

USES OF ELECTRONIC PATIENT INFORMATION SYSTEMS AND NATIONAL REGISTERS

– Implementation of the clinical practice guideline and evaluation of costs and use of resources in patients with incident type 2 diabetes in Finland

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RATIONALE

Finland has a long tradition in comprehensive electronic registry data^{1,2}. However, the use of electronic patient records of primary and secondary health care together with national registers is uncommon in nationwide studies. The problem is that relevant data are scattered between different register holders.

Effective management of diabetes is the cornerstone for prevention of diabetic complications. However, how well the Finnish Current Care guideline³ for diabetes is implemented in practice is unknown.

OBJECTIVES

One purpose of the ongoing study is to identify how the Finnish electronic patient information systems and national registers can be used to explore the treatment for patients with incident type 2 diabetes. To survey the implementation of the Current Care guideline we aim to collect all relevant structured variables from different data systems.

METHODS

As often in pharmacoepidemiological studies, we collect nationwide patient data on prescriptions, hospital and primary care, reimbursed dental care, and the causes of death. In addition to the national patient registers we selected primary and specialty care organizations in seven different geographical regions representing four patient information system providers to participate in the study (Figure 1). In all, study permit applications were sent to 11 local register holders, three local study sites declined to participate in the study and one was left out for financial reasons (Figure 1).

Local registers are mainly used as a source of information on laboratory values, diagnoses and prescriptions, but also on medical procedures, contact types and billing to estimate the health economical aspects. Nationwide cost data will be based on hospital benchmarking database, sickness allowances and rehabilitations.

The study protocol was sent for ethics committee review and the Office of the Data Protection Ombudsman was informed of the study.

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Research permissions

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All data analysis and reporting was carried out according to the approved research protocol and amendments.

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RESULTS: STUDY DATABASE

We are currently collecting a cohort to study the implementation of the clinical practice guideline and evaluate the costs and resource uses in diabetes patients. The actual size of the cohort will be determined after the data has been collected. The inclusion criteria are:

- diagnosis for diabetes (ICD-10 code E10*, E11*, E13* or E14*, or ICPC-2 code T89 or T90)
- a written or purchased prescription for diabetic medication (ATC code A10A* or A10B*)
- special reimbursement status for diabetes (refund code 103)
- HbA1c value $\geq 6.5\%$
- glucose tolerance test ≥ 11 mmol/L, or
- nutrition counselling related to diabetes

The data will be gathered from 2009 to 2012. For this particular study the analysis data will include incident type 2 diabetes cases only. Only those citizens that have been living in Finland for two years prior to index date will be included in the study.

The cohort study database is special because in addition to nationwide data we use local providers as information source on e.g. high quality laboratory data. The structured variables that we requested from the local registers were:

- ID number
- date of birth
- gender
- place of domicile
- smoking habits
- BMI/weight & height
- waist circumference
- dietary habits
- nutrition counselling
- physical exercise
- exercise counselling
- all medications
- all diagnoses
- all laboratory measurements
- blood pressure
- foot therapy
- ocular fundus photography
- all operations
 - incl. amputations of the lower extremities
- name of the hospital/health centre
- date
- resource use
 - type (visit, phone call, email)
 - professional (doctor, nurse, dentist etc.)
 - billing

