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Swedish MS registry: an overview

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Disclosure Statement of Financial Interest

I, Omid Beiki, DO NOT have a financial interest or arrangement with one or more organizations that could be perceived as a real or apparent conflict of interest in the context of the subject of this presentation.

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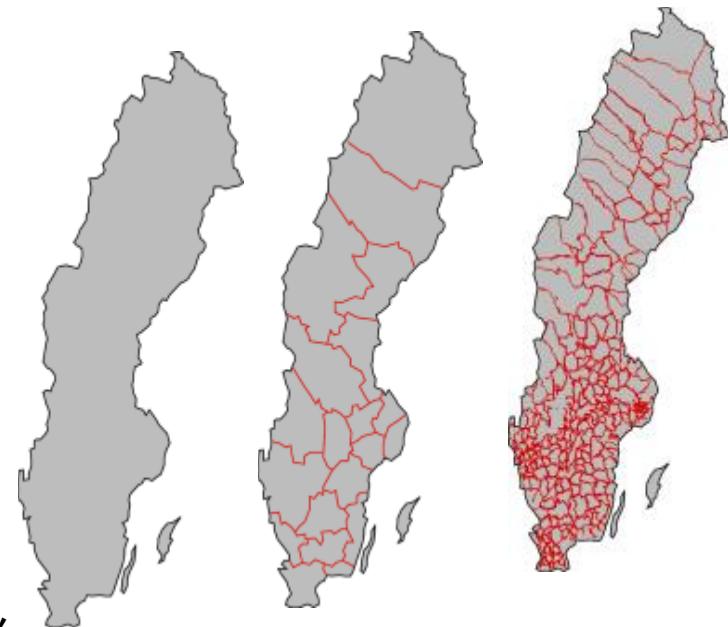
Outline

1. Swedish health care system
2. Swedish population based registration
3. Swedish quality registers
4. Swedish MS register

Decentralized health care

Equal access to health care services for everyone

- **Public funded system with shared responsibility between national government and local authorities**
- **National level legislation, monitoring and education/training**
- **County councils and regions (20)** healthcare, but also regional development and support to cultural activities and public transport
- **Municipalities (290)** social services; care of elderly and disabled people, schools and school health care, spatial planning and building, health and environmental protection, rescue services, order and security and lots more



National initiative builds on close cooperation

Swedish Association of Local Authorities and Regions (SALAR) close agreements with the national government to improve the quality of care nationwide. These national initiatives builds on consensus and close cooperation at all levels, takes advantage of everyone's skills and optimises quality and benefits for the patients.

Examples of initiatives:
Patient Safety
Cancer care
Care of elderly
Psychiatric care
National Quality Registries



