FinDM II

On the register-based measurement of the prevalence and incidence of diabetes and its long-term complications

A technical report

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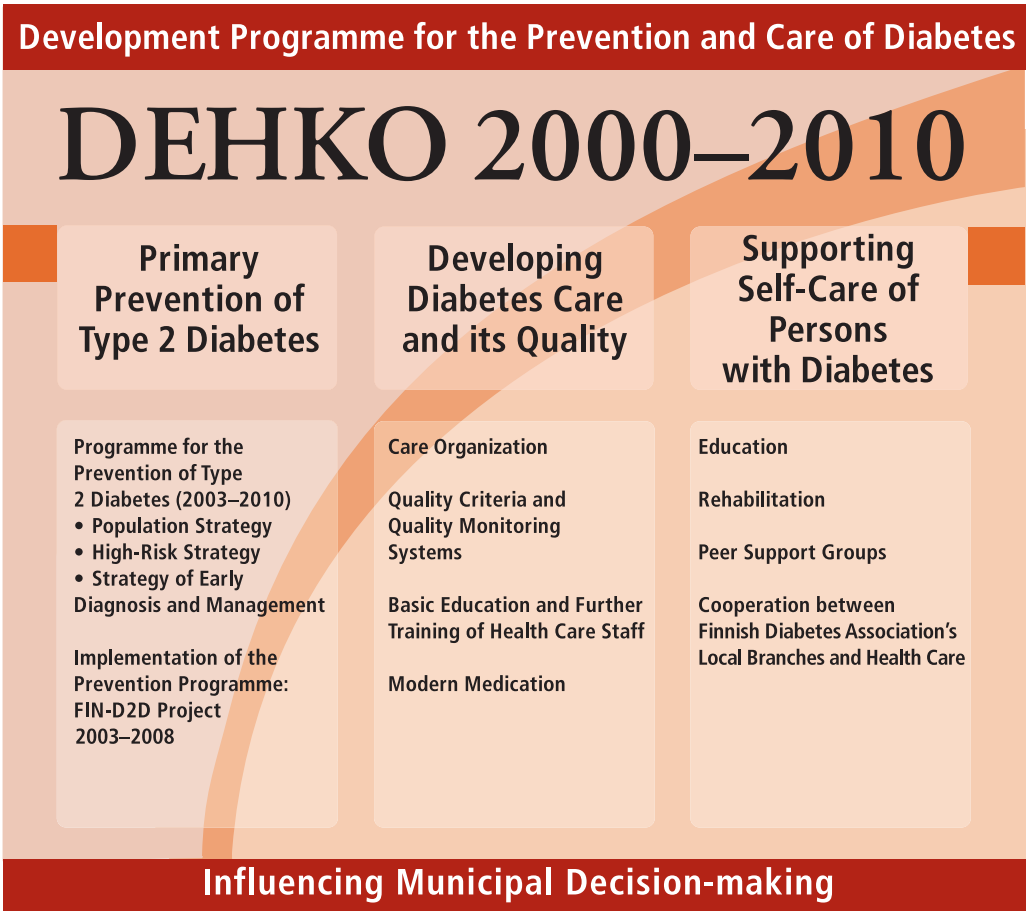
Development Programme for the Prevention and Care of Diabetes
DEHKO 2000–2010
Primary Prevention of Type 2 Diabetes
Developing Diabetes Care and its Quality
Supporting Self-Care of Persons with Diabetes
Programme for the Prevention of Type 2 Diabetes (2003–2010)
• Population Strategy
• High-Risk Strategy
• Strategy of Early Diagnosis and Management
Implementation of the Prevention Programme: FIN-D2D Project 2003–2008
Care Organization
Quality Criteria and Quality Monitoring Systems
Basic Education and Further Training of Health Care Staff
Modern Medication
Education
Rehabilitation
Peer Support Groups
Cooperation between Finnish Diabetes Association's Local Branches and Health Care
Influencing Municipal Decision-making

Background

A great deal of background information is needed in order to arrange the treatment of people with diabetes. In national healthcare policy information on the incidence and progression of diabetes and the complications it causes is essential. Hospital districts and decision-makers in primary health care need corresponding information on regional and local level for purposes of arranging treatment. Moreover, information is needed on the quality of the care already provided. The appropriate allocation of resources requires a clear picture of the treatment resources needed for the most important national diseases, the number of people to be cared for and the productivity, effectiveness and quality of treatment.

The Development Programme for the Prevention and Care of Diabetes (DEHKO 2000–2010) had as its objective the reduction of the persons with diabetes cardiovascular diseases by at least one third, the reduction of amputation of the lower extremities by at least a half, the reduction of reticular diseases by at least a third and the reduction of kidney diseases by at least a third from 2000 to 2010 (1). These targets can be achieved with good diabetes care.

In order to ensure good care for persons with diabetes a monitoring system has been proposed in Finland which would provide information on the state of care of persons with diabetes and its development in treatment units both regionally and nationally (2). As a result of this proposal a co-operation project entitled Diabetes in Finland (FinDM I) was initiated by the National Research and Development Centre for Welfare and Health (STAKES), the Social Insurance Institution of Finland (KELA) and the Finnish Diabetes Association to ascertain the suitability of the administrative registries for monitoring the incidence of diabetes and its long-term complications and their regional differences during the period 1988–2002 (3). The FinDM II - study now at hand organized jointly by the National Institute for Health and Welfare (currently THL, formerly Stakes) and the Finnish Diabetes Association (Dehko) is a continuation of the FinDM I Project, the period under scrutiny being the years 1997–2007.

