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Evaluation of case inclusion in two population-based diabetes registers

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Abstract

Chronic conditions are the major cause of illness, disability and death. A disease register is effective in supporting new models for delivering chronic care. To improve the care of diabetes two stand-alone diabetes registers have been recently constructed in Finland – a national diabetes register (FinDM II) and a regional diabetes register (T2DR) in the Helsinki metropolitan region. Both compile information from multiple, but separate, databases and could be therefore validated by comparing them with each other.

A total of 38 898 and 37 611 diabetic persons were identified from Helsinki and Espoo in the national and regional register, respectively. The numbers were very well matched in the youngest (0-19 years) and oldest (over 95 years) age groups; in Espoo the match was good also for persons aged 20-40 years. There were significant differences in the numbers of diabetic persons aged 20 to 65 years; over 3 800 more diabetic persons were retrieved in the FinDM II Helsinki data than in the T2DR data, whereas the T2DR identified 3 100 more senior citizens over the age of 65 years with diabetes than the FinDM II. The possible reasons and implications of these findings to the validity of the registers are discussed.

Keywords: data collection, diabetes registers, validation, outcome and process assessment, quality of health care, chronic care

Introduction

Chronic diseases are the main causes of mortality and morbidity in the developed countries and account for 49 % of the global burden of disease [1]. Diabetes mellitus is becoming a major threat for world health in the 21st century. The global figure of people with diabetes is predicted to rise from the current estimate of 150 million to 220 million in 2010 and 300 million in 2025 [2]. Many attempts have already been undertaken to shift a major emphasis onto health promotion and disease prevention, so as to dimin-ish the diagnosis-specific burden of disease. However, despite enormous expenditures patient care is often deficient and health care systems designed to deliver acute care do not meet the needs of the chronically ill population [3].

How can the quality of existing care for chronic diseases be improved? The chronic care model pro-posed by Wagner [4] identifies the essential elements of a health care system that encourage high-quality chronic disease care. These elements include delivery system design, self-management support, decision support and clinical information systems. The chronic care model is rooted in the assumption that care for chronic diseases can only be improved by systems of care and that information technology plays a critical role in supporting these systems. The model is akin to continuous quality improvement approaches including evidence-based care, organizational learning and knowledge management ideas to the health care context [5].

According to a recent review [6], three technologies have been evolving into more comprehensive health care systems - a disease register, an electronic medical record (EMR), and a chronic disease management system. A disease register is typically intended to support the management of a specific disease. This disease-based approach is also recognized as a useful technique for the comparisons of health systems [7].

First disease registers were developed in the 1980s as a primary tool for improving chronic care [8]. Dis-ease registers are databases that contain condition-specific information for a group of patients and may generate patient reports or aggregate information across the population. Registers can be simple databases that require manual data entry or integrated registers where the database is updated by data retrieval from EMRs or other patient information systems. Integrated registers track all patient cases with a given disease or health condition in the population. In addition, some disease registers are based on administrative register data [9].

Registers are most often used for monitoring disease status at a population-level. Registers may also be used to track progress of the disease using process and outcome measures. Action plans may be based on these results in order to slow down the disease progress [10]. Integrated registers also provide feed-back to providers of care on overall performance by patient and by population. IT-enabled diabetes management has the potential to improve care processes, delay diabetes complications and save costs [11]. Consequently, diabetes registers have been created for various purposes [12-15].

For instance, in Scotland at Tayside (DARTS) one of the first diabetes registers was created on the recommendation of NHS that regional diabetes registers should be established in the UK to facilitate sys-tematic, population based monitoring of outcomes of diabetes and to ensure that diabetes care is effec-tive, efficient and equitable [16]. A national systematic approach since 2000 towards quality improve-ment of diabetes care included the creation of managed clinical networks and the Scottish Diabetes Sur-vey reporting annual improvements in diabetes care [17]. This has led to a significant change in clinical practice providing a national platform to underpin clinical networks of diabetes care.

There are variations in inclusion criteria of the registers as well as in the clinical registration of patients into the health information systems [18]. Such issues are important for the quality of register, and it is important to analyse the completeness of registration in the diabetes registers. In Finland, two separate diabetes registers have been constructed recently to improve the care of diabetes – a national diabetes register for monitoring of the prevalence and incidence of diabetes and its complications (FinDM II) [19], and a regional diabetes register for operational tracking and aggregate information on care quality from two municipalities and their health centers (T2DR) [20].