Swedish population register and PIN

Total Population register

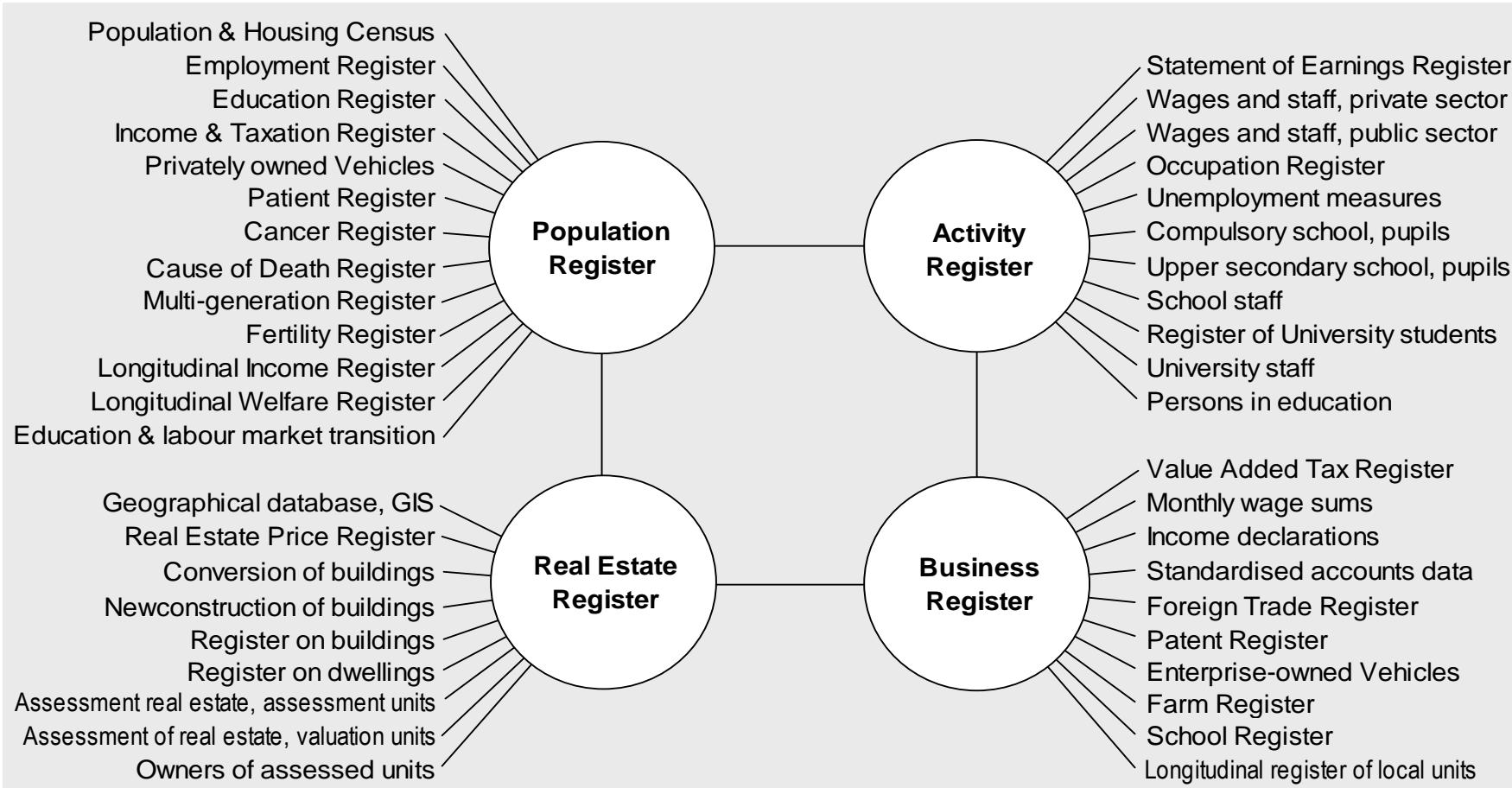
The personal identity number (PIN):

- Introduced in 1947 (consisted of date of birth and a 3-digit number)
- In 1967, a check digit was added to the 3-digit Number
- Daily basis update from Swedish Tax Agency to other administrations, including Statistics Sweden
- Statistics Sweden stores all notifications with updates in a notification database



Swedish population-based registries

Chart 2.10 A system of statistical registers – registers by object type and subject field



Note: This model is not a model of Statistics Sweden's system, the model shows general possibilities.

Swedish population-based registries

- **Virtually complete coverage**
- **High validity of information**
- **Few "soft" variables**
- **Lack of clinical detail**
- **Data collected via routine systems, e.g. tax office**
- **Reporting mandatory by law**
- **Register holders are typically authorities, e.g. Statistics Sweden, National Board of Health and Welfare**

Swedish Quality registries

Vision

Quality Registries are used in an integrated and active way for continuous learning, improvement, research and management to create the best possible health and care together with the individual

- The registries contain individualized data
- Medical interventions, procedures and outcomes
- Integrated into clinical workflows and generate data in real time
- Supported by a jointly responsible organization of health care professionals, researchers and patient representatives
- Contribute to innovative eHealth services, patient-centered approaches and decision support functionalities, as well as IT development and integration
- Annually monitored and approved for financial support by an Executive Committee
- Four certification levels; 1 (highest), 2, 3 and the candidate level (lowest).

