Danish MS registry	1948/1996	12,500	16	no
France	EDMUS Coord. Center	1976	~ 40,000		yes
Germany	MS society	2001	~ 30,000	~ 150	no
Greece	MS society	2011	3,500		yes
Italy	Network of MS centers	2001	~ 20,000	40	bi-annually
Norway	University of Bergen	1998	5,100	20	yes
Russia	Healthcare ministry	2006	21,500		unknown
Serbia	MS society	2000	3,500		no
Spain	Vall d'Hebron university	2008	616	~ 20	CIS pts only
Sweden	Swedish MS registry	1997	12,900		yes
Switzerland	University of Basel	2012	270	8	bi-annually
UK	University of Swansea	2009	8,300	5 (pilot)	yes

All registries indicated that they collect personal data (date of birth and gender) and basic disease data (i.e. disease course, time of disease onset and diagnosis, symptoms at onset and diagnostic accuracy). Data on disease-modifying treatment are documented by 11 registries, whereas symptomatic treatment is recorded in 7 registries, mainly as optional. Socio-economic data (employment, care/support due to MS) are collected in 9 and 7 registries, respectively.

Only 6 registries included patient-reported outcomes:

Country	HRQoL	Depression	Fatigue	Disability
Croatia	-	not specified	-	-
Denmark	-	-	-	-
France	not specified	not specified	not specified	-
Germany	-	-	-	-
Greece	-	-	-	-
Italy	FAMS/MSQoL-54	BDI/Hamilton	FSS	-
Norway	MSIS-29/EQ5d	-	FSS	
Russia	-	-	-	PDDS
Serbia	-	-	-	-
Spain	-	-	-	-
Sweden	MSIS-29/EQ5d	-	-	-
Switzerland	-	-	-	-
UK	MSIS-29/EQ5d	HADS	-	-

Conclusions

The present survey on MS registries in Europe shows that (1) national MS registries exist in many European countries, (2) these registries differ widely from country to country, and (3) despite this heterogeneity, a considerable number of registries share common objectives. Patient-reported outcomes are underrepresented in the existing registries but need to be considered in future basic sets.

The detailed information obtained in this study is a prerequisite to evaluate comparability of existing registry data. These results will serve as a basis for several studies conducted within the framework of EUReMS.

References

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european register euremms multiple sclerosis

European Register For Multiple Sclerosis
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