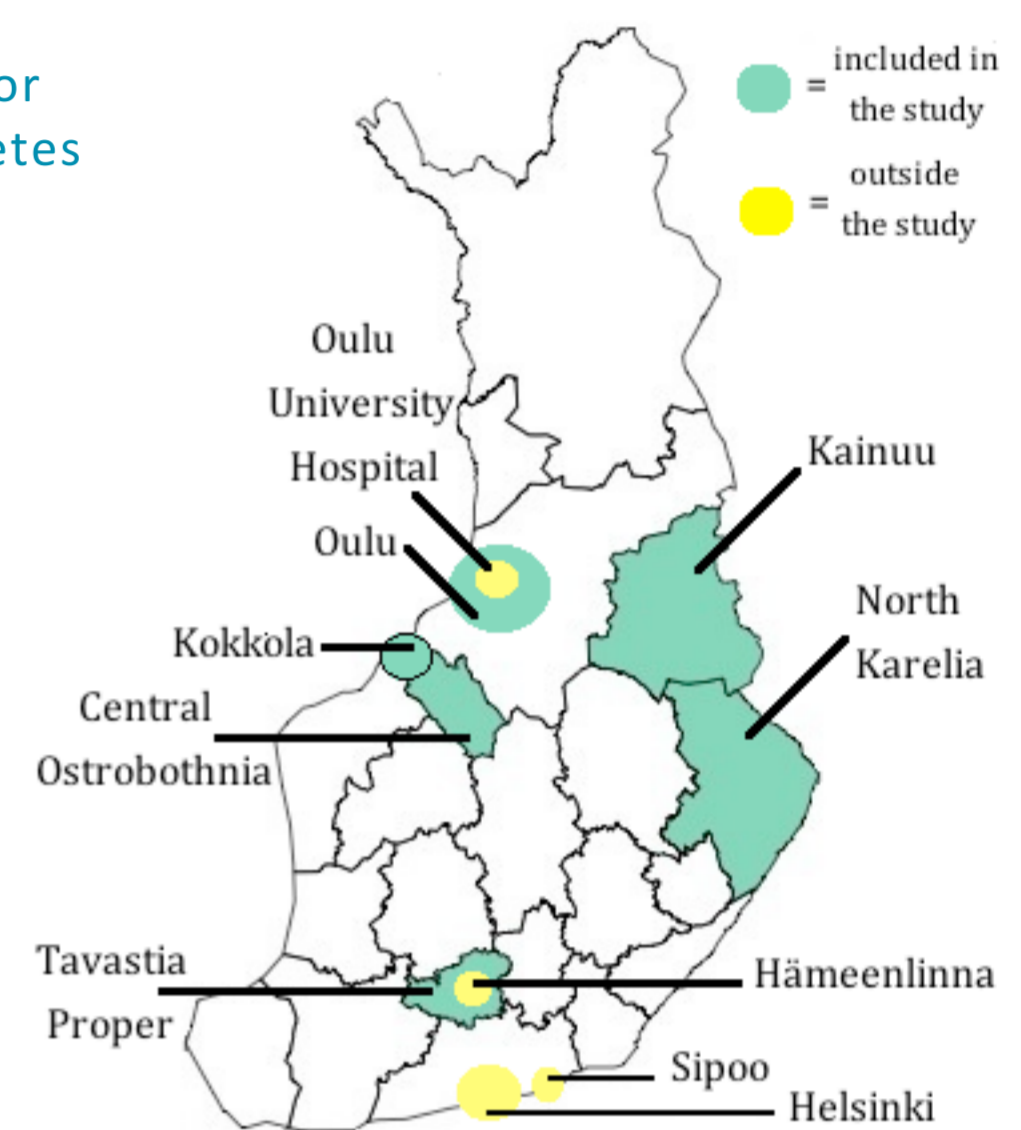


Figure 1. Hospital districts and cities included in the study and areas that opted out of the study.

The persons are identified in the registers with unique personal identification numbers. These IDs also enable the data linkage between different registers.

Our unique combined register database of diabetic patient cohort (Figure 2) improves the evaluation of prognosis and care of diabetic patients.

Nationwide data includes detailed information also on:

- drug purchases
- special reimbursements
- dental care
- sickness allowance
- rehabilitation
- inpatient days
- causes of death

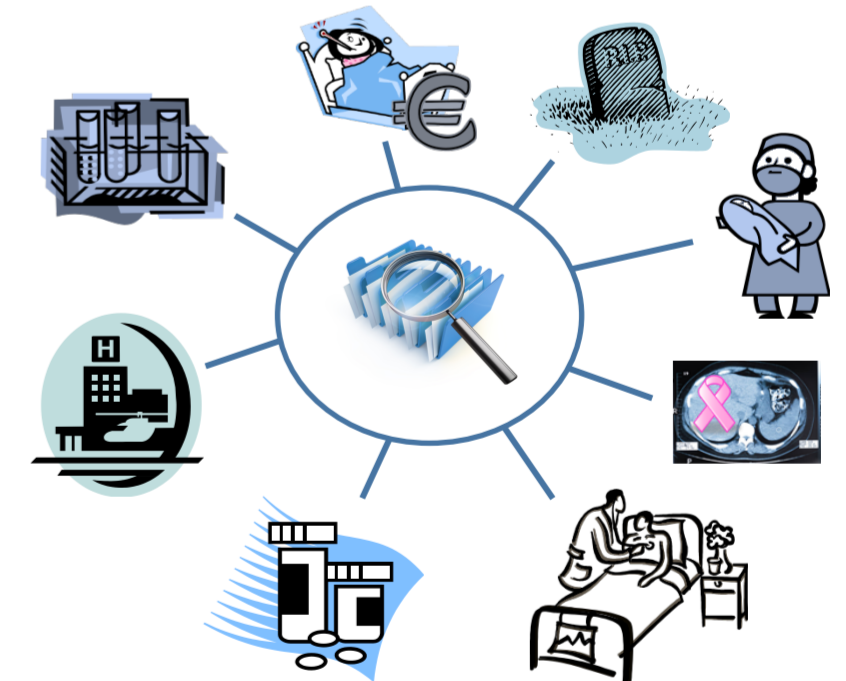


Figure 2. A unique study database is created by linking several nationwide and local patients register data with personal identification numbers.

CONCLUSIONS

Register linkages enable longitudinal follow-up of patients for research purposes in Finland. Combining local and nationwide patient registers provide a valuable resource for evaluating risks, benefits and costs. The combining allows also us to compare the equivalency of local and nationwide patient register data. In Finland the coverage of the nationwide registers is up to 100%. Also the quality of local registers e.g. in laboratory data is very high. However, the data has not been collected for study purposes, which may affect the quality of some data. We did not aim to text mining, thus only structured data were requested from the register holders. Some variables (smoking, exercise and dietary habits etc.) may be registered only in the open text fields and are then not available for this study. Nationwide prescription data includes reimbursed medications only. In this study we have access to all prescriptions via the local registers.

Gathering information from different information providers was laborious. The workload and the costs needed for data mining varied widely between different data systems. Data from Helsinki had to be excluded from the study due to financial reasons. This affected the population size and generalization of the results significantly. The assessment time of the study permit applications varied widely between different register holders and were unreasonably long for two nationwide permits. The benefits of the register studies, such as quick reactions to safety signals by research using the existing data, should be cherished.