

# 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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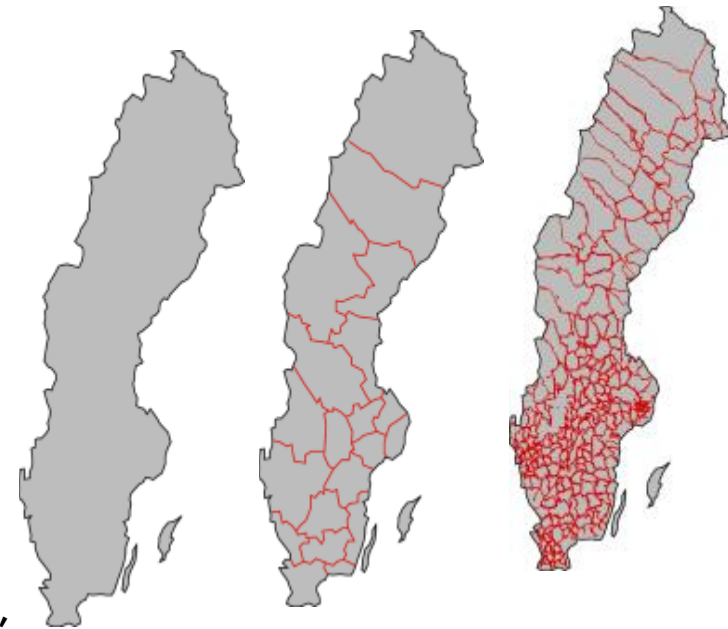
## Outline

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*

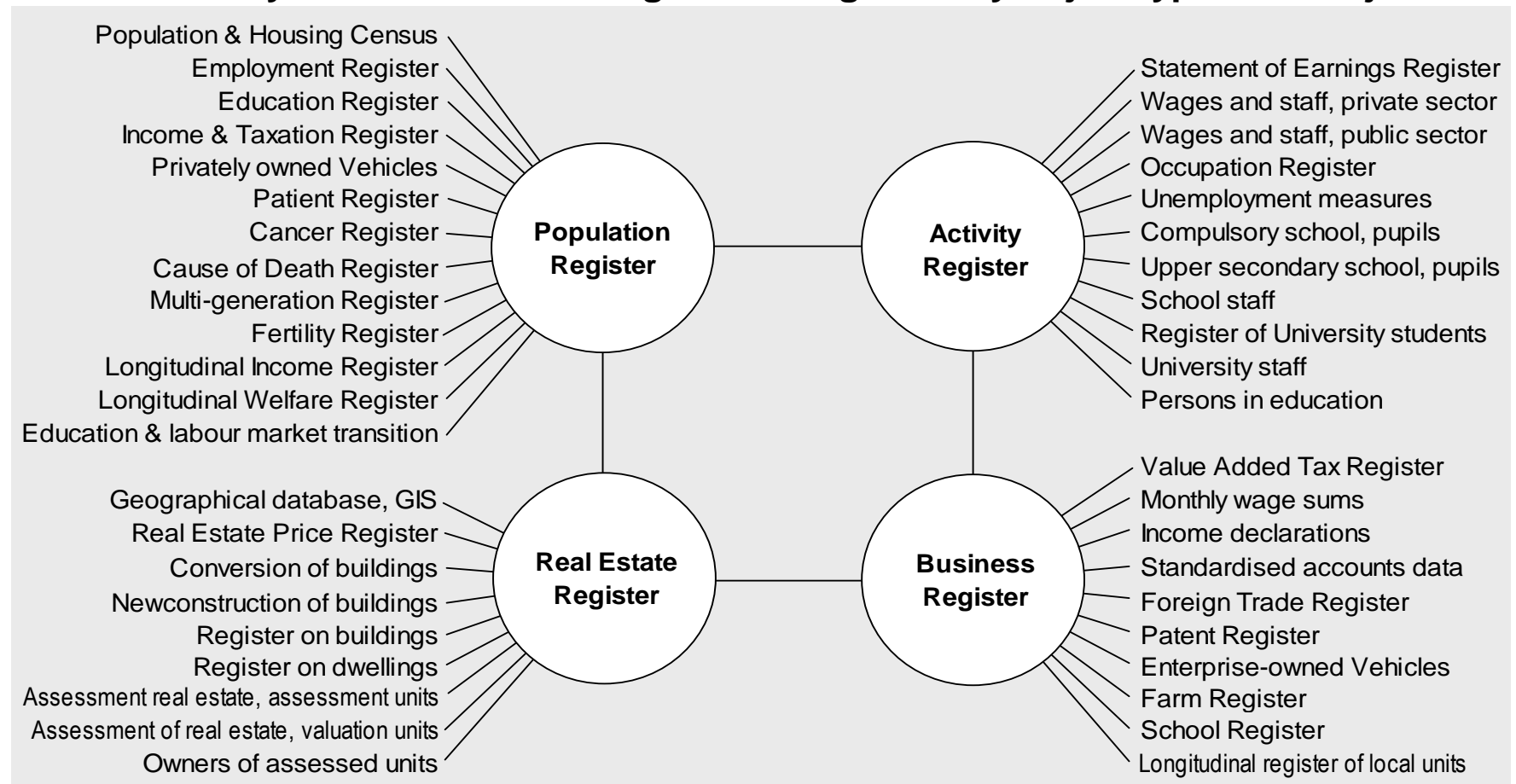
### *The personal identity number (PIN):*

