

DESCRIPTION OF DANISH REGISTERS

The National Diabetes Register

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Abstract

Introduction: A National Diabetes Register was established in the National Board of Health in 2006 following a pilot study showing the feasibility of doing so based on existing registers. **Content:** The register contains data of birth, date of inclusion, and date of death as well as information on the criteria met for inclusion. **Validity and coverage:** The register is more than 90% complete when compared to records of general practitioners, and it covers the entire Danish population. **Conclusion: The register is a source of demographic information for the diabetes population in itself, but also a source of linkable information for studies of diabetes as outcome and as determinant.**

Key Words: Diabetes register, disease surveillance, linkage, research database

Introduction

In the years 2003–04, the Diabetes Steering Group of the National Board of Health (mainly consisting of experts from outside the National Board of Health), had discussed options for setting up a nationwide monitoring system of diabetes.

The primary aim was to establish a database where the clinical course of patients could be monitored, but to ensure completeness, it was essential that a comprehensive register of all diabetes patients be established too.

A small working group was given the task to find out whether it was possible to construct a comprehensive register based on existing registers and obtain a reasonable coverage. A pilot study concluded that this was feasible [1].

On the basis of this, the National Diabetes Register was established in the fall of 2006, based on the Danish Civil Registration System (CRS), the National Patient Register (NPR), and the National Health Service Register (NHSR), constructed and maintained by the National Board of Health. From

2007, permission to use data from the Danish National Prescription Registry (DNPR) was obtained and data from this register is now included since 1995.

The National Diabetes Register is updated annually, usually in August or September.

Content

A person is included in the National Diabetes Register if one of the following criteria is met:

- Registration in NPR with a diagnosis of diabetes, defined as ICD-10: DE10–14, DH36.0, DO24 (excluding DO24.4), and ICD-8 (prior to 1994): 249, 250
- Registration of chiropody (as diabetic patient) in NHSR
- Five blood-glucose measurements in a 1 year period in NHSR
- Two blood-glucose measurements per year in 5 consecutive years in NHSR
- Purchase of oral anti-diabetic drugs (OAD) in DNPR. An exception is females aged 20–39

prescribed metformin alone, since metformin is also used as medication for polycystic ovarian syndrome

- Purchase of prescribed insulin recorded in DNPR.

The date of inclusion in the register is the earliest of the following dates:

- NPR-date: the earliest recorded date with a diagnosis of diabetes
- Chiro-date: the earliest date of chiropody
- 5-date: the date of the fifth blood-glucose measurement within a 1-year period.
- 2-date: the date of the second blood-glucose measurement in a 1-year period, where each of the four preceding 1-year periods had seen two measurements
- OAD-date: the date of second OAD-purchase
- Insulin-date: the date of second insulin purchase.

The register contains the Danish unique personal identification number (CPR-number), sex, date of birth, date of death, date of inclusion, as well as the six dates defined above. It is not possible to distinguish type 1 and type 2 diabetes on the basis of the information used to construct the register.

Additionally, the municipality of residence at time of inclusion is available. There are 98 municipalities in Denmark as of 2007, but this geographical coding has been extended back in time to 1995. Incidence data are complete from 1995; inclusions in the register on earlier dates are not necessarily the first date that the inclusion criteria were met, because the earlier dates may be missed – it is unlikely that a person first meeting the criteria in 1995 would have met the criteria earlier without a registration (with a date prior to 1995).

Other diabetes registers

The National Indicator Project (NIP) for diabetes [2] is a register attempting to collect clinical information for all diabetes patients on a regular basis (at least annually). The purpose is to monitor the treatment of diabetes patients. This register however only covers less than 20% of all diabetes patients; the coverage for patients in outpatient clinics is high, generally over 80%, but the coverage from general practice is very poor – only some 7% of general practices currently report to the NIP register.

The Danish National Childhood Diabetes Register [3] was