The aim of this study is to briefly describe these registers and to validate the completeness of condition-specific patient registration in both of these databases by comparing them with each other.

Material and methods

Register for national monitoring of diabetes and its complications (FinDM II)

FinDM II –project, organized by the National Institute for Health and Welfare and the Finnish Diabetes Association, aimed to build a nationwide monitoring system for diabetes and its complications (as well as direct costs of care in a subproject CoDiF) by combining data from several administrative registers maintained by the National Institute for Health and Welfare (THL), Social Insurance Institution (SII), Statistics Finland, and Finnish Centre for Pensions (ETK). Consent for data use was applied from each register maintainer separately.

The collection of data consisted of two phases: 1) the identification of the diabetes cohort, and 2) the gathering of follow-up data for the cohort. In order to identify as complete a diabetes cohort as possible, all persons with diabetes were screened from the Finnish Hospital Discharge Register (all inpatient health care during 1969-1993), the Finnish Health Care Register (all inpatient health care and day sur-gery during 1994-2007), the Benchmarking Database (outpatient hospital care during 1998-2007), the Medical Birth Register (pregnancies during 1987-2007), the Causes of Death Register (deaths during 1988-2006), the Drug Reimbursement Register (entitlement to special refunds during 1988-2007), and the Prescription Register (medication purchases during 1994-2007) by using manual database queries (Figure 1).

