Scientific projects

The SMSreg has been used as a source of data for over 180 scientific publications. In the recent years more and more researchers are using data for population-based analyses on the national level. Some of the major ongoing projects are:

1. RIFUND, a randomised prospective comparison of rituximab and dimethyl fumarate
2. COMBAT MS, a prospective and retrospective comparison of all used DMTs.
3. IMSE, a prospective safety and efficacy assessment of each newly registered MS DMT since 2006.
4. Post Authorization Safety Studies of newly launched DMTs so far including Oral cladribine and ocrelizumab.
5. Multiple MS, EU supported multicenter study utilizing large scale analyses omics data in the context of clinical information.
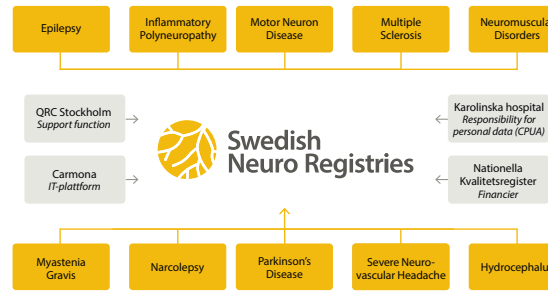
In addition, many studies of epidemiology, pharmaco-epidemiology and socioeconomy are ongoing.

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Collaborators

Swedish Neuro Registries
Multiple Sclerosis

The Swedish Multiple Sclerosis Registry – SMSreg

For quality of care and research

Summary

1. The SMSreg is a voluntary clinical MS registry with > 20,000 MS patients

2. Its clinical usefulness has resulted in high population coverage and data density

3. The SMSreg gives data back to clinicians and patients

4. The SMS is a basis for major retrospective and prospective research projects
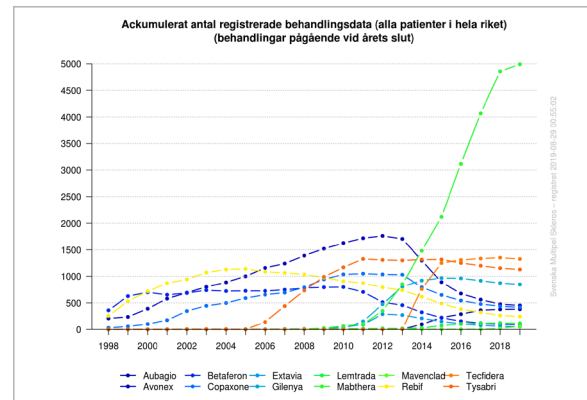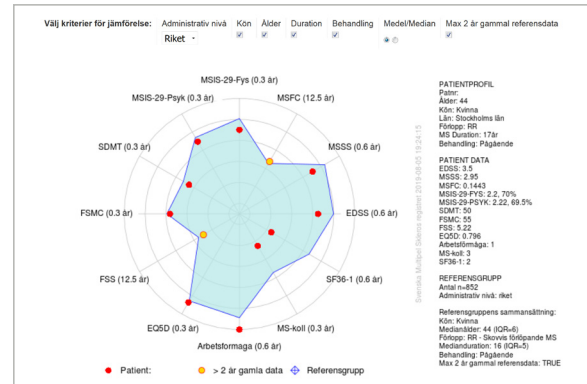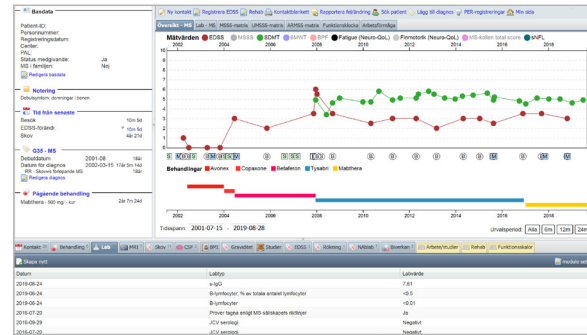
This is SMSreg

The SMSreg was launched in 2000. It has an internet-based IT interface, COMPOS, designed as a decision support tool, which is used in all Swedish and Danish MS clinics.

Clinical tool

COMPOS offers a summary of key elements of the patient's medical history in graphic form available one click away in the electronic health record. For a dozen outcome measures, the patient's latest score is put in perspective by being compared to the results of matching reference group of MS patients.

Variables

The SMSreg focuses on a minimal data set of base-line variables and limited number of follow-up variables expected to be collected at least annually. In addition, for patients participating in the nationwide safety protocol Immuno-modulation in MS Epidemiology (IMSE), which includes all disease modifying drugs except interferon betas and glatiramer, additional assessments of cognition, i.e. SDMT, and health related quality of life, i.e. MSIS-29 and EQ5D, are included. Number of MRI lesions are recorded in a semi-quantitative way.

Patient-reported outcome measures (PROMs)

The SMSreg contains several patient reported outcomes reflecting national guidelines but also some local preferences. Most data points are found for MSIS-29 and EQ5D. We are also implementing Neuro-QoL with a computer assisted function – CAT, and presently the fatigue domain is implemented with five more to follow shortly.

Cognitive testing of processing speed

Since 10 years, the symbol digit modalities test (SDMT) has been used as a safety assessment in MS treatment in Sweden, which has resulted in its implementation at a larger scale in Swedish MS care. To date, over 60,000 SDMT scores have been recorded in altogether 10,251 patients.

Data return

Another motivating property of The SMSreg is to give reporting centers excellent access to its own data and results. We do this mainly in three ways:

1. The possibility of each center to export all its data in the Excel format at any time for further analysis

2. A multitude of different reports in the form of tables, graphs and lists, many of which can be customized according to the user's preferences, including the so called Visualization and Analysis platform – VAP (http://msvap.demo.carmona.se).

3. A quarterly report to participating centers showing results of nationally defined quality of care indicators for use in the development of care.

	N=	EDSS	Attacks	DMT episodes	DMT now	Follow- up yrs	MRI	CSF	MSIS-29	SDMT	EQ5D
All	19,754	117,223	30,314	34,741	10,739	11,2	57,966	17,57	44,752	61,197	30,827
RRMS	11,564	71,247	20,423	24,698	8,985	8,7	45,041	9,771	36,745	50,49	26,166
SPMS	5,578	36,478	8,870	8,202	1,242	18,3	9,932	5,778	6,017	8,952	3,606
PPMS	1,695	6,638	316	948	236	11,4	1,652	1,431	629	607	507