**National cancer
Registry
ROC-Regional
Oncology Centers**

Legally required

Reports from
- pathology dpt
- clinics

**Swedish Childhood
Cancer Registry**

Voluntary

Reports from
- Treating centres

Crosscheck

History of Swedish Quality Registries

- **Knee replacement registry; 1975**
- **Hip replacement registry; 1979**
- **Vascular Registry; 1987**
- **Oxygen registry; 1987**
- **Hip fracture registry; 1988**
- **Pacemaker registry; 1989**
- **Registry for coronary angioplasty; 1990**
- **Registry for active uremia care; 1990**



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Swedish Quality Registries

- "Dagmar agreement" (1990) between the government and health authorities created a framework for the all resources supporting the development and operation of the registries.
 - The National Board of Health and Welfare (Socialstyrelsen) responsible for central administration
- Financial support from SKL (Sveriges Kommuner och Landsting, SALAR Swedish Association of Local Authorities and Regions)
 - Annual budget: 20 mln kr 2003; 45,8 mln kr 2008; 189.4 mln kr 2014; 320 mln kr 2015

Swedish Quality Registries

- Legal basis
 - Regulation and General Recommendations on Quality Systems in Health Care and medical services adopted by National Board of Health and Welfare (SOSFS 1996:24)
- Quality registers as a part of the Medical Access and Result System (MARS), 1993;
 - National guidelines, clinical guidelines, patient information, statistics, classifications, publications, quality registers (<http://www.kvalitetsregister.se>)

Swedish Quality Registries 2016

108 registries covering a wide range of interventions and diseases

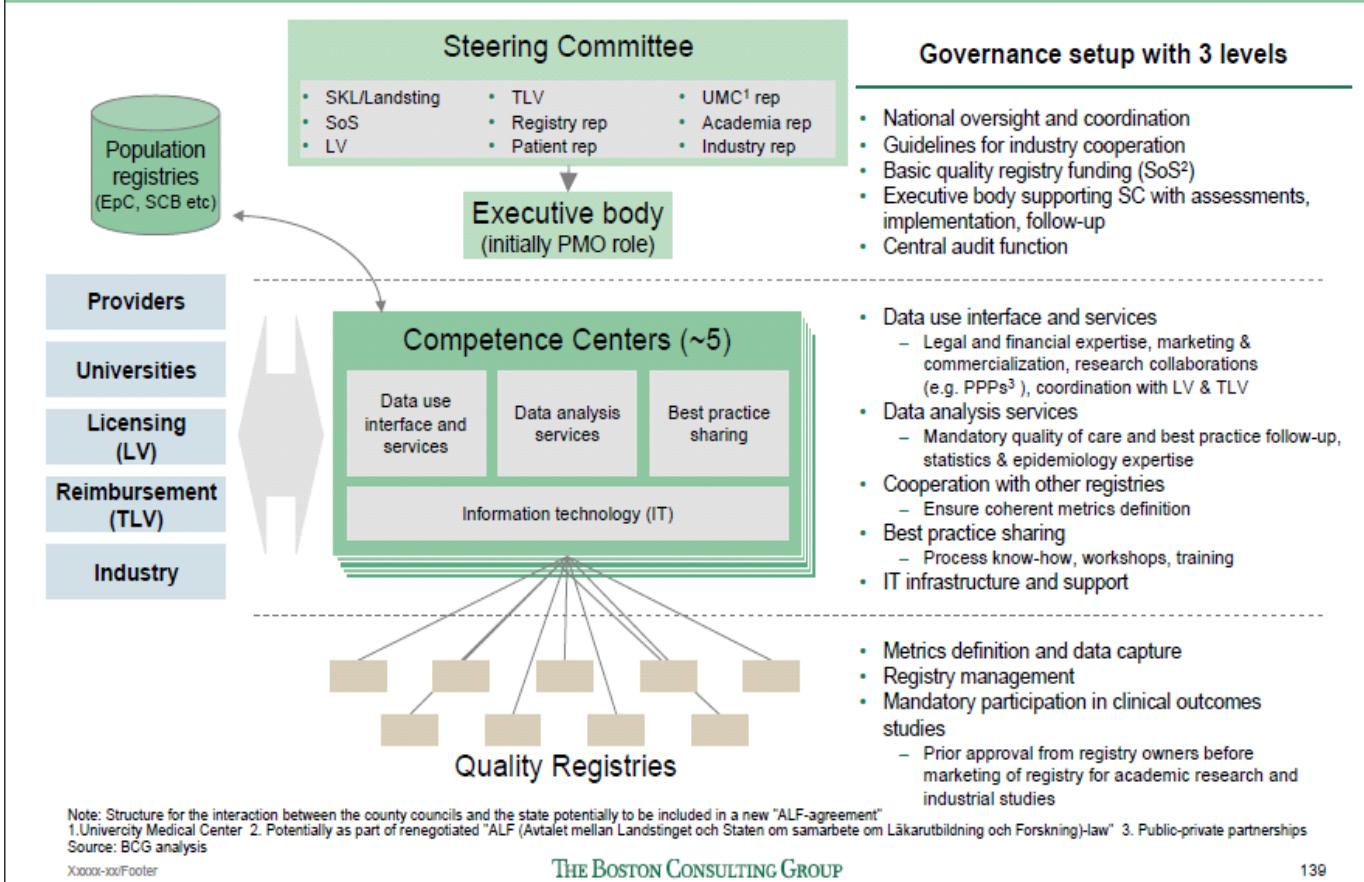
- **13** on level 1
- **29** on level 2
- **54** on level 3
- **12** candidates to become certified registries

