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

  - Method and results

  - NPDC today and onwards

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.

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.**

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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.

- **NBHW runs the Swedish SNOMED CT National Release Center.**

National quality registries – what, why and how

Quality registries in Sweden

- **There is a system of national quality registries in Swedish health/social care – 110 registries in total.**

- **A quality registry contains individualized data about a specific disorder/problem, medical intervention or outcomes after treatment.**

A film (in English) about the registries is available here:

http://www.kvalitetsregister.se/sekundarnavigering/inenglish.132.html

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The purpose of the quality registries

- **Monitor the outcome of the healthcare given to patients.**

- **Generate valuable knowledge to improve healthcare.**

- **Provide a unique base for quality development and research.**

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However …

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

- **Extremely time-consuming!**

- **Registry variables are often expressed differently from the data recorded in the EHR – not many 1:1 equivalences.**

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The National Programme for Data Collection

The National Programme for Data Collection (NPDC)

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

The purpose is to:

- Promote easier collection of EHR 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.

Benefits

- **Less administration and resources needed for health/social care services.**

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

- **Better foundation for data transfer – common structure and terminology in IT systems.**

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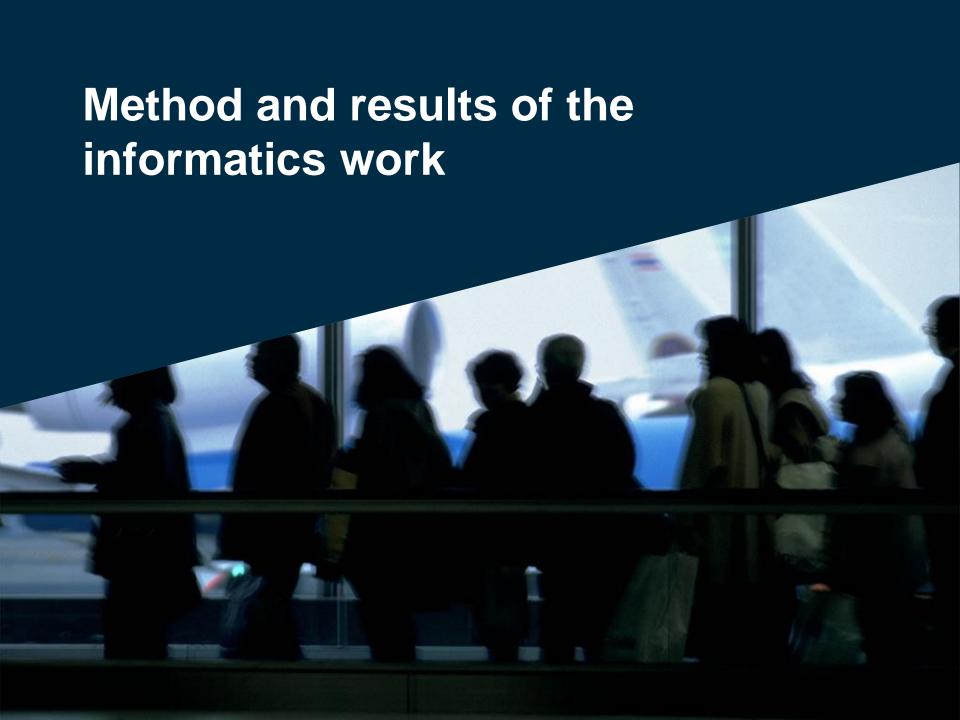THE NATIONAL BOARD OF HEALTH AND WELFARE

NPDC sub-projects

- *Informatics* – common information structure and terminology

- *Technical Architecture* – national infrastructure solutions

- *Pilot implementation projects*

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Method and results of the informatics work

Informatics work to promote automated data transfer

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 that comply with the National Information Structure Initiative.

Method for mapping work

- **A national network of mappers was established with participants from different healthcare regions.**

- **The mappers were trained by SNOMED CT terminologists from the National Release Center, and a specified mapping method was followed.**

- **The variables for each registry needed to be checked and "cleaned" to enable coding – this also included regular discussions with registry representatives.**

Issues and difficulties

- Finding the accurate concepts in SNOMED CT.

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

- Out of scope: making the necessary adjustments to the structure and terminology of the EHR systems to allow for encoded data and for automated transfer to the registries (but pilots are being done to support this aspect since it will be a challenge!).

Conclusion 1: the necessity of validating/updating the map source

- **The variables were often not clear and/or were too complex to be coded.**

- **Continuous discussions with registry representatives were necessary.**

- **Possible to change unclear/complex variables to make the encoding simpler?**

Conclusion 2: the necessity of post-coordination

- **Many of the variables couldn't be expressed using single SNOMED CT codes.**

- **A better map result would be achieved with post-coordination.**

- **The more advanced mappers in the network have started creating post-coordinated expressions.**

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Conclusion 3: the necessity of adding new content to SNOMED CT

- In spite of the post-coordination efforts there were still many gaps in the maps.

- Numerous change requests to the NRC about adding the non-existing concepts to the Swedish SNOMED CT extension.

- For this purpose the collaboration between the programme and the NRC was increased.

NPDC 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/social care services and their IT vendors!

Nationella programmet för datainsamling (NPDi)

National programme of data collection (NPDC)

El programa nacional de recolección de datos (PNRD)

Le programme national de collecte de données (PNCD)

Nationale Programm der Datenerhebung (NPDe)

(BWDB)برنامج وطني لجمع البيانات

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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