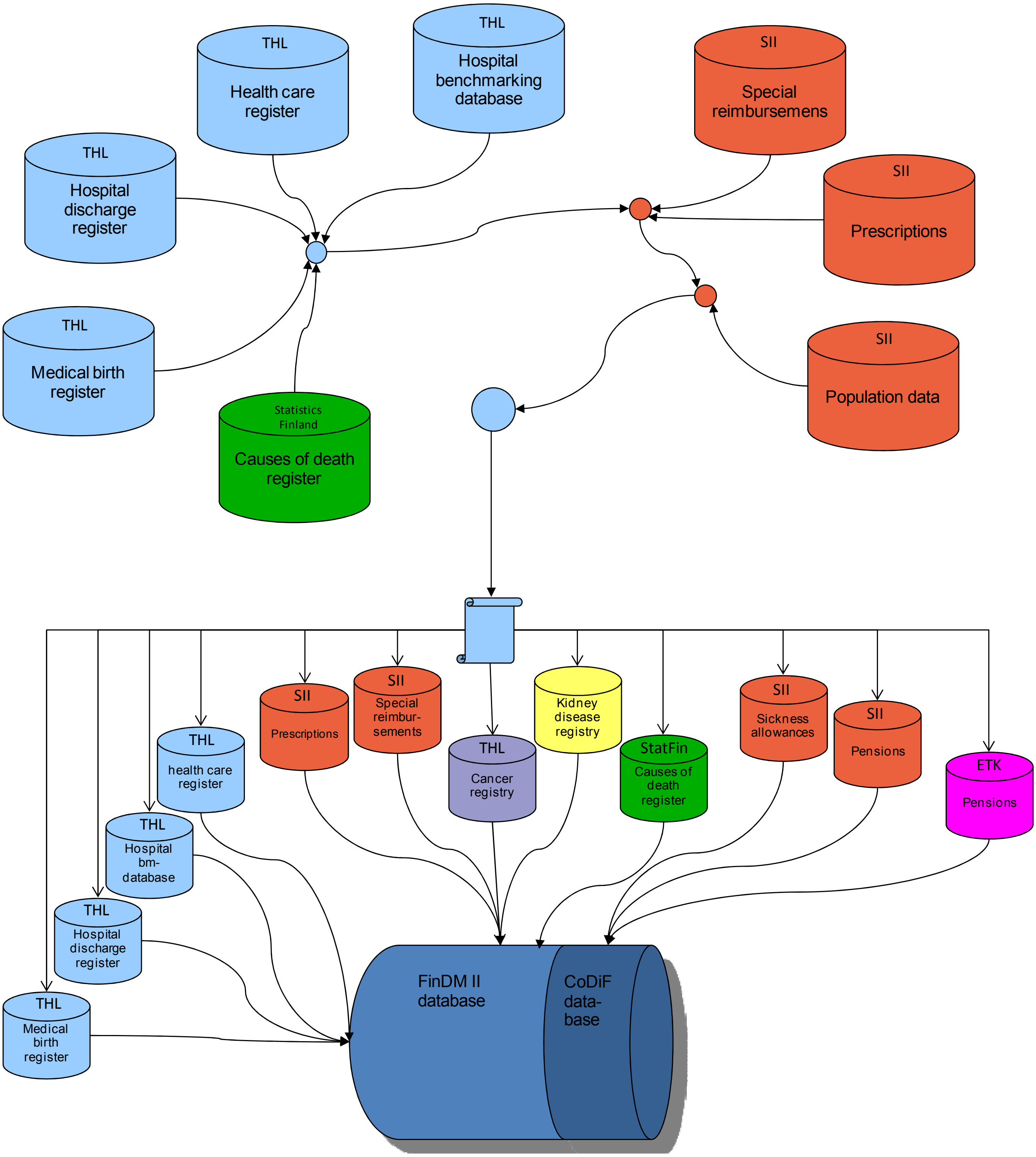


Figure 1. Data acquisition process in FinDM II. The cohort was identified from the registers of National institute for welfare and health (THL), Statistics Finland, and Social insurance institution (SII). Personal identity codes were checked and the place of residence at the last days of the years 1988-2007 were obtained from the SII registers for the whole cohort. Follow-up data were extracted from several registers and stored into an Oracle database at THL. For the purposes of a companion project CoDiF also sickness allowance and pension data were obtained from SII and the Finnish Centre for Pensions (ETK). Personal identity codes were replaced with study numbers in the Oracle database. Further data preprocessing resulted in a derived tables in the database, and separate research datasets can be con-structed by using tailored SQL-queries to the basic database.

A total of 637 585 persons in Finland with potential diabetes were found. By using personal identity codes of this cohort, follow-up data were obtained from the above mentioned registers as well as from the Finnish Cancer Registry and the Finnish Registry for Kidney Diseases. The whole data containing about one hundred million records were stored in an Oracle database at THL. Personal identity codes were replaced by study numbers, and the key was stored separately. Persons were considered having diabetes since the first diabetes diagnosis, beginning of the drug reimbursement right for diabetes medi-cation, or the first purchase of diabetes medication. With the help of special algorithms persons were further classified to have either insulin-dependent diabetes (IDDM), non-insulin dependent diabetes (NIDDM), gestational diabetes only, or no confirmed diabetes9.

Regional T2Diabetes Register (T2DR)

The T2DR is an integrated register based on the Ecomed platform (Datawell Ltd). Patient cases from 2008 were collected from four separate IT- systems (figure 2). Two of these systems were Ecomed Pa-tient Consulting systems in the Helsinki University Central Hospital (HUCH) and in the municipal health centre of Helsinki. One feeder system was an Ecomed system used for reporting in the clinical laboratory (HUSLAB) providing services to HUCH and the region including the cities participating in the T2DR. Furthermore, we retrieved information from the EMR in the municipal health centre of Espoo (Effica, Tieto Ltd). Both municipalities gave written consent for the data utilization.