Three different categories

1. **Interventions, hip arthroplasty operation or heart surgery**
2. **Diagnosis-based on an episode of a certain acute disease, myocardial infarction or stroke**
3. **Diagnosis-chronic diseases, diabetes or rheumatoid arthritis**

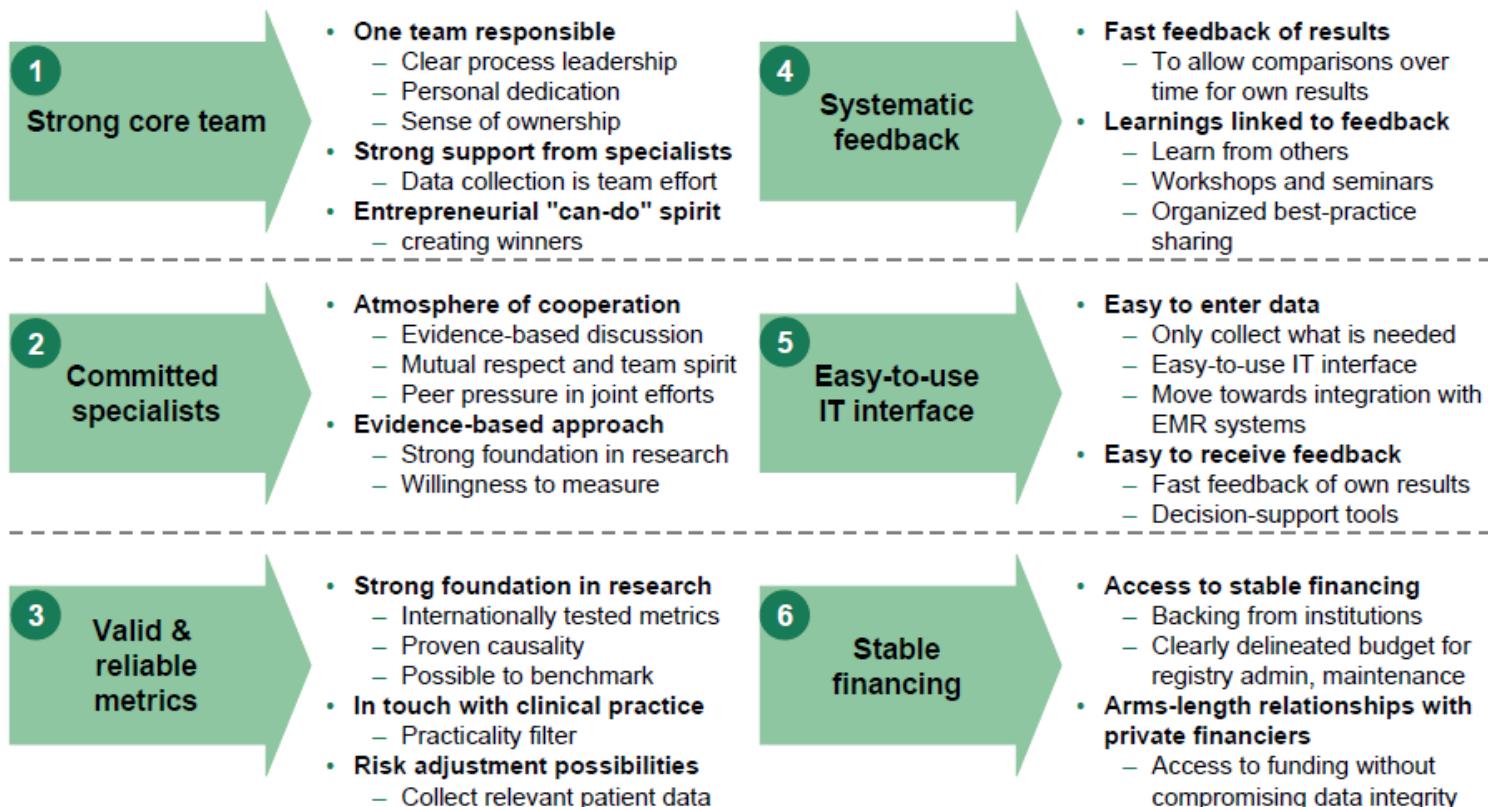
Swedish Quality Registries

Proposed governance structure strikes balance between central scale and local leadership



Swedish Quality Registries

First-class quality registry fulfill six requirements



Source: BCG analysis

Value guided healthcare_Final Documentation_Aug09.ppt

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Swedish MS Registry



Swedish MS Registry

- Start in 1996: **Database locally developed at Huddinge** (dBase and Access)
- 1997-98: **Hudmus (Huddinge Multiple Sclerosis Database)**
- 1999: **IDMS (Interactive Database for Multiple Sclerosis)**
- 1999: Commenced cooperation with **Carmona** which provided with our **SMSreg (Swedish MS Registry)**, a twin to RA Registry (SRR - SRQ)