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Diabetes

Numerous reasons contribute to the aetiology of diabetes, its basic feature being an increase in the glucose content of the blood sugar or plasma, i.e. hyperglycaemia. Hyperglycaemia is a consequence either of impaired or lacking insulin secretion or of the impaired effect of insulin or then of both. Diabetes affects the quality of life, causes further diseases and increases mortality. Its treatment requires great and constantly increasing resources.

Classification of diabetes and glucose metabolism disorders

According to the WHO criteria a diagnosis of diabetes is based in the case of a symptom-free subject either on recurring elevated plasma glucose content in fasting (at least 7 mmol/l) or in testing on a two-hour elevated glucose level (over 11 mml/l). If the fasting level is 6.1–6.9 mmol/l it is referred to as impaired fasting glucose (IFG). If the two-hour value is 7.8–11 mmol/l it is referred to as impaired glucose tolerance (IGT). In the prevention of diabetes it is important to detect these pre-diabetes stages. Gestational diabetes (diabetes during pregnancy) entails the use of different criteria. (5)

- type 1 diabetes: caused by the destruction of the betacells which produce insulin as a consequence of an autoimmune process
- type 2 diabetes: caused by the impaired effect of insulin (insulin resistance) or a disturbance in the secretion of insulin or both
- gestational diabetes: caused by in elevated need for insulin due to hormonal changes
- diabetes due to other reasons: caused, for example, by pancreatitis, hormonal disturbance, pancreatectomy or haemochromatosis.
- All types of diabetes may present with differing symptomatology.

Prevalence of diabetes

There are some 280,000 people diagnosed with diabetes receiving treatment in Finland, most of them (85%) with type 2 diabetes. In recent years diabetes has been one of the most rapidly spreading diseases in Finland according to the KELA Health Insurance Register of medications subject to elevated reimbursement. (4) According to the KELA register, 269,181 people were being reimbursed for antidiabetic medication in 2008. Moreover, it has been estimated that some 200,000 Finnish people have diabetes without knowing it (9). At the present rate the number of persons with diabetes receiving treatment is expected to double in Finland each 12 years unless major preventive measures are undertaken. (7) It was observed on the Diabetes in Finland (FinDM I) Study that there are major regional differences in prevalence. The prevalence of type 1 diabetes is highest in the east of Finland and lowest in northern Finland. Type 2 diabetes is found most commonly in Ostrobothnia and eastern Savo and least in Ahvenanmaa. (3)

The increase in type 2 diabetes is likely attributable to ageing of the population and to the increase of overweight and obesity in the population. In the area of the Finrisk Study the average body mass index of men aged 30–59 was just under 26 kg/m^2 in 1972 whereas in 2007 it varied between 26.7 kg/m^2 and 27.7 kg/m^2. For women in the same age group the development in body mass index has been variable, and no similar steadily rising trend as for men could be discerned. In 2007 the average body mass index weighted for age and region was 27.0 kg/m^2 for men and 26.5 kg/m^2 for women. People of normal weight (body mass index under 25 kg/m^2) weighted for age and region accounted for in 34% of men and 47% of women. (8)

Over the years waist circumference has increased in both sexes. In 1987 the average waist circumference of men aged 25–64 was 92–93 cm. In 2007 it ranged from 96 cm to 99 cm. For women of the same age the average waist circumference has increased from 80 cm in 1987 to 86–88 cm in 2007. (8)

Other factors with bearing on the increase in the number of persons with diabetes are improved diagnostics and better treatment leading to longer life (7,9). The development of type 2 diabetes at ever younger ages is a cause for concern and imposes demands to step up both primary and secondary preventive work. Type 1 diabetics account for some 15% of all diabetes cases, thus there are some 40,000 people with type 1 diabetes. (3) Diabetes is moreover one of the most common chronic diseases among children. The number of new children with diabetes is currently increasing at an annual rate of 3%. (10)

Diseases associated with diabetes

Long-term elevated plasma glucose levels and the general metabolic symptomatology of diabetes make diabetics susceptible over the years to various complications. These can be divided into diabetes-specific and other diseases occurring more frequently among diabetics than among general population. Long-term complications of diabetes include microangiopathic illnesses caused by damage to the capillaries such as retinopathy, nephropathy and neuropathy. (11)

Other diseases occurring more frequently among diabetics include vascular diseases such as circulatory problems in the lower extremities, cardiovascular disease and cerebral circulatory diseases. Most of these are attributable to atherosclerosis, which are caused by many other factors in addition to diabetes. (12)

The significance of diabetes to the health of the nation is largely due to these diseases. Vascular diseases are numerically the largest group of diseases associated with diabetes. Diabetes is the main reason for coronary and brain infarcts and for amputations of the lower extremities as a consequence of vascular diseases in these organs. Diabetes is also associated with serious diseases of the kidneys and the eyes. (3) Diabetes costs society a great deal, consuming 10–15% of the costs of healthcare. Of these at least two thirds is consumed by the treatment of preventable long-term complications. (13,14,15)

Purpose and objectives of the research

The purpose of the current study is to improve the monitoring of the incidence and prevalence of diabetes and its long-term complications on the basis of the data held in national registries. The research is being conducted as co-operation between the National Institute for Health and Welfare (THL) and the Finnish Diabetes Association. It constitutes a continuation of the earlier Diabetes in Finland (FinDM I) Project.

The objectives are

- to create a research register suitable for the monitoring of diabetes and its long-term complications by combining national registry data
- to harmonise the indicators used in monitoring the prevalence and incidence of diabetes and its long-term complications (AMIs, strokes and amputations of the lower extremities related to vascular diseases)
- to calculate indicators for the years 1997–2007 on the basis of the registry data
- to ascertain whether it is feasible to use registers for monitoring the incidence of eye and kidney diseases
- to generate more information on changes in the prevalence of long-term complications by region and time period
- to scrutinize the co-occurrence of diabetes and mental health problems.