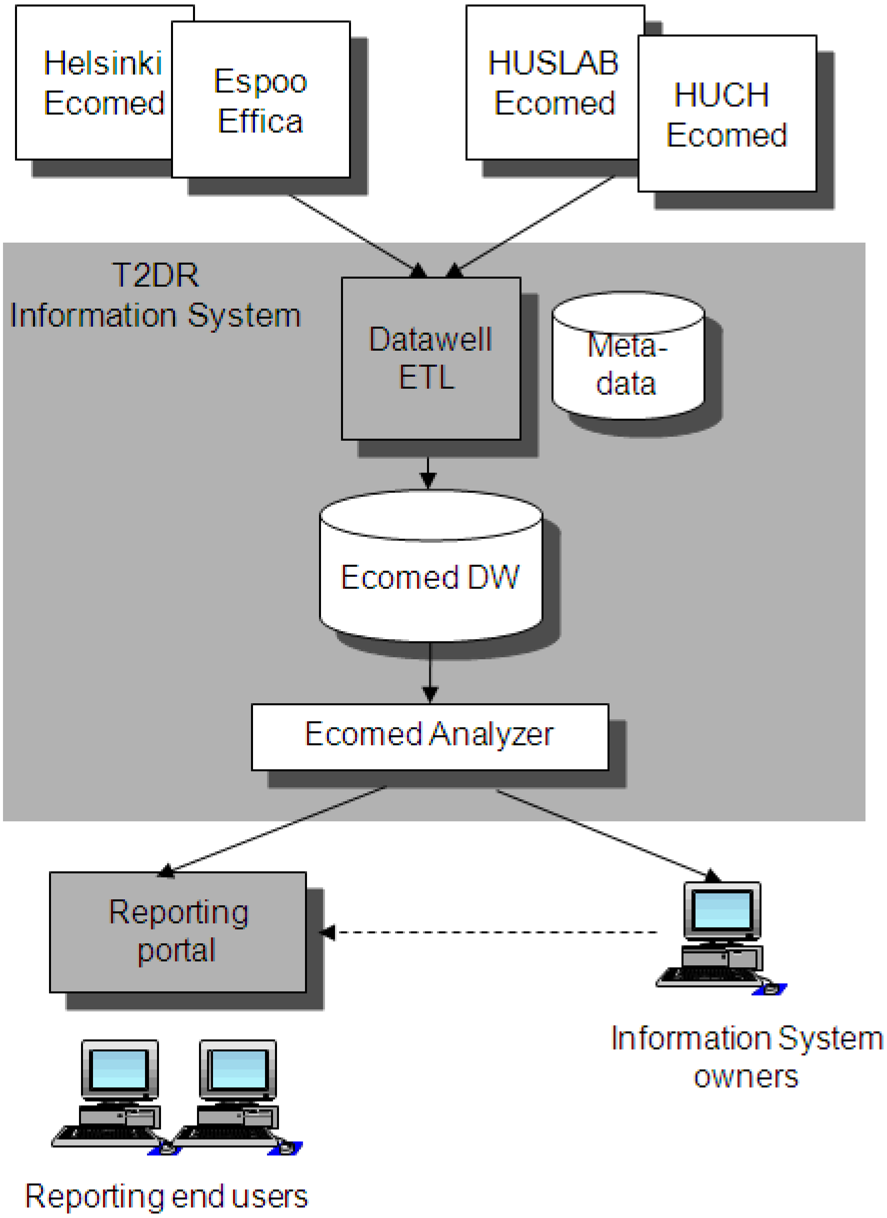


Figure 2. T2DR dataflow model. Information was derived from four feeder data systems. Three of these were Ecomed (Datawell Ltd) data systems in Helsinki Health Centre, Helsinki University Central Hospital (HUCH), and HUSLAB, a laboratory service provider. Data was also obtained from an elec-tronic medical record (Effica, Tieto Ltd) of Espoo Health Center. Data cleansing, coding standardiza-tion and case matching were done during the ETL process. Data were filed into Ecomed database which was then used for end user analytical purposes.

All patient identification (personal identity codes) were encrypted using an encrypting tool (DWCrypt 4.0) based on an asymmetric encrypting algorithm and a specified process. This approach allows linking patient data from multiple sources.

To identify the group of diabetic patients four criteria were used: 1) ICD-10 diagnosis codes E10-E14, 2) ICPC (International Classification of Primary Care) code T90, 3) glycated haemoglobin A1c > 6% and, 4) more than one visit for care utensil dispensing services of the City of Espoo. The ICD-codes E10-E14 and ICPC code T90 were searched from 2008 data in Helsinki and HUCH databases. In Espoo, the data extraction query included patients with these codes during the whole life span of the electronic patient register (from 2003 onwards). Glycated haemoglobin measurement results were ex-tracted from the HUSLAB Ecomed database.

Self-care utensil dispensing units are used by diabetic persons to receive blood glucose self-monitoring tabs, syringes, and needles etc. Dispensing visits were registered only in Espoo, and were stored in the electronic medical record database. Diabetic persons who had deceased during 2003-2007 in Espoo were eliminated from the query by running a check against the National Causes of Death Register.