- 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**

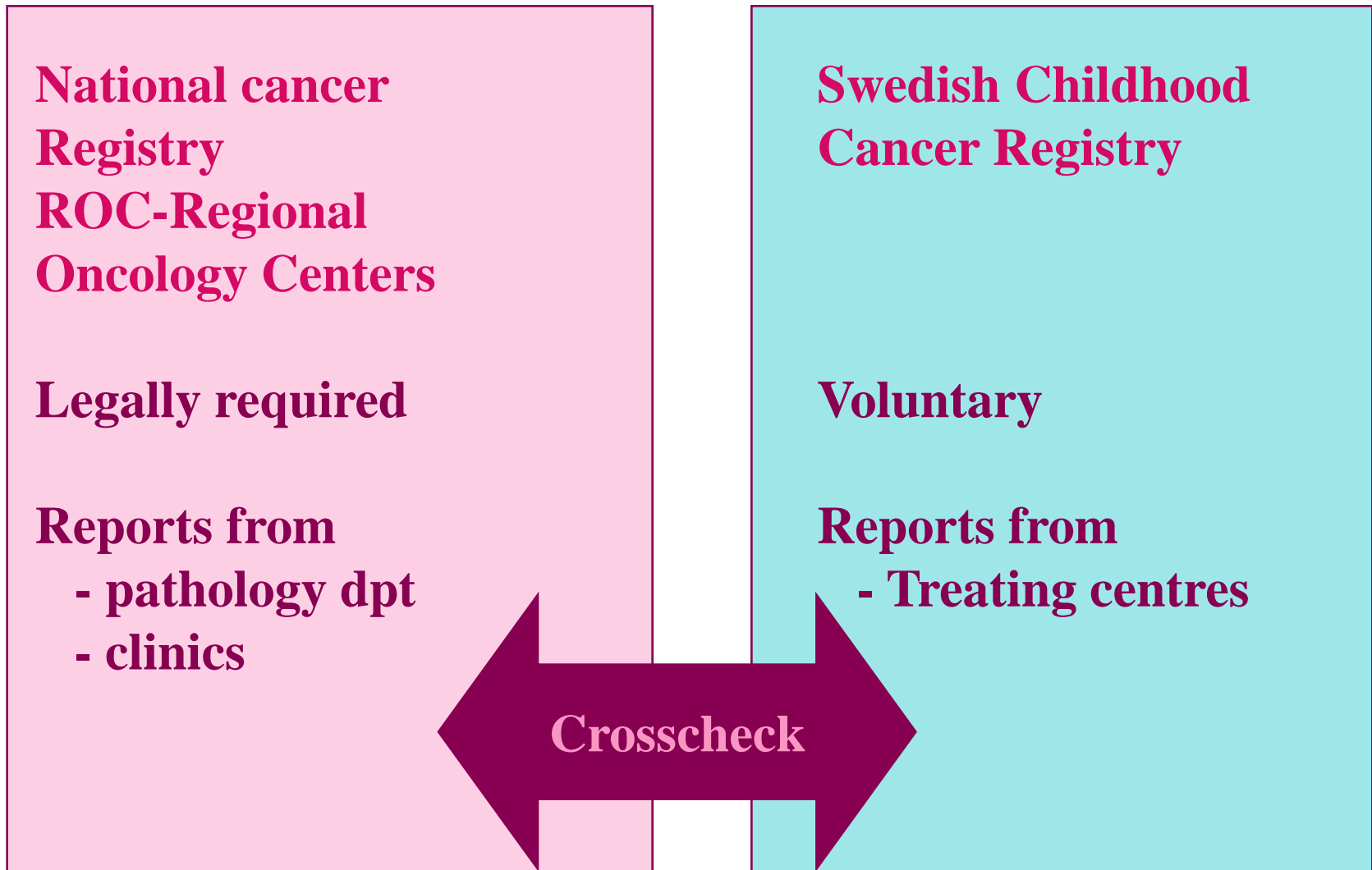


# Swedish Quality registries

## 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).



# 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**



## 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>)
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## Swedish Quality Registries 2016