Data and definitions

To create the research register we used register-based data from national registries.

The purpose of the research register is to enable the monitoring of the incidence and prevalence of diabetes and its long-term complications in Finland (the FinDM II Project). The research register is also to be used in a 'Costs of Diabetes in Finland' (CoDiF) study that examines the regional differences in the use of healthcare services as well as incosts occasioned by diabetes, and for several other scientific investigations.

The research data comprises register information from the National Institute for Health and Welfare (THL), the Social Insurance Institution of Finland (KELA), the Finnish Centre for Pensions and the Finnish Kidney and Liver Association. Permission to use the data of THL is derived from a co-operation agreement between THL and the Finnish Diabetes Association and an additional agreement. Permission to use the data from KELA, Statistics Finland, the Finnish Kidney and Liver Association and the Finnish Centre for Pensions was obtained through applications to the respective organisations.

Identification of people with diabetes

The first aim in the creation of the research register was to identify as comprehensively as possible all the persons with diabetes in Finland by using the register data.

Individuals were deemed potentially diabetic if they met at least one of the following criteria

- diabetes diagnosis from the Hospital Discharge Register ICD-8 (1969–1986)
- diabetes diagnosis from the Hospital Discharge Register ICD-9 (1987–1993)
- diabetes diagnosis from the Finnish Health Care Register ICD-9 (1994–1995)
- diabetes diagnosis from the Finnish Health Care Register ICD-10 (1996–2007)
- diabetes diagnosis from the Hospital Benchmarking database (1998–2007)
- diabetes entry (insulin_initiated=K or Diabetes=K) or diagnosis from the Medical Birth Register 1987–2007 (ICD-9 and ICD-10)
- information from the Diabetes in Finland (FinDM I) Study data
- diabetes diagnosis from the Register of Causes of Death (1988–2006)
- entitlements to elevated reimbursement for antidiabetic medications (Code 103) on the register of the Social Insurance Institution of Finland (KELA) 1988–2007
- entry of purchase of antidiabetic medications (ATC codes A10) in the KELA prescription database 1994–2007.

Diagnoses used in the in the identification of persons with diabetes are presented in Table 1.

Table 1. Diabetes diagnoses used in the identification of persons with diabetes

	ICD-8	ICD-9	ICD-10
Type 1		250?B (DM type I)	• E10 (diabetes in youth) • O24.0 (diabetes prior to pregnancy treated with insulin)
Type 2		250?A (DM type II)	• E11 (adult diabetes) • O24.1 (diabetes prior to pregnancy not treated with insulin)
Other		250?C (MODY)	• E12 (diabetes associated with malnutrition) • E13 (other diabetes) • O24.2 (diabetes prior to pregnancy associated with malnutrition) • P70.2 (neonatal diabetes)
Gestational diabetes	7611 (diabetes mellitus matris	6480 (diabetes mellitus 7750 (child of a diabetic mother)	• O24.4 (gestational diabetes) • O24.9 (unspecified diabetes in pregnancy) • P70 (effect of mother's diabetes in pregnancy on newborn) • P70.1 (child of diabetic mother)
Unspecified	250 Diabetes mellitus	250?X (DM not further specified) 3620 (diabetic retinopathy)	• E14 (unspecified diabetes) • G59.0 (disease of one nerve in diabetes) • G63.2 (disease of multiple nerves in diabetes) • H28.0 (diabetes-related cataract) • H36.0 (diabetic retinopathy) • I79.2 (peripheral angiopathy in diabetes) • M14.2 (diabetes-related articular disease) • M14.6 (diabetes-related neuropathic disease) • N08.3 (diabetes-related glomerular disorder) • O24.3 (unspecified diabetes prior to pregnancy) • Z83.3 (family history of diabetes)

Figure 1 provides a graphic representation of the identification of the study cohort. The personal identity codes (pic:s) of the potential persons with diabetes found from the causes of death Register (maintained by Statistics Finland) and from the THL registers were forwarded to KELA, where the personal identity codes of persons with diabetes in the KELA registers added to the cohort. For purposes of research on costs (CoDiF) non-diabetic controls in general population were picked for persons with diabetes dying in 2006. Utilizing KELA general information it was possible to take account of individuals' changed personal identity codes. Information on municipality of residence in the last days of the years 1988–2007 for those included in the cohort was obtained. The final cohort comprised 637,585 individuals potentially suffering from diabetes and 9,824 non-diabetic controls.