- 1997-2001: Crucial role of **"MS-Forum"**
- 1996-2000: Meetings, travel costs etc sponsored by Hoechst Marion Rousell AB Serono Nordic AB, etc
- Since 2001: Financial support got from **Socialstyrelsen/SKL** as a part of the **Quality Register** funding's initiative (only federal funding)

Swedish MS Registry

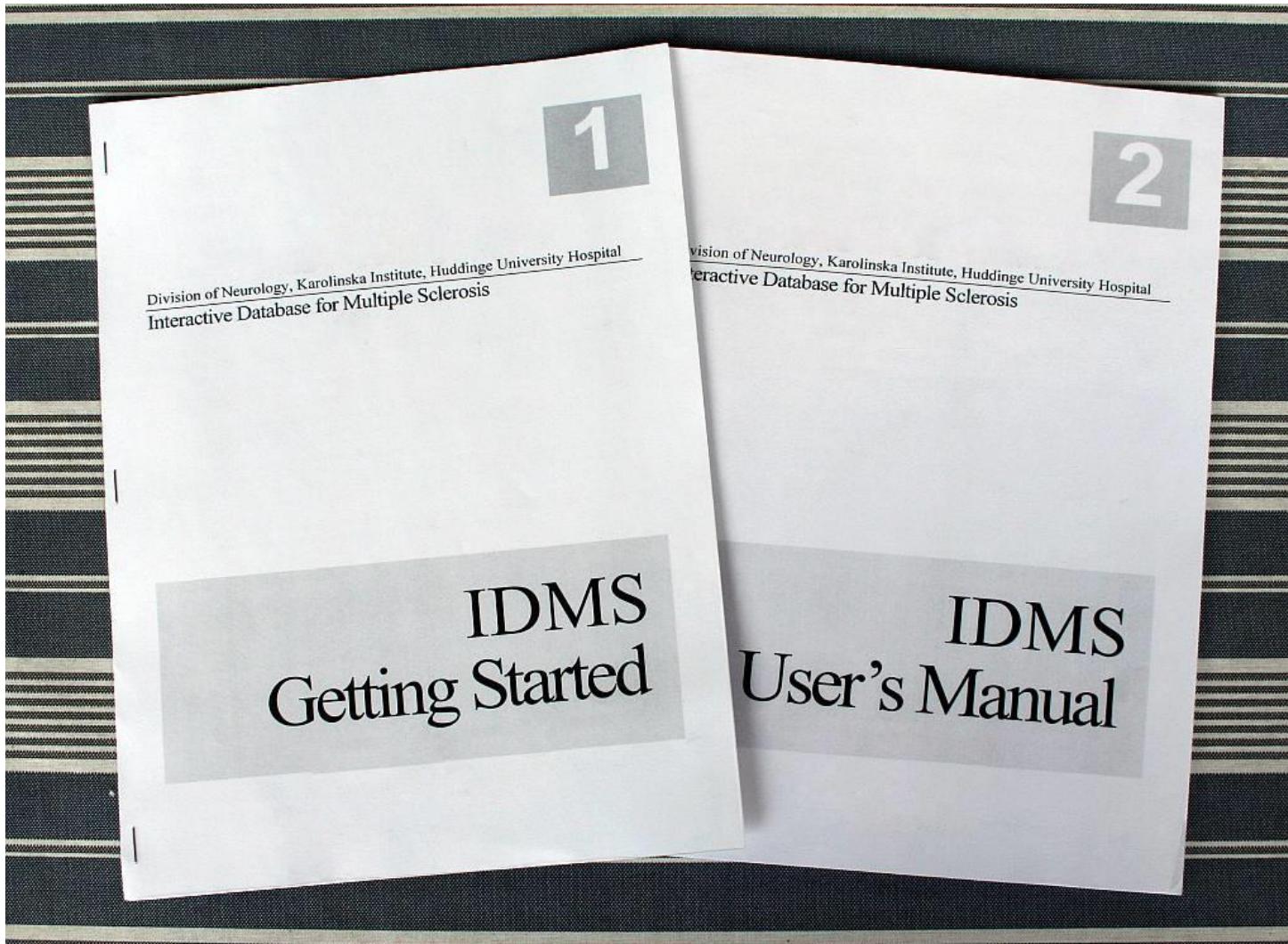
- Since 2001: **Web-based SMS-Registry**
- 2001-2006: New functions-scales, implementation of **NAB Lab**, registration of **Adverse events**
- 2007: **Monitoring of Tysabri treatment, 2nd line DMT (IMSE projects), genetics (GEMS project), environment (EIMS project)**
- 2008: Merge with **Total Population Register**, first linkage between SMS reg and EHR/EMR system **Take Care**
- 2014 **Visualization and Analysis Platform (VAP), Patients own registration (PER)**
- 2016 **One of over 100 active Quality Registers in Sweden**