Confining the validation to geographical location and time period

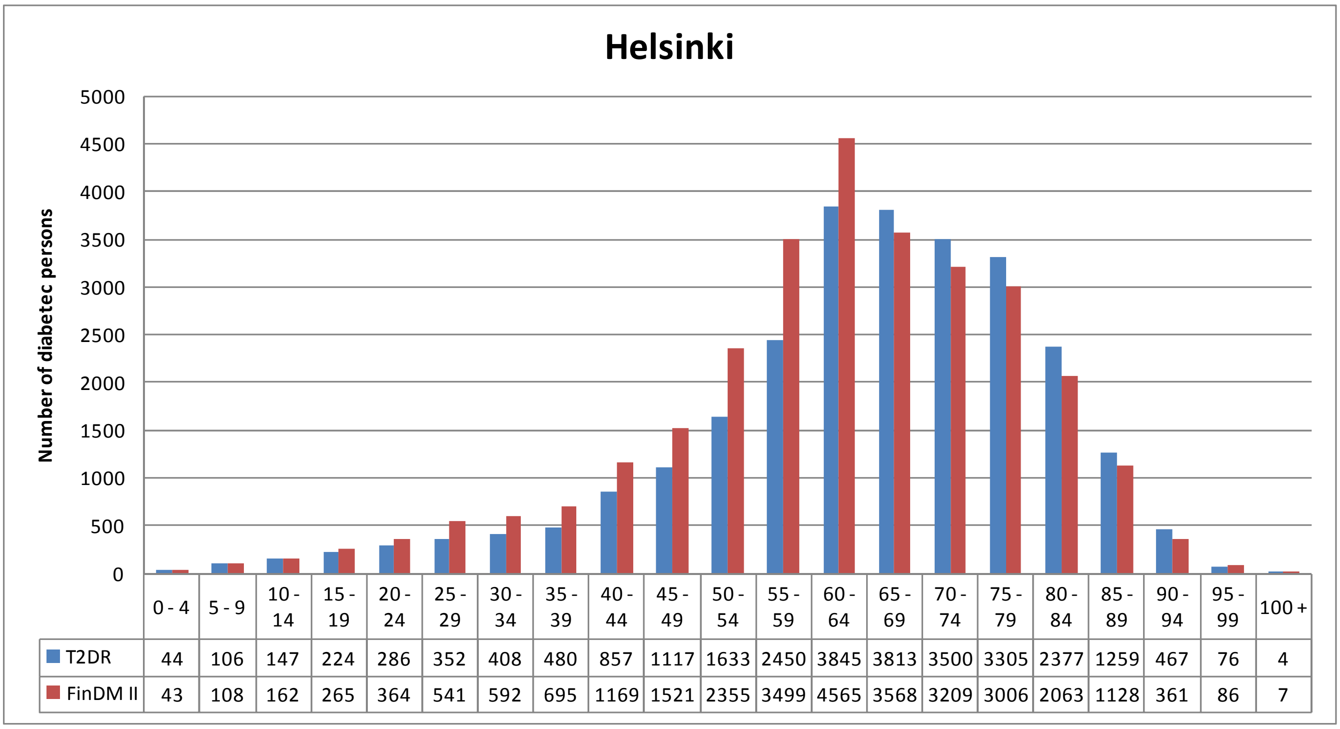
The numbers of diabetic persons alive in 2008 were estimated in five-year-age-groups from both data sources. Individual-level record linkage of the databases was not possible, and therefore comparisons were based on tabulated data. Validation could be performed only for the two municipalities. Persons living in these two municipalities were determined using municipality codes.

As the FinDM II data did not contain complete data for 2008, the number of diabetic persons alive in 2008 was approximated by summing the prevalence of persons with IDDM or NIDDM on the last day of the year 2007 and the estimated number of new cases during 2008 (estimated as the number of new cases during 2007).