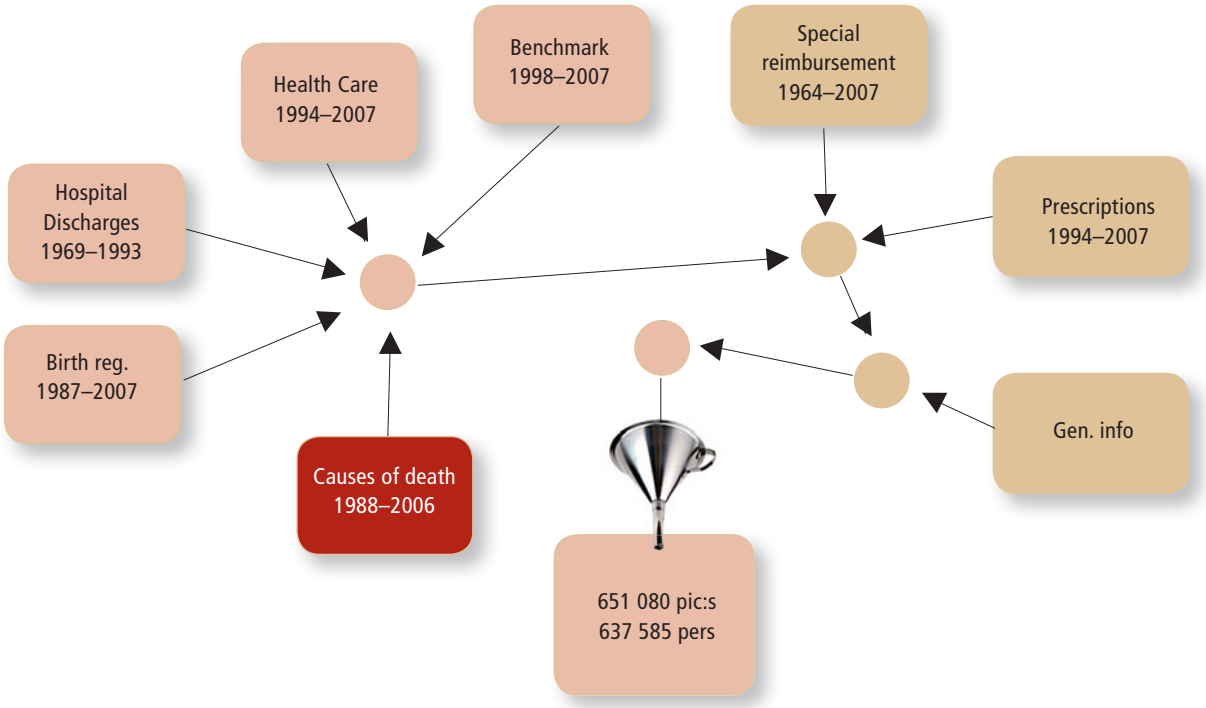

Figure 1. Identification of the diabetes cohort

Follow-up data

Figure 2 presents how follow-up data on the identified cohort were collected. Information on inpatient care during the years 1969–1993 were obtained from the Hospital Discharge register and for the period 1994–2007 from the Health Care register. Outpatient surgical procedures 1994–2007 were taken from the Health Care Register and outpatient visits to specialized healthcare for the period 1998–2007 from the Benchmarking database. The register data compiled included variables describing among other service provider, specialty, date of arrival, mode of arrival, date of discharge, discharge destination, main and subsidiary diagnoses, main procedure and date of procedure, likewise other procedures. Information on all deliveries for the period 1987–2007 was obtained from the Medical Birth Register. Information on cancers for the period 1953–2007 (year and diagnosis) was obtained from the Finnish Cancer Registry.

The Causes of Death Register was used to obtain the dates and cause of death as determined by a doctor, diagnosis pertaining to the primary cause of death, immediate cause of death, indirect cause of death and contributory causes of death.

The register of kidney diseases of the Finnish Kidney and Liver Association was used as a source of information for times of treatment and diagnoses of kidney patients.

The KELA register of special reimbursements was used as a source of entitlements to special reimbursement for the period 1988–2007. The data include information on the day such special reimbursement was authorized and of the possible termination date of such reimbursement, likewise more precise diagnostic codes for the more recent years. The KELA prescription database was used as a source for data on reimbursable purchases of medicaments by purchase including ATC code, package size, date of purchase, costs and average daily dose (DDD). In addition data on sickness allowances and pensions paid by KELA were obtained from the registers.

The Finnish Centre for Pensions database was used as a source for other information on pensions for information on those included in the cohort.