Swedish MS Registry

- Research registry 1997-
- Quality registry 2001-
- ...
- Clinical tool used in daily neurological practice
2009-

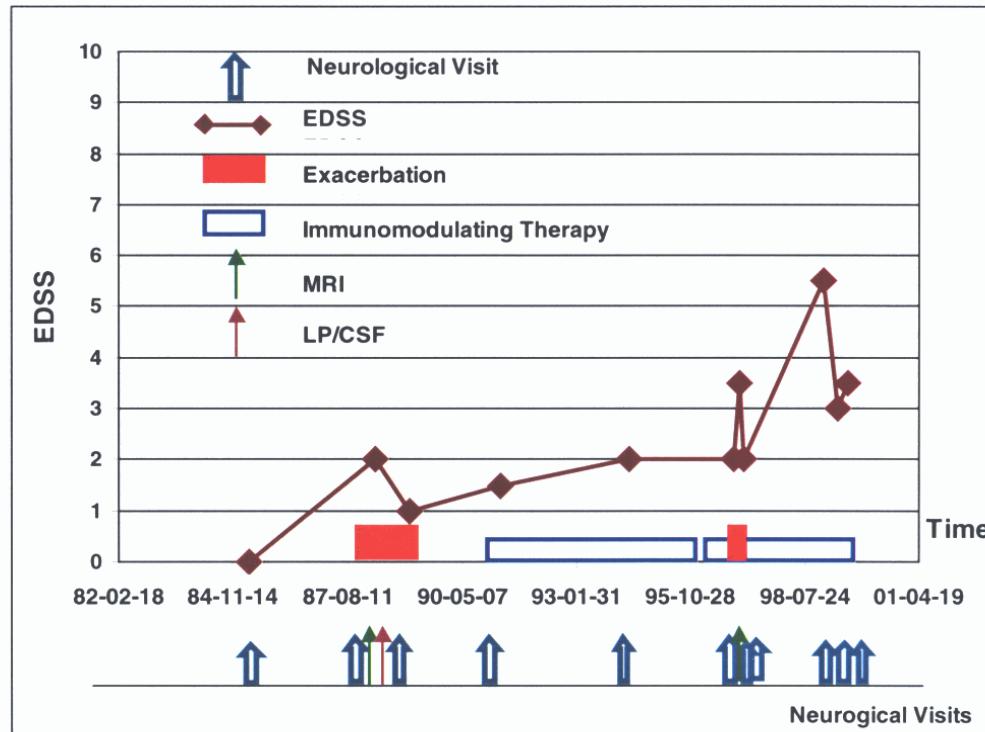