Results

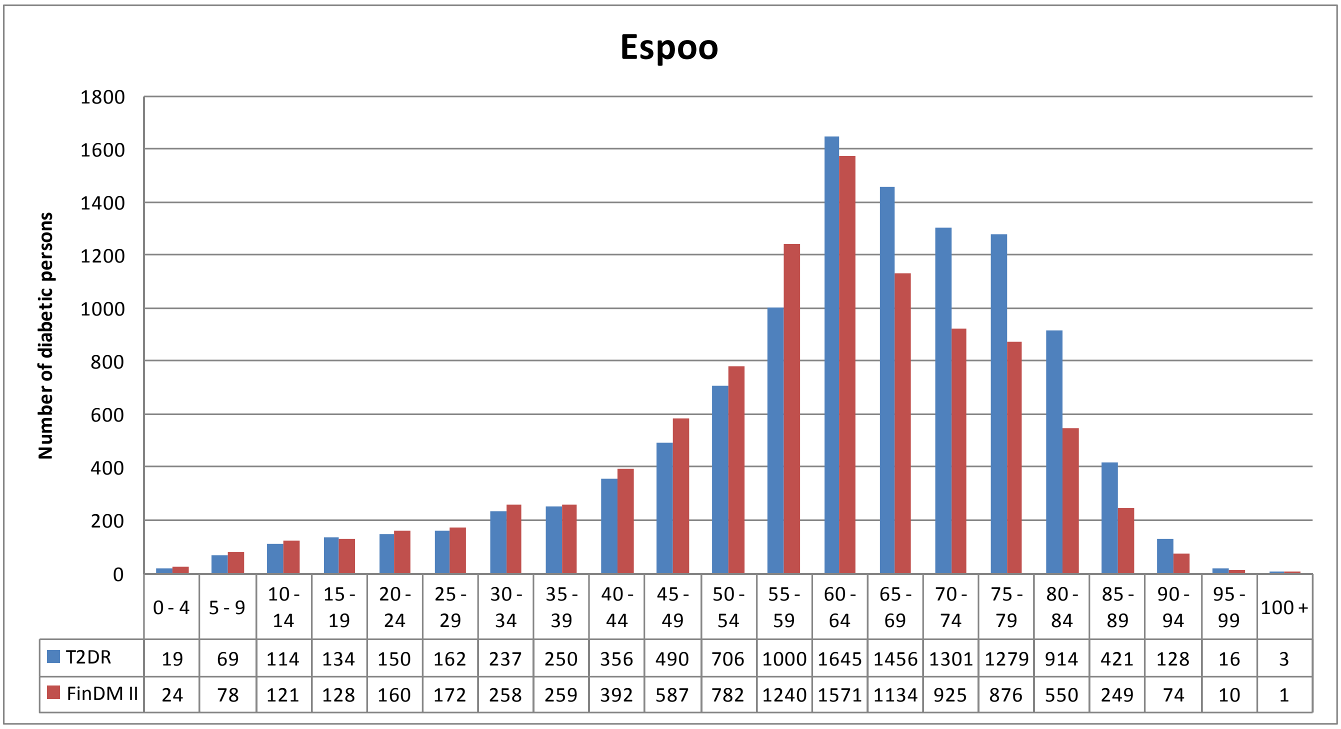
Based on the above criteria a total of 38 898 and 37 611 diabetic persons (residing in Espoo or Helsinki in 2008) were identified in the national and regional register, respectively. The difference in the number of known diabetic persons between the two registers was 1 287 (3,4% more persons with diabetes in the FinDM II data). The estimated prevalence of known diabetes was accordingly 4,75% (FinDM II) and 4,60 % (T2DR).

The number of diabetic persons and their age distribution in the two municipalities is shown in figures 3 and 4. Age was unknown in T2DR for 11 persons. In Espoo, T2DR detected 1 270 (13%) more diabetic persons than FinDM II, and in Helsinki FinDM II was able to identify 2 557 (9,6%) more diabetic per-sons than T2DR.



	0 - 4	5 - 9	10 - 14	15 - 19	20 - 24	25 - 29	30 - 34	35 - 39	40 - 44	45 - 49	50 - 54	55 - 59	60 - 64	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90 - 94	95 - 99	100 +
🟦 T2DR	44	106	147	224	286	352	408	480	857	1117	1633	2450	3845	3813	3500	3305	2377	1259	467	76	4
🟥 FinDM II	43	108	162	265	364	541	592	695	1169	1521	2355	3499	4565	3568	3209	3006	2063	1128	361	86	7

Figure 3. The age-group specific numbers of identified diabetic persons in 2008 in Helsinki from the T2DR and FinDM II registers



	0 - 4	5 - 9	10 - 14	15 - 19	20 - 24	25 - 29	30 - 34	35 - 39	40 - 44	45 - 49	50 - 54	55 - 59	60 - 64	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90 - 94	95 - 99	100 +
🟦 T2DR	19	69	114	134	150	162	237	250	356	490	706	1000	1645	1456	1301	1279	914	421	128	16	3
🟥 FinDM II	24	78	121	128	160	172	258	259	392	587	782	1240	1571	1134	925	876	550	249	74	10	1

Figure 4. The age-group specific numbers of identified diabetic persons in 2008 in Espoo from the T2DR and FinDM II registers