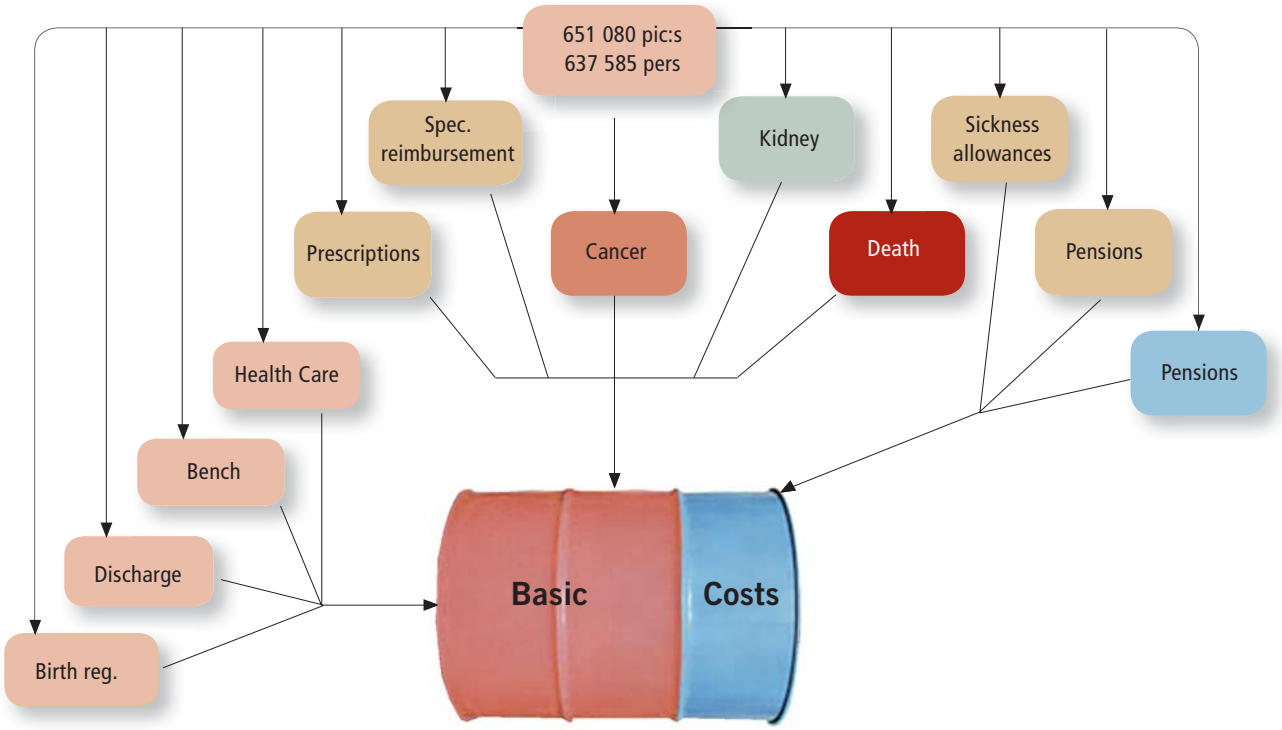

Figure 2. Collection of follow-up data on the diabetes cohort

Research data and definitions

The personal identity codes used for data selection were replaced with research numbers and the follow-up data was stored in a database. An estimated date for the beginning of diabetes was obtained by searching for the first diabetes entry. Diabetes entry refers here to a diabetes diagnosis in the Hospital Discharge Register, the Finnish Health Care register, the Hospital Benchmarking database or the mortality statistics, information on entitlement to special reimbursement for antidiabetic medications or information on the purchase of antidiabetic medications.

Classification of persons with diabetes

Potential persons with diabetes alive during the period 1997–2007 were divided on the basis of register data into three groups: persons with insulin-dependent diabetes mellitus (IDDM), non-insulin-dependent diabetes mellitus (NIDDM) and gestational diabetes mellitus.

First persons died prior to 1997 were excluded. Next those individuals were classified into a group of their own for whom no record of entitlement to special reimbursement, purchase of antidiabetic medications or clear diabetes diagnosis could be found.

Gestational diabetes group was defined to include those women of fertile age for whom (gestational) diabetes entries could be found only in connection with pregnancy (i.e. solely diagnoses of gestational diabetes, purchase of antidiabetic medications only in connection with pregnancy or entry of diabetes only in the Medical Birth Register).

The classification into insulin-dependent and non-insulin-dependent persons of diabetes was made primarily on the basis of medicament purchases. It was assumed that in practice all persons with IDDM require constant insulin therapy (ATC:A10A) but that they do not use tablets intended to increase pancreatic insulin secretion (sulphonylureas A10BB, sitagliptin/vildagliptin A10BH, repaglinide A10BX02, nateglinide A10BX03 or exenatide A10BX04).

On the basis of this assumption those individuals were classified as persons with NIDDM who had purchased medicaments intended to increase the secretion of pancreatic insulin or for whom there were more years of tablet medication (ATC:A10B) than years of purchasing insulin. Thereafter those persons deemed insulin-dependent who had regu-

larly purchased insulin and for whom more years of purchasing insulin were found than years of purchasing medicaments in tablet form. If the age at first diabetes entry did not exceed 40 years and if the years of purchasing insulin were as many as the years of purchasing tablets, the individual was classified to have IDDM. Other subjects classified as insulin-dependent included those who after 1999 had been granted entitlement to special reimbursement for medications on a diagnosis of type 1 diabetes. The remaining subjects were classified to have NIDDM. The numbers of individuals classified into the various groups are presented in Table 2.

Table 2. Numbers of persons with diabetes in the various groups within the cohort

Class	Number
Died prior to 1997	180,813
No actual diabetes entries	7,740
Gestational diabetes	52,715
Insulin dependent diabetes (IDDM)	50,027
Other diabetes (NIDDM)	346,290
Total	**637,585**

Describing the indicators used in follow-up

For the purposes of the study the indicators reported in the publication Diabetes in Finland were reviewed. The descriptions of the indicators were made according to the model of the report Diabetes Outcome Indicators (16) by applying where possible the indicator definitions used in the FinDM I Study.

The descriptions of the respective indicators are accompanied by the aim of the indicator, the bases and possible modes of application. Possible limitations of the respective indicators are also considered.

The descriptions of the indicators are presented in Annex 1.

Description of the primary data

Numerous different registers were used in this study for the identification of persons with diabetes. On the basis of the information contained in them the registers can be divided into those reflecting medication (special reimbursement entitlement for antidiabetic medications, purchases of antidiabetic medications), those describing use of services (the Finnish Health Care Register, the Hospital Discharge Register, the Benchmarking database) and demographic registers (Medical Birth Register, Causes of Death Register). Tables 3 and 4 show from where the persons with diabetes alive during the period 1997–2007 were identified.

Table 3. Persons with diabetes by source of data

	Insulin-dependent	Other	Gestational
Medication only	1,836	156,285	564
Services only	0	24,961	23,703
Demography only	0	1,783	2,360
Meds + services	38,703	123,279	1,298
Meds + demography	79	4,906	75
Services + demogr.	0	2,376	21,187
Meds + services + demography	9,409	32,700	3,528
Total	50,027	346,290	52,715

Table 4. Persons with diabetes by source of data

	Insulin dependent	Other	Gestational
Medication, with	50,027	317,170	5,465
Special reimbursement only	81	4,463	0
Purchases only	1,618	101,403	5,465
Reimbursement + purchases	48,328	211,304	0
Use of services with	48,112	183,316	49,716
Treatment info only	9,698	103,024	11,459
Outpatient only	1,252	25,387	11,604
Treat. + outpatient	37,162	54,905	26,653
Demographic regs.	9,488	41,765	27,150
Med. Birth Reg.	3,214	980	27,148
Causes of Death Reg.	6,321	40,790	2
Total	**50,027**	**346,290**	**52,715**

