

«FS –SYSTEMET»
DEVELOPING A SYSTEM FOR DATA
COLLECTION OF DIABETES MELLITUS
IN NORWAY

Tomislav Dimoski, MBA, Graduated Electrical Engineer

“FS-SYSTEMET” – DIABNOR at HelsIT 2015

- “FS-SYSTEMET”
 - The origins and when the innovation happened?
 - Who has been using FS-systemet?
- “FS-SYSTEMET” - DIABNOR
 - When, What, Who and How?
 - Why and What Now?

“FS-SYSTEMET” – was there a genuine need & were the right people involved?

- In 1995, a research foundation (HELTEF) expressed a need for “simple” IT solution to administer patient satisfaction questionnaires to all patients from two hospitals over a three year period
 - Bjørn Guldvog give ideas (now Director General at The Norwegian Directorate of Health)
 - Tove Kopperud (now retired IT specialist at Akershus University Hospital) help to choose reliable, structured data from the Patient Administrative System (PAS)

“FS-SYSTEMET” – Objectives and concept

- “FS-SYSTEMET” has two objectives
 - To improve the efficiency of research at hospitals
 - To build a system which facilitates the practical use of scientific findings within hospitals
- “FS-SYSTEMET” is:
 - A concept for multi-center research studies, team building and collaboration
 - A modular system of MS Access and SQL databases for the retrieval of data from the patient administrative systems (PAS) and other IT systems

“FS-SYSTEMET” – required to be “simple” but also to meet legal requirements

- “FS-systemet” has been reviewed (legally and technically) on several occasions by an independent review group and The Data Protection Agency in Norway.

A review in 2009 concluded:

The review group considers “FS-systemet” as a suitable, thoroughly prepared and justifiable technical solution for processing personal data within the type of research that was evaluated.

Who used “FS-SYSTEMET” in Norway (1995-2015)?

- Patient and user experience surveys
- National quality indicators (30 days mortality and readmissions to hospital)
- National occurrence studies (cardio vascular diseases, diabetes, hip fractures)
- Key performance indicators (KPI) at hospitals
- Supplementing the dataset of The Medical Birth Registry of Norway

“FS-SYSTEMET” – Quality of data?

- 30 days mortality projects (CVD, hip fracture, stroke)
 - 45 hospitals controlled 6.500 patient medical records
 - Project leaded independent control of 15 hospitals (2.250 patient medical records)

The report concluded:

“The quality control revealed that more than 99% of the data in our data set for the following variables: date and time of admission, main diagnosis and index diagnosis, was correct as compared to the patients’ medical records.”

“FS-SYSTEMET” – which data are collected?

- Administrative data from all Norwegian health trusts for all/selected/sampled in- or outpatients
 - **personal identification number**
 - patients’ name and address
 - survival status
 - ward and department time of admission and time of discharge
 - type of admission (acute or planned)
 - primary and secondary diagnoses and procedures
- Linked laboratory data from all Norwegian health trusts

“FS-SYSTEMET” DIABNOR - Healthcare and IT systems within hospitals in Norway in 2011

- 65 hospitals
- 3 Patient Administrative Systems (PAS)
- Norwegian Patient Register with person identified from 01.01.2008. Incomplete in 2008 and 2009.
- THE MOST Restrictive privacy protection policies
 - The Norwegian Prescription Database is “pseudonymised” dataset
 - “The privacy of the individual is strictly protected and data is anonymous”



“FS-SYSTEMET” DIABNOR – which data WERE linked?

- FS-data was collected from all somatic hospitals comprising admissions; day surgery and outpatient care for the 7-year-period 2004-2010 on patients with diabetes mellitus (ICD10 E10*-E14*)
- **Personal identification number** enabled efficient linking of FS-data to:
 - National Population Register
 - Statistics Norway
 - The Norwegian Prescription Database: Waiting to link this data - **the FS-data will thereafter be anonymous**

Quality of DIABNOR “FS-data” compared to NPR-data

- The FS-data for patients with diabetes mellitus was compared with the data collected by the Norwegian Patient Register for the year 2010.
- The general conclusion for year 2010 is that FS-systemet collected as much or more identifiable patients, admissions, day surgery and outpatient consultation as the Norwegian Patient Register
 - 173 951 patients with diabetes mellitus
 - More than 3.8 million admissions, day surgery and outpatient consultations

“FS-SYSTEMET” DIABNOR – which data can be linked additionally in 2015?

- **Personal identification number** enables efficient linking of FS-DIABNOR data to:
 - Data from primary care (from 2004-now)
 - Norwegian Patient Register (from 2009-now)
 - National Health Registries (15)
 - Health quality registries (47) and most interesting among them:
 - **Norwegian Diabetes Register for Adults**
 - Norwegian Child Diabetes Registry

“FS-SYSTEMET” DIABNOR – How can the data be used?

- The central registry/research project can establish controlling policies and procedures and ask for control of quality of data at source of data
- The issuing organization can control the quality of each piece of data at the origin
- Each patient can be contacted by treating hospital/primary care doctor/.. for treatment or PROM, Patient experience, or
- The contact can be done by the central registry on behalf of the treating institution

“FS-SYSTEMET” DIABNOR – Who can use the data?



FS-SYSTEMET – CVDNOR (CardioVascular Disease in NORway), 1994–2009

CVDNOR Data Sources

www.cvdnor.no



FS-SYSTEMET – CVDNOR 1994–2009

www.cvdnor.no

The banner features a dark blue background with a grid of white binary code (0s and 1s). A red ECG line is overlaid on the grid. In the top right corner, there is a circular logo for Universitas Bergensis, which contains an owl. The text 'CVDNOR' is written in large, bold, white letters, and 'Cardiovascular Disease in Norway' is written below it in a smaller, white, italicized font. At the bottom of the banner, there is a dark grey navigation bar with the following links: Home, Data Sources, About, Subprojects, Publications, Data access (highlighted), and Contact us. To the right of these links is a search bar with a magnifying glass icon and the word 'Search'.

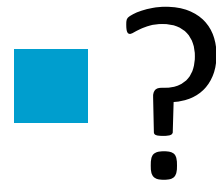
How to apply for data access?

All scholars affiliated with institutions with research expertise can apply for permission to analyze data from CVDNOR.



“FS-SYSTEMET” DIABNOR – Spørsmål?

- Interessant å diskutere hva som gjør det ene registrert bedre egnet enn det andre til forskningsformål (FS vs NPR vs Kvalitetsregister)
- Er det problemstillinger rundt tilgang og bruk av disse dataene?



“FS-SYSTEMET” – Organic growth?



Tomislav Dimoski, tod@nokc.no