**108** registries covering a wide range of interventions and diseases

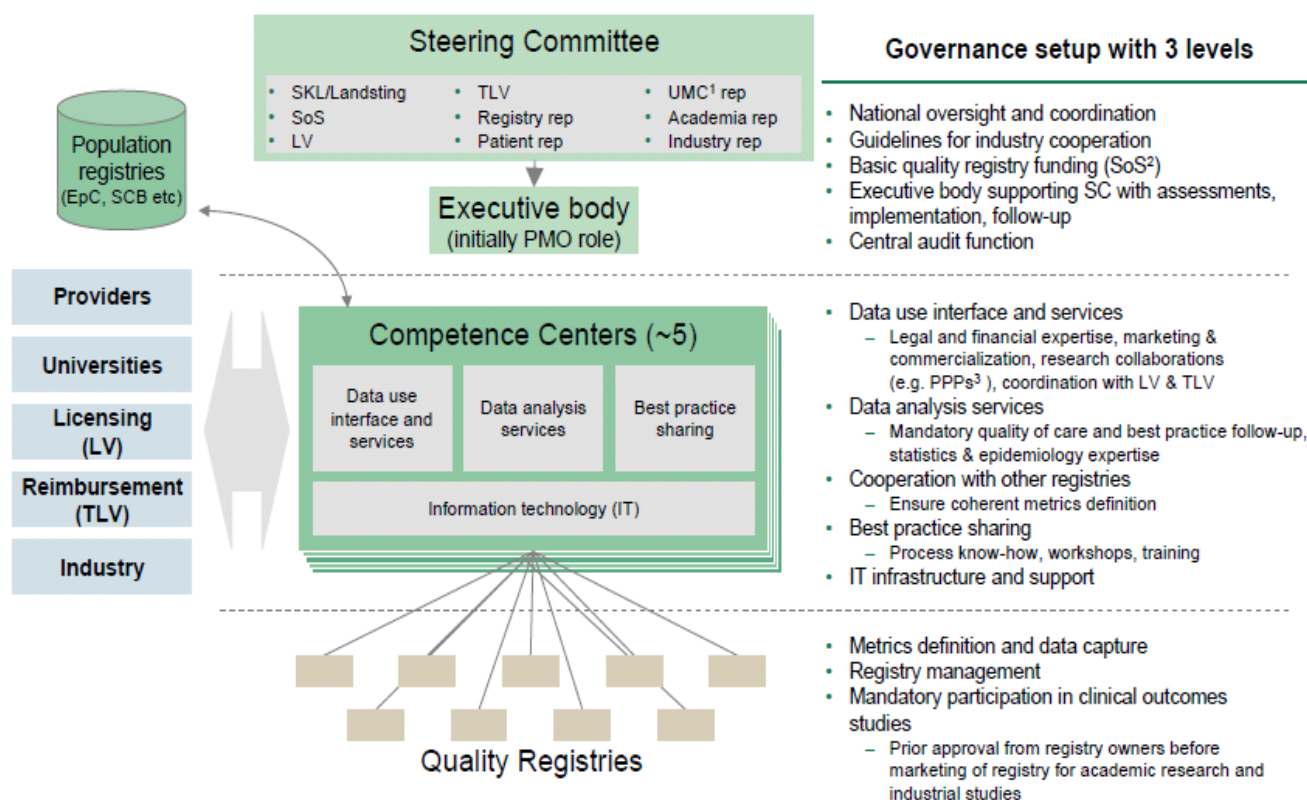
- **13** on level 1
- **29** on level 2
- **54** on level 3
- **12** candidates to become certified registries

### 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



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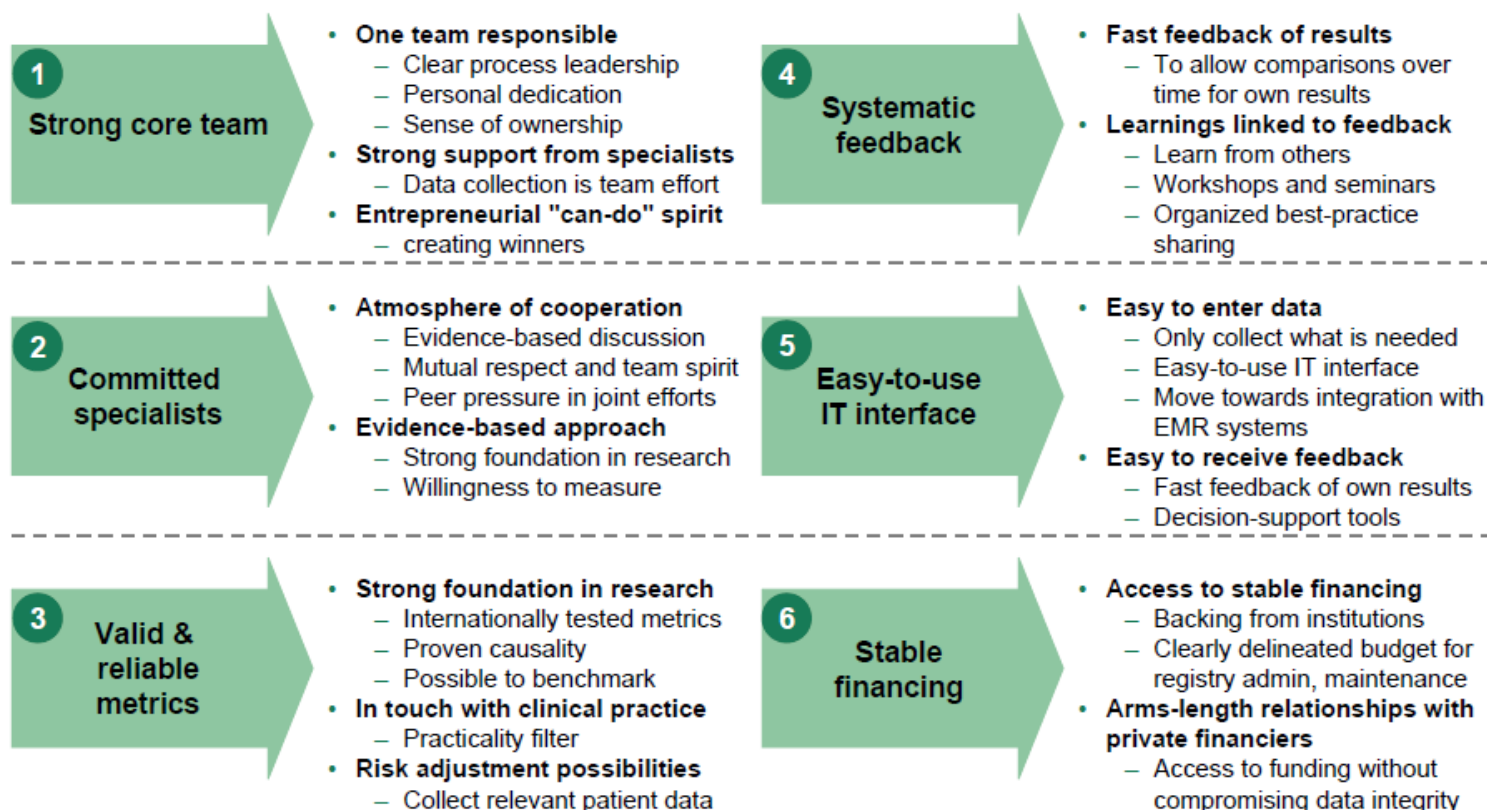
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# Swedish Quality Registries

## First-class quality registry fulfill six requirements



Source: BCG analysis

Value guided healthcare\_Final Documentation\_Aug09.ppt

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14

# 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, 2<sup>nd</sup> 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



## Hudmus 98 © a new Multiple Sclerosis register for clinical and research purposes

The Hudmuss MS database system - HUDMUS 98 has been developed at the Division of Neurology, Huddinge University Hospital, Karolinska Institute, Stockholm, Sweden in collaboration between the MS Centre and the Swedish MS Database Co-ordinating Group.

### Main purposes of the system

Hudmus 98 has been designed to cope with several clinical and research related tasks. It primarily aims to:  
provide "condensed" patient information helping in clinical settings  
ensure the quality of the clinical data  
document laboratory and paraclinical data  
be a source of information necessary for different research projects  
help in the participation in clinical trials

### General objectives

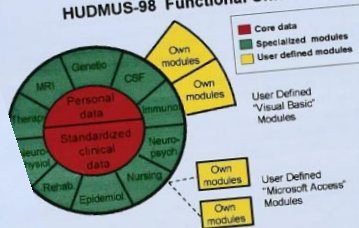
The large interest expressed and need of a MS register at many neurological clinics in Sweden encouraged us to find a solution integrating a short standardised clinical description of a patient, accepted by many centers, with local, extended needs. The latter is expressed in a vast number of variables containing results of specialised tests or examinations of a particular type.

This has resulted in a specific system design with easy to fill-in forms, a simple user interface not overloaded by different variables, flexibility in many aspects, high speed of performed operations, built-in on-line help and security of data transfer and storage.

Development of a separate query software has been considered necessary in order to achieve high versatility in extracting information and printing reports. This facility has become one of the central objectives in the system.

**System design**  
The key concept of the system is its modular design. Three functional units can be outlined in Hudmus 98 database, each consisting of several different modules:  
• Locked **Standardized Core** with basic personal information and clinical data (allowing multicenter data links)  
• Surrounding **Specialized Modules** (adjustable for local needs, proposed by the Swedish MS Database Co-ordinating Group)  
• Open structure for **User Defined Modules**

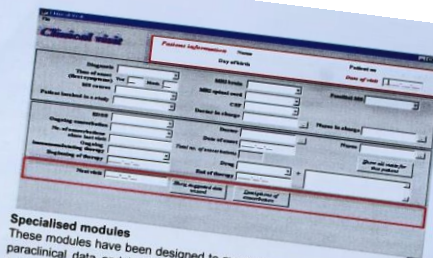
### HUDMUS-98 Functional Units



### Standardized core

The HUDMUS 98 database is built around a standardised core of basic personal data and a form named "Clinical Visit". In this form a limited amount of information is collected when the patient visits the outpatient ward or clinic. This data includes such variables as relapse/relapse index, current immunomodulating treatment, relapse/relapse index, etc. Additional clinically relevant information such as the disease, pathologic CSF or MRI, or familial MS is given in

time-independent data or slowly changing variables from a been implemented. Tools to browse through descriptions exacerbations as well as facilities to help in booking time has been built-in into the system.



### Specialised modules

These modules have been designed to meet with the needs of collecting paraclinical data and information originating from a number of diverse research projects. Selective access to data of different type was a key goal in planning of the system. This resulted in ten specialised modules comprising of the categories depicted in Fig. 1.

### Current development and future features

Current work focuses on a simple query-generator based on the standardised core of a system (personal data and clinical data) and standardisation of local specialised modules (MRI, epidemiology, rehabilitation, neuropsychology, nursing). On-line help is being extended and upgraded. Additionally we have started developing a comprehensive query-generator for seeking and extracting information in a flexible way, an editor for defining own modules, a reports' editor and facilities for graphical presentations of time-dependent data.

### Technical details

Hudmus 98 is a 32 bits application written in the Microsoft Visual Basic 5.0. Source data structure is created under the Microsoft Access 6.0 database.

Hudmus 98 is a modern program supported with a graphical user interface (GUI) compatible with all standardised Microsoft applications such as Microsoft Office. This means that the design, all tools and many details are familiar to the user from the very beginning. The user will find the same facilities and recognise similar features in Hudmus 98 as in other standard applications running on Windows 95 or Windows NT platform.

The system depends on the rights set-up for the system. For this particular goal in planning of the system, the assignment of different rights to the system, encrypted links between

in and a database is compiled and way access time. Therefore Hudmus 98 is performed almost instantly.

A flexible structure which means concerns the system units such as modules, defined reports etc.

in local adaptations and adjustments tools such as list boxes and users on the pre-defined answer

MUS 98 register.  
processor or higher

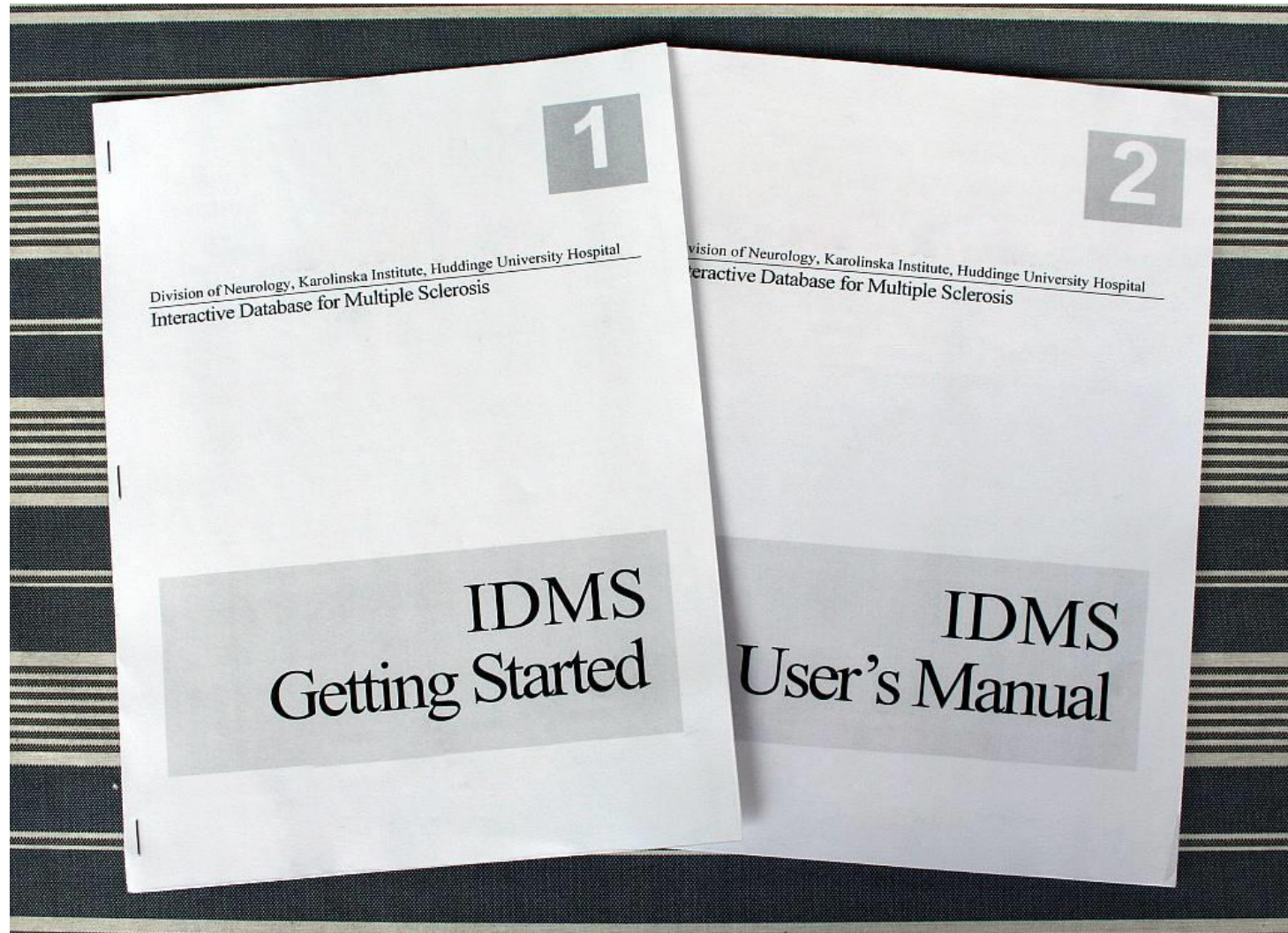
SVGA 800x600 resolution  
g system

Hudmus 98 database system has been sponsored by  
Hoechst Marion Roussel AB and Serono Nordic AB.

KAROLINSKA  
INSTITUTET  
a medical university

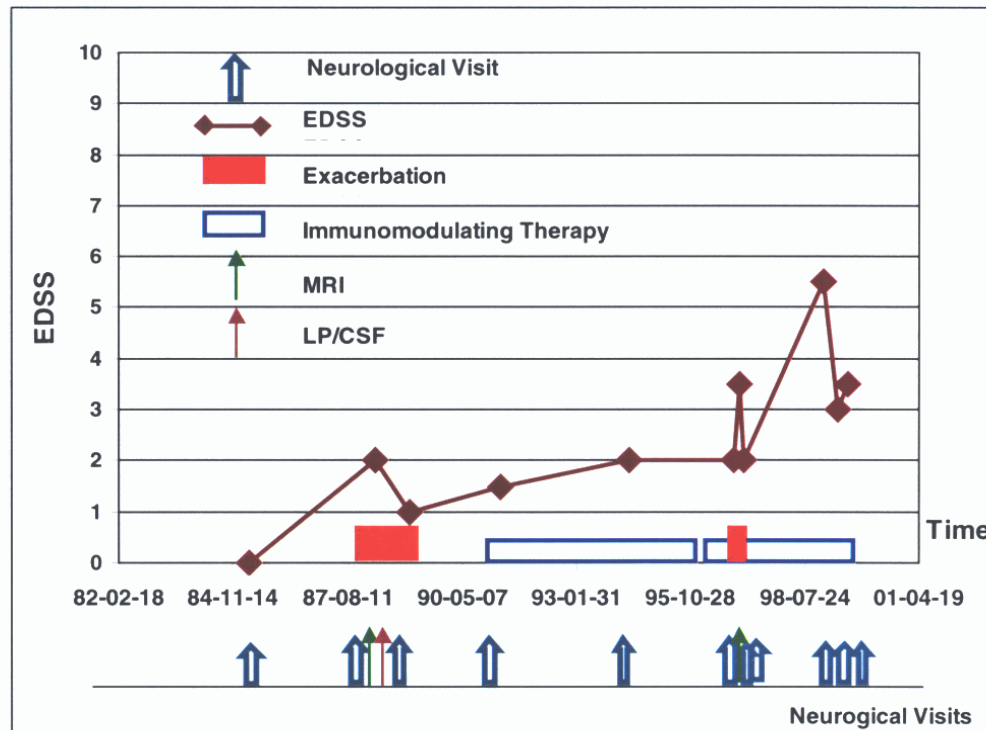
HS  
Huddinge Hospital

# Swedish MS Registry



# Swedish MS Registry

## Graphical presentation of the disease course

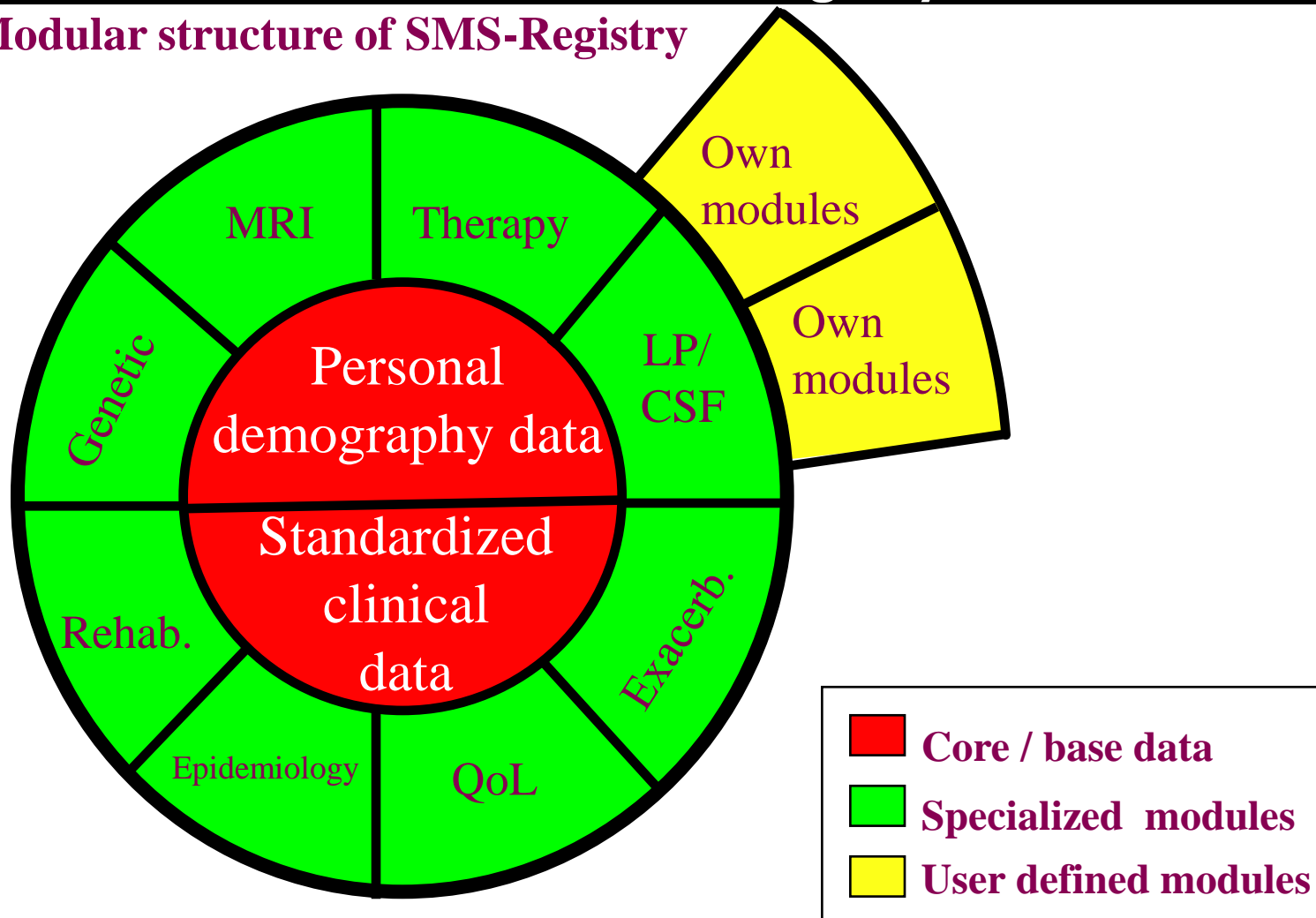