The absolute numbers were very well matched in the youngest (0-19 years) and oldest (aged 95 years or older) age groups; in Espoo the match was rather good also for persons aged 20-39 years. There were significant differences in the numbers for other age-groups. The largest absolute difference in the num-ber of diabetic persons was detected in persons aged 20 to 64 years living in Helsinki; over 3 800 (34%) more diabetic persons were retrieved in the FinDM II data than in the T2DR data. In Espoo, difference in the same age group was only 425 person (8,5%). Among the persons aged 65 years or more, the T2DR identified in Helsinki almost 1 400 (10%) and in Espoo 1 700 (44%) more persons with diabetes than the FinDM II.

Conclusions

Both FinDM II and T2DR are new stand-alone registers that contain anonymous individual-level infor-mation from multiple databases. FinDM II is a nationwide research database currently containing com-plete data on identified diabetic persons alive during 1988-2007, and is especially suitable for monitor-ing of the prevalence and incidence of diabetes and its complications in Finland as well as for regional comparisons of these factors.

T2DR contains data for 2008 from operational patient databases of two of the largest Finnish municipal-ities and public hospital covering clinical and laboratory services to the region. It is well suited to sup-port diabetes care in the public sector and population care management. T2DR permits monitoring of performance of the care system, individual health centers and diabetes teams by providing population reports and trends after repeated data retrieval periods. It allows segmenting patient data, pinpointing patient cases with suboptimal care, and then returning this data to the point of care, which may help to apply resources in a more targeted way.

In this study, we evaluated the completeness of registration in these two databases. Data from Helsinki and Espoo were available in both registers. However, as the last complete year in FinDM II was 2007 but only the year 2008 was available in T2DR, there was a need to predict the numbers for the year 2008 were predicted in the FinDM II data. The used prediction algorithm may have resulted in a small underestimation as the number of new cases has probably been a bit higher in 2008 than in 2007.

It was known a priori that virtually all persons with purchases of diabetes medication were included in the FinDM II data, but persons on diet therapy only were missed if they had not received any inpatient or hospital care as there were no nationwide data on outpatient primary care available. Since FinDM II utilized only administrative registers, persons with unknown diabetes could not be detected. On the other hand, T2DR collected results on glycated haemoglobin A1c from the laboratory database and this may be reflected in the numbers of diabetic persons with either diet only or indicate unknown diabetes.

The evaluation of case inclusion in T2DR and FinDM II registers showed that the overall figures were to a large extent identical (3,4% difference in the size of the cohorts). There were two notable excep-tions – working age adults in Helsinki (an excess of about 3 800, i.e. 34 %, diabetic persons were de-tected in FinDM II) and retired seniors in both municipalities (an excess of almost 3 100, i.e. 18%, di-abetic persons in T2DR). Working age adults acquire their medical services from mostly private occu-pational health clinics, whereas the retired older citizens are dependent on the public health care servic-es.

This health care service use probably explains the differences in the age-specific numbers of diabetic persons in the two registers. T2DR probably missed working age persons treated in occupational health clinics in Helsinki, but FinDM II was able to identify them because of the medication use. T2DR de-tected almost as many persons in working age as FinDM II in Espoo, which is explained by data collec-tion procedures, since also those diabetic persons from Espoo are included who receive their self-care utensils from the municipality although they may still be treated outside public health care. The diagno-sis codes in Espoo were also queried for a longer time period (2003-2008) compared to Helsinki (2008) which may, in part, explain the differences between the two cities. The difference among senior citizens is for the most part due to the fact that administrative data used in FinDM II was not able to detect the persons on diet only and persons with unknown diabetes are missed, although they may be included in T2DR because of diagnosis coding in primary care or laboratory data.

In conclusion, both registers missed some diabetic persons, and therefore the prevalence of diabetes in these two municipalities may be estimated to clearly exceed 5%. Capture-recapture techniques could not be utilized in the estimation of the size of diabetic population as only tabulated data were available for comparisons. As the comparisons were made for two large cities, the results may be generalized to the rest of Finland, i.e. the FinDM II may miss as much as 40% of diabetic persons aged 65 years or more, who are either on diet treatment only or have unknown diabetes. Although the registers are intended for somewhat different purposes, they are complimentary to each other. In the future, it might be an appealing option to compile a register that includes data from all of the data sources of FinDM II and T2DR.

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