Swedish MS Registry

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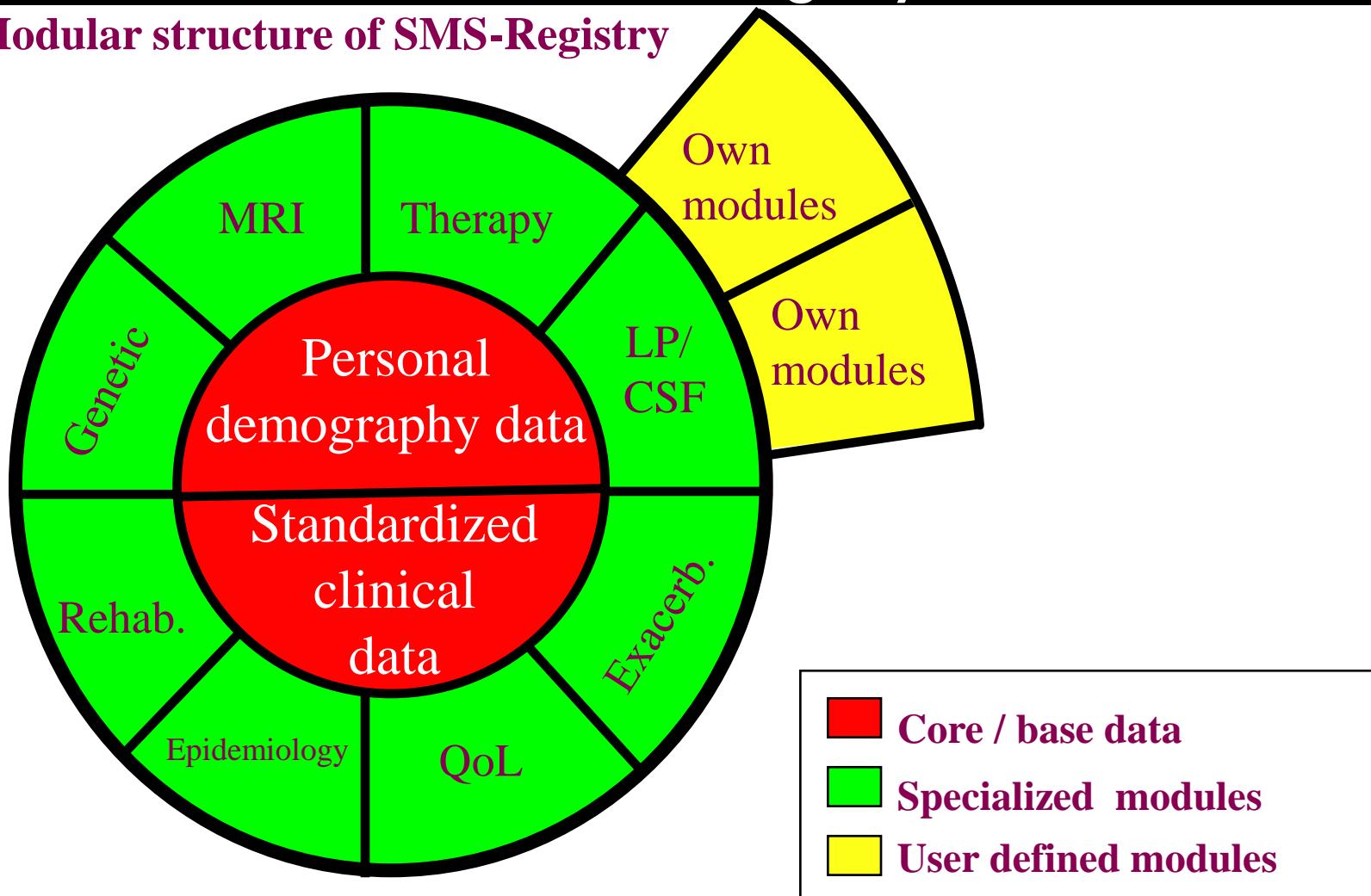
Graphical presentation of the disease course