Prevalence of diabetes

Factors with bearing on the annual number of persons with diabetes are affected not only by the number of new cases of diabetes diagnosed but also by mortality among persons with diabetes. Scrutiny of the annual number of persons with diabetes revealed that at the end of 1997 the total number of persons with diabetes was 171,596, of whom 33,259 (19%) had IDDM and the other 138,337 (81%) had NIDDM. At the end of 2007 the total number of persons with diabetes had risen to 284,832. Here persons with IDDM numbered 39,575 (13%) and persons with NIDDM 245,257 (87%). The total number increased 65% from 1997 to 2007 (Table 5). The increase in the number among IDDM was 19% among NIDDM the increase was 77%. Examination of the annual percentage increases in the total number among diabetes revealed an average increase of 4.7% per year: the annual growth percentage among IDDM was 1.3 and among NIDDM 5.5.

Table 5 Annual numbers of persons with diabetes on the last days of the years 1997–2007

Year	Total	Women (%)	IDDM	Women (%)	NIDDM	Women (%)
1997	171,596	53.6	33,259	44.1	138,337	55.9
1998	178,991	53.1	33,596	43.8	145,395	55.2
1999	186,446	52.6	34,016	43.6	152,430	54.6
2000	194,718	52.0	34,512	43.3	160,206	53.9
2001	204,019	51.5	35,097	43.2	168,922	53.2
2002	213,988	51.0	35,615	43.1	178,373	52.6
2003	224,246	50.5	36,259	42.8	187,987	52.0
2004	238,294	50.1	36,926	42.7	201,368	51.4
2005	252,163	49.7	37,759	42.5	214,404	51.0
2006	265,567	49.4	38,598	42.3	226,969	50.6
2007	284,832	49.0	39,575	42.1	245,257	50.1

It was observed in the Diabetes in Finland Study (9) that the share of women among persons with diabetes constantly declined. The same was observed in the present study regarding the gender distribution of persons with diabetes. (Table 5) The share of women among persons with IDDM was considerably smaller than that of men. In 1997 women accounted for 44.1% of persons with IDDM and this declined to 42.1% by 2007. For persons with NIDDM women had been in the majority. In 1997 they accounted for 55.9% of persons with NIDDM but by 2007 the share of women had diminished to 50.1%. Thus with regard to both types of diabetes the disease is becoming increasingly a disease of men.

Incidence of diabetes

The annual number of new diabetes cases was also scrutinized in this study (Table 6). In 1997 a total of 16,676 new cases of diabetes were identified. Of these 1,264 (8%) had IDDM and 15,412 (92%) had NIDDM. In 2007 a total of 30,677 new cases of diabetes were identified of whom 1,944 (7%) had IDDM and 28,733 (93%) had NIDDM. Between 1997 and 2007 there was an increase of 83% in the number of annually identified new cases of diabetes. There was an increase of 53% in the incidence of persons with IDDM and an increase of 86% in the incidence of persons with NIDDM. In both types of diabetes the share of women continued to decline. The marked increase in NIDDM can likely be explained by the early identification of diabetes in recent years and the active improvement in diagnosis, effective initiation of medication in consequence of a change in the treatment recommendations and at population level the undesirable development in eating and exercise habits and the marked increase in obesity, likewise aging of the population.

Table 6. New cases of diabetes annually during the period 1997–2007

Year	IDDM	Women (%)	NIDDM	Women (%)	Total
1997	1,264	38.1	15,412	52.9	16,676
1998	1,366	38.9	15,556	50.6	16,922
1999	1,385	39.4	15,724	49.3	17,109
2000	1,474	36.3	16,675	49.3	18,149
2001	1,513	38.7	17,504	48.2	19,017
2002	1,455	39.4	18,740	48.4	20,195
2003	1,542	36.8	19,065	47.5	20,607
2004	1,587	37.5	22,556	47.4	24,143
2005	1,727	38.7	22,650	47.3	24,377
2006	1,760	37.7	22,437	46.9	24,197
2007	1,944	36.7	28,733	46.6	30,677

Summary

The aim of the study was to update information on the prevalence and incidence of diabetes and its long-term complications in Finland. The registers available were used to generate new information on the prevalence and incidence of diabetes and certain long-term complications in Finland and on their distribution by hospital district. The study moreover yielded data of the people with diabetes age structure, gender distribution and mortality. The prevalence and incidence of non-insulin-dependent diabetes (NIDDM) showed a dramatic increase. So far there are no indications of a levelling out of the trend. The prevalence and incidence of insulin-dependent diabetes (IDDM) are likewise increasing annually.

Reliability and interpretation of register-based data

The registers used in the study were set up for administrative purposes and they were not primarily intended for research on diabetes and its long-term complications. Although the information in Finnish registers is generally of a high standard their use for purposes of scientific research entails numerous challenges.

Identification of people suffering from diabetes was done by combining data from registers of different types. The KELA register of those entitled to special reimbursement and the prescriptions database are good basis sources for identifying people with diabetes on medication. However, it is not possible to identify from the registers of medicaments those living permanently in institutions or people with diabetes only on diets or those individuals who have not purchased the prescribed glucose products. However, these people can indeed be identified through information on treatment periods if an individual has been hospitalized or attended a hospital as an outpatient and if the information entered in the Finnish Health Care Register includes a diagnosis of diabetes. Regrettably there is no register available covering the entire country for outpatient visits made to primary health care or occupational health care, thus not all people with diabetes treated by diet and coming within the sphere of care can be identified by means of register-based data. Further challenges in identifying people with diabetes were posed by variation in the use and entry of diagnoses, especially secondary diagnoses in different areas and in different years.