**First idea of a graphical presentation of patient's overview 1998**



# Swedish MS Registry

## Modular structure of SMS-Registry



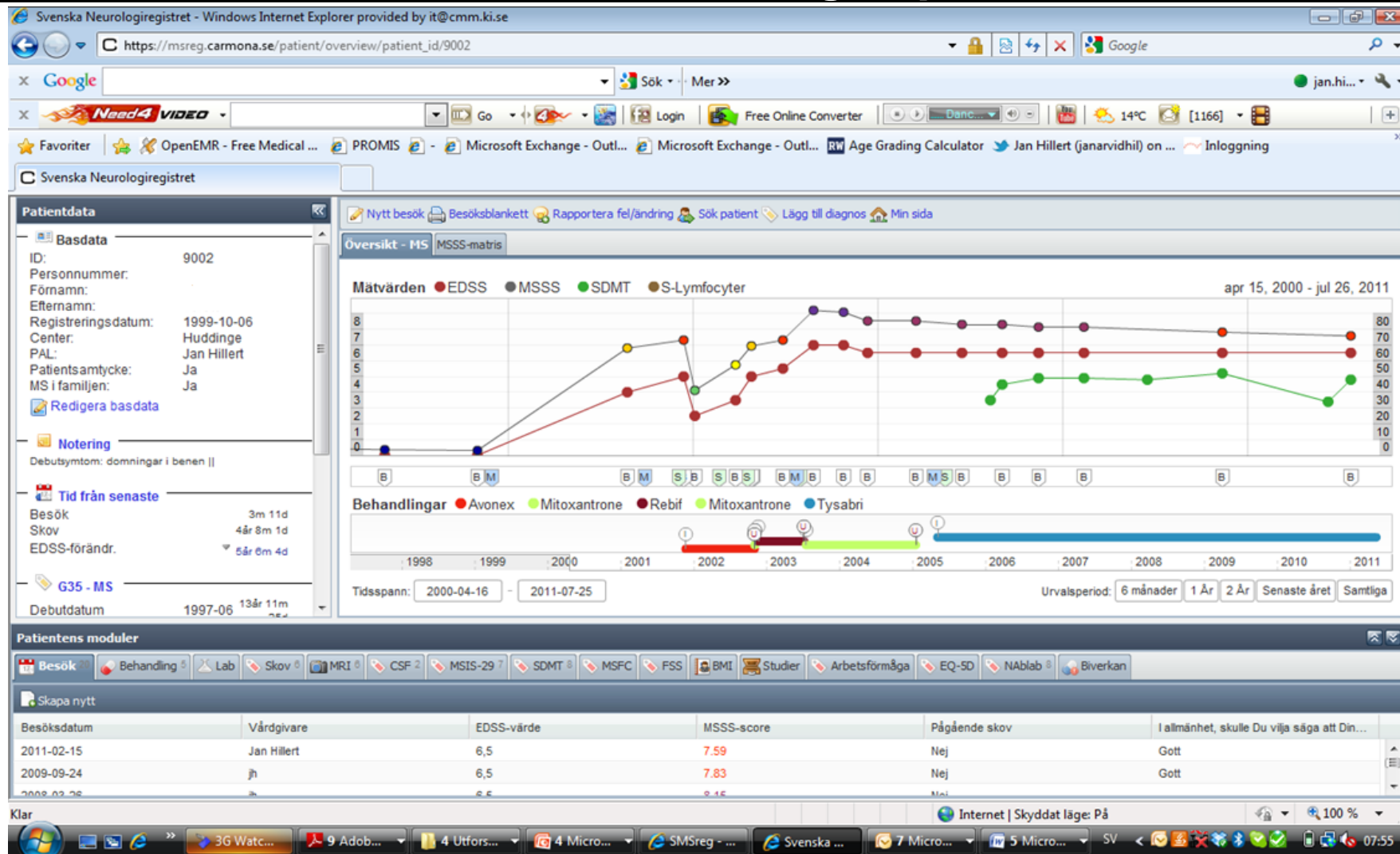
## Swedish MS Registry

- 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







- **Thank you**
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