First idea of a graphical presentation of patient's overview 1998

Swedish MS Registry

Modular structure of SMS-Registry



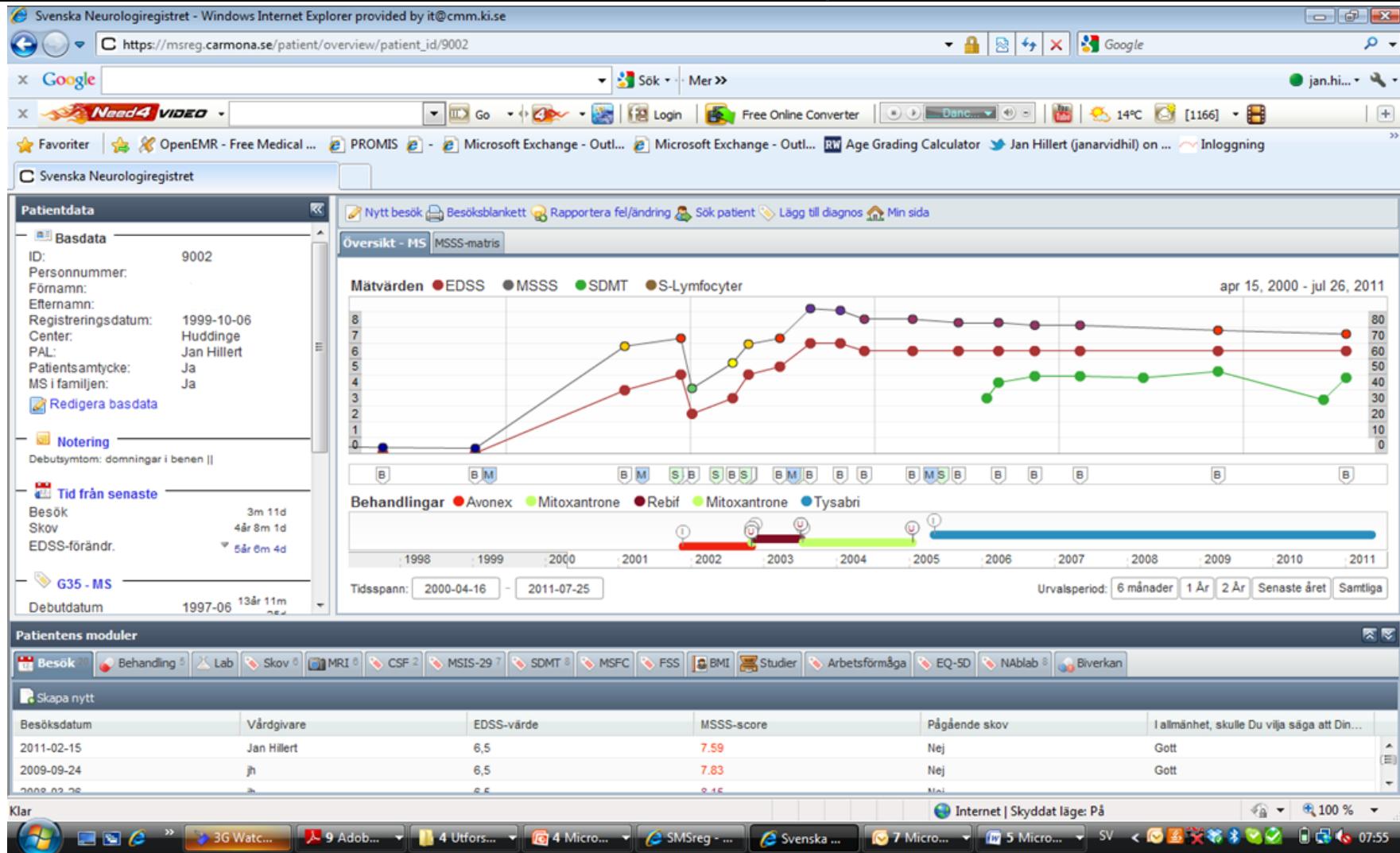
Swedish MS Registry

- 63 reporting Centers
- Over 18,300 registered MS-patients (approx. 1000 per year) ~ 82% of all prevalent cases
- 120,000 registered neurological visits 1,630 deceased
- Over 700 registered users
- ~ 15,000 accesses annual

Swedish MS Registry



Swedish MS Registry





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- **Thank you**
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