In the present study age at onset of diabetes was defined on the basis of the chronologically first entry on diabetes found in the registers used. For persons with IDDM this information can be deemed a good estimate of the time of onset but for persons with NIDDM the real onset may have been 5 to 10 years earlier.

In spite of the heterogeneous nature of the aetiology of diabetes and although a clear classification of the various types of diabetes (excluding extreme forms) may be difficult if the classification is based on the doctor's subjective assessment (13), in the present study we wanted to form a conception of the prevalence and incidence of different types of diabetes and of the development of a prediction.

Determining the type of diabetes by means of registers was challenging. In the present study we endeavoured to find a theoretically reasoned definition consonant with the possibilities afforded by the registers and their information content. Thus the point of departure was taken to be difference in medications between types of diabetes. Information on the purchase of medicaments reveals the medications actually in use, thereby providing an evidence-based means for classifying people suffering from diabetes. Therefore in the present study we preferred to classify diabetes types into insulin dependent and other types rather than into type 1 and type 2 diabetes, although the definition to a large extent corresponds to these.

Despite the limitations of the registers there is no reason to assume that the registers do not provide a fairly accurate picture of the prevalence and incidence of diabetes and its long-term complications in various parts of Finland and in various age groups.

Conclusions

The research findings can be contemplated as temporal trends both regionally and nationally. Instead of scrutinizing differences between hospital districts it is recommended that each hospital district concentrate on its own yearly trend and evaluate the development of the situation with the help of treatment practices and resources and of changes in population age and gender structure.

This technical report, in addition to describing data collection, indicator definition and modes of analysis, also describes its findings on national trends in the prevalence and incidence of diabetes. The project moreover ascertained the prevalence and incidence of long-term complications of diabetes both nationally and by hospital district. These findings are to be published on the net pages of both the National Institute for Health and Welfare (www.thl.fi) and the Finnish Diabetes Association (www.diabetes.fi).

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APPENDIX 1. Indicators of the FinDM II

Prevalence of diabetes

Aim	Description	Technical description	Limitations	Justifications	Potential applications	Users	Sources
Monitor numbers of persons with diabetes to target measures at reducing risk. Implement right preventive and screening methods. Also in order to assess future need for treatment and rehabilitation resources	Diabetes prevalence in Finnish population. Diabetes prevalence nationally and by hospital district, according to age, gender, type of diabetes and year.	Persons with diabetes to be identified and classified according to the following data: • diabetes diagnosis on Hospital Discharge Register • diabetes diagnosis on Finnish Health Care Register • diabetes diagnosis on Hospital Benchmarking register • diabetes entry or diagnosis in Medical Birth Register • diabetes diagnosis in Causes of Death Register • right to special reimbursement for antidiabetic medications in KELA register • entries of antidiabetic medications purchased in KELA register • information in FinDM I project data	Diabetes controlled by diet not identified Changes in guidelines of care affect identification of persons with diabetes Registry data not conclusive in distinguishing between types 1 and 2. Antidiabetic medications also used partly for other reasons (gestational diabetes, PCO)	FinDM I (2005) ascertained prevalence of diabetes and its complications in Finland. Over 300,000 persons with diabetes identified in STAKES and KELA registers on FinDM I. According to FinDM I study 5.1% of Finns have diabetes	Monitoring national trends. Making comparisons for health care and political decision-making.	Health care units and decision-makers, political decision-makers at national level.	Niemi M, Winell K. Diabetes in Finland. Prevalence and variation in quality of care. STAKES reports 8/2006

Incidence of diabetes

Aim	Description	Technical description	Limitations	Justifications	Applications	Users	Sources
Monitor annual numbers of cases to target measures to reduce risk of diabetes and develop appropriate preventive and screening methods, likewise to assess future need for treatment and rehabilitation.	Incidence of diabetes in Finnish population Incidence of diabetes to be tabulated nationally and by hospital district by age, gender diabetes type and year.	Persons with diabetes to be identified and classified by type of diabetes on the basis of the following information: • diabetes diagnosis from Hospital Discharge register • diabetes diagnosis from Finnish Health Care register • diabetes diagnosis from Benchmarking database • diabetes entry or diagnosis in Medical Birth register • diabetes diagnosis in causes of death statistics • special reimbursement for antidiabetic medicaments on KELA register of elevated reimbursements • entries of purchases of antidiabetic medicaments on KELA prescription database • information from FinDM Project data	Diabetes controlled by diet goes unidentified Changes in guidelines of care affect identification of persons with diabetes Register data do not permit unambiguous distinguishing of various diabetes types Antidiabetic medicaments also used partly with other indications (gestational diabetes, PCO).	Diabetes in Finland (2005) study ascertained incidence of diabetes and its long-term complications in Finland. Over 300,000 persons with diabetes were identified from the STAKES and KELA registers in the study. According to the study the number of new diabetes-cases increased 38% from 1989 to 2002. Type 1 diabetes has increased markedly, especially among younger children (Harjutsalo et al. 2008).	Monitoring national trend, making comparisons for health care and political decision-making.	Health care units, decision-makers in health care, political decision-makers at national level.	Harjutsalo V, Sjöberg L & Tuomilehto J. Time trends in the incidence of type 1 diabetes in Finnish children: a cohort study. Lancet 2008; 371: 1777–82 Niemi M, Winell K. Diabetes in Finland. Prevalence and variation in quality of care. STAKES reports 8/2006

Amputations of lower extremities among persons with diabetes

Aim	Description	Technical description	Limitations	Justifications	Potential applications	Users	Sources
Monitor prevalence and incidence of diabetes complications. Reduce risk of complications by improving quality of care	Incidence of first lower extremity amputations per 100,000 persons with diabetes. Indicator to be tabulated nationally and by hospital district by age, gender, diabetes type, amputation level and year.	Identify and classify amputations to major and minor from Hospital Discharge and Health Care registers through codes for measures. Include only first lower extremity amputations in category of interest in year of discovery of diabetes or thereafter.	Amputations among persons with pre-diabetes or diet controlled diabetes not included. Only first amputations considered.	Good care and early identification of risk factors can reduce amputations (Bartus & Margolis 2004). FinDM I (2005) showed a 58% decrease in incidence of all first amputations of persons with diabetes from 1988 to 2002.	Monitoring incidence of lower extremities of persons with diabetes amputations enables indirect assessment of quality of diabetes care by region. Monitoring national trend and effects of diabetes, making comparisons for needs of health care and decision-making.	Health care units, health care decision-makers, political decision-makers at local and national levels.	Bartus CL, Margolis DJ. Reducing the incidence of foot ulceration and amputation in diabetes. Current Diabetes Reports 2004; 6:413-418. Niemi M, Winell K. Diabetes in Finland. Prevalence and variation in quality of care. STAKES reports 8/2006

Acute myocardial infarctions among persons with diabetes

Aim	Description	Technical description	Limitations	Justifications	Potential applications	Users	Sources
Monitor development in complications of diabetes, reduce risk of complications	Incidence of acute myocardial infarction (AMI) 100,000 persons with diabetes Indicator to be tabulated nationally and by hospital district by age, gender and diabetes type and year.	AMIs to be identified from diagnoses in Hospital Discharge Health Care registers and Causes of Death Register Include only AMIs in category examined in year of diabetes diagnosis or thereafter.	AMIs in persons with pre-diabetes or diet-controlled diabetes not included. Restricted to first infarcts.	Diabetes among main independent risk factors for CHD (Haffner et al. 1998). Poor glycaemic control, dyslipidaemia, elevated BP and smoking are risk factors for death from coronary infarct (Stevens et al. 2004). FinDM I (2005) showed overall decline in first infarct incidence among Persons with diabetes from 1988 to 2002. Reduction in incidence in age stabilized first AMI was 4.6% in men and 4.0% in women.	For monitoring national and regional trends, quality of diabetes care. To serve needs of political decision-making and in health care.	Health care units, health care decision-makers, political decision-makers at local and national levels.	Haffner SM, Lehto S, Rönnemaa T, Pyörälä K, Laakso M: Mortality from coronary heart disease in subjects with type 2 diabetes and in nondiabetic subjects with and without prior myocardial infarction. New England Journal Medicine. 1998; 339:229-234. Niemi M, Winell K. Diabetes in Finland. Prevalence and variation in quality of care. STAKES reports 8/2006 Stevens R, Coleman R, Adler A, Stratton I, Metthews D, Holman R. Risk Factors for Myocardial Infarction Case fatality and Stroke Case Fatality in Type 2 Diabetes UKPDS 66. Diabetes Care 2004;27:201-207.

Strokes among persons with diabetes

Aim	Description	Technical description	Limitations	Justifications	Potential applications	Users	Sources
Monitor prevalence of diabetes complications, reduce risk of complications	Incidence of first stroke per 100,000 persons with diabetes. Indicator to be tabulated nationally and by hospital district by age, gender and diabetes type and year.	Strokes to be identified from Hospital Discharge and Health Care register codes and from the Causes of Death Register Include only first strokes in category examined in year of diabetes diagnosis or thereafter	Strokes in persons with pre-diabetes or diet-controlled diabetes not included.	Diabetes is an independent risk factor for ischaemic stroke. Most acute stroke patients have problems with glucose metabolism. (Matz et al. 2006) FinDM I (2005) showed overall decline in period of interest 1988–2002 in all age groups. Change clearly greater in women. Also highly significance decline in fatal strokes among persons with diabetes.	For monitoring national trends and quality of diabetes care, for needs of health care and political decision-making.	Health care units, decision-makers in health care, political decision-makers at local and national levels.	Matz K, Keresztes K, Tatschl C, Nowotny M, Dachenhausen A, Brainin M, Tuomilehto J. Disorders of Glucose Metabolism in Acute Stroke Patients. An underrecognized problem. Diabetes Care 2006; 29:792-797. Niemi M, Winell K. Diabetes in Finland. Prevalence and variation in quality of care. STAKES reports 8/2006

Persons with diabetes and depression

Aim	Description	Technical description	Limitations	Justifications	Potential applications	Users	Sources
Monitor incidence and prevalence of co-occurrence of diabetes and depressions	Prevalence of depressions as a percentage of persons with diabetes Indicator to be tabulated nationally and by hospital district by age, gender, diabetes type and year.	Identify depression from purchases of anti-depressants in prescription database. Include for each year with diabetes with at least one purchase of medication in year of discovery of diabetes or thereafter.	Purchases of antidepressants by persons with pre-diabetes or diet-controlled diabetes not included. Antidepressants also used to treat neuropathic pain. Possibly difficult to distinguish this with register data. However, painful neuropathy may cause depression. Depression mainly treated in the community, i.e. health centres, occupational health care or mental health services.	Research shows that risk of depression is elevated in type 1 and type 2 diabetes. Increased risk same in both. Depression more common in women with diabetes than men with diabetes. (Anderson et al. 2001)	For monitoring national trend, co-prevalence and co-incidence of diabetes and depression.	Health care units, decision-makers in health care. Political decision-makers at both local and national levels.	Anderson RJ, Freedland KE, Clouse RE, Lustman PJ. The prevalence of comorbid depression in adults with diabetes. Diabetes Care 2001;24:1069–1078.

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