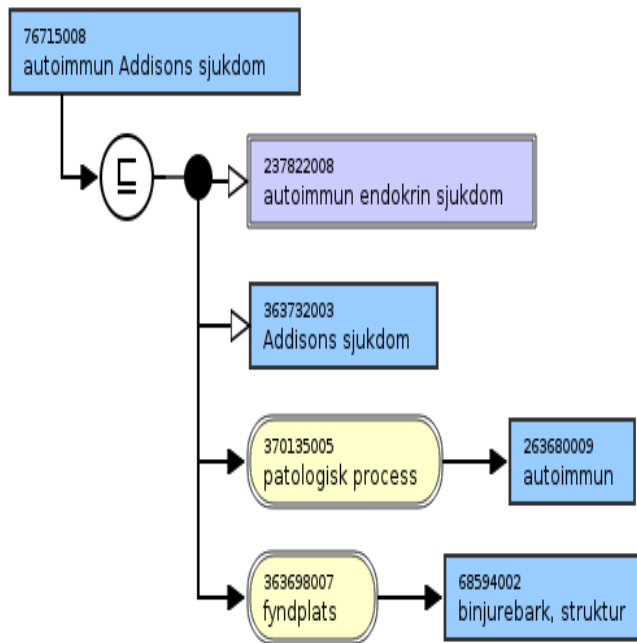# Promoting Automated Data Transfer to National Quality Registries Using SNOMED CT

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- **Background**
  - The Health and Social Care System in Sweden

- **National Quality Registries**
  - What, why and how

- **The National Programme for Data Collection**
  - Purpose and benefits
  - Method and work
  - Issues and results

Health and Social Care in Sweden

– 21 self-governing counties.

– Responsible for regional services e.g. **health and medical services**.

– 290 self-governing municipalities

– Responsible for local services and administration e.g. **social services** and **care of the elderly.**

– National level = legislation, standards, knowledge management, inspectorate.

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The Swedish Association of Local Authorities and Regions, SALAR

- An organization that represents and advocates for local government in Sweden.

- All of Sweden's municipalities, county councils and regions are members of SALAR which represents and acts on their initiative.

- SALAR runs the central office for national quality registries, including the national programme for data collection.

Sveriges Kommuner och Landsting

The National Board of Health and Welfare

- A government agency under the Ministry of Health and Social Affairs.

- Has different duties within the fields of social services, health and medical services, patient safety and epidemiology.

- Runs the Swedish SNOMED CT National Release Center.

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National Quality Registries – what, why and how

Quality Registries in Sweden

- **A system of national quality registries has been established in Swedish healthcare in the last decades – 110 registries in total.**

- **A national quality registry contains individualized data about patient problems, medical interventions, and outcomes after treatment.**

- **There are about 100 registries that receive central funding.**

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The Purpose of the Quality Registries

- **Built up by dedicated healthcare professionals with the aim of monitoring the outcome of the healthcare given to patients.**

- **The objective has been to generate valuable knowledge in order to improve healthcare.**

- **The quality registries provide a unique base for quality development and research in healthcare.**

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However …

- **The data collection to most registries is done manually by health-care staff filling in registry forms with patient data from the EHR.**

- **This task is extremely time-consuming for health-care services who want to contribute to the registries.**

The National Programme for Data Collection

The National Programme for Data Collection (NPDi)

Managed by the *Swedish Association of Local Authorities and Regions (SALAR).*

The purpose is to:

- **Promote easier collection of data submitted to the quality registries**

- **Restrict the necessity to record patient data several times for different purposes.**

- **Promote automated data transfer to the registries.**

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Benefits of the NPDi

- **Less administration for the health and social care services.**

- **Better quality and a higher level of coverage of the data reported to the quality registries.**

- **Better foundation for data transfer – a common ground.**

- **More common information structure and terminology in IT systems.**

NPDi Sub-Projects

- *The Informatics Sub-Project* **– developing common information structure and terminology**

- *The Technical Architecture Sub-Project* **– using national infrastructure solutions**

- *Pilot Implementation Projects* **– collaborating with health-care services and their IT vendors**

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Method and Results

The Informatics Sub-Project

Includes:

- **Translating variables in quality registries to codes from classifications and other coding systems and terminologies – SNOMED CT.**

- **Finding common information in different registries and making sure they are expressed and coded in a uniform way.**

- **Developing information models for the quality registries as per the National Information Structure Initiative.**

Method

- **The variables in the quality registries were mapped to codes from appropriate coding systems, SNOMED CT being one of them.**

- **To perform the mappings, a network of mappers was established with participants from different health-care regions.**

- **The mappers were trained by SNOMED CT terminologists from the National Release Center.**

Issues and Difficulties

- Finding the accurate concepts in SNOMED CT.

- Dechiffering the complex way variables are expressed, often combining different questions into one.

- Making necessary adjustments to the structure and terminology of the EHR systems to allow for encoded data and for automated transfer to the registries.

Result 1: the Necessity of Post-Coordination

Many of the variables couldn't be expressed using single SNOMED CT codes, and it soon became clear that a better map result would be achieved if post-coordination was to be used.

Result 2: the Necessity of Validating and Updating the Map Source

It was necessary to discuss with registry representatives if the variables could be changed in order to improve their clarity and thus facilitate the encoding.

Result 3: the Necessity of Adding New Content to SNOMED CT

Another part of the solution was to request that the non-existing concepts were added to the Swedish SNOMED CT extension, and for this purpose the collaboration with the National Release Center was increased.

NPDi Today and Onwards

Current and Future Situation

- Out of the 110 quality registries, about 11% have been coded using national terminologies and classifications.

- Work will be ongoing in 2016 and onwards – a center of competence has been established to manage and drive the work forward.

- More pilot projects will be added to the list as they come along – requires committment from health-care organizations and their IT vendors!

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Questions?

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For more information:
http://www.kvalitetsregister.se/projekt/nationellaprogrammetfordatainsamlingnpdi
http://www.socialstyrelsen.se/nationellehalsa/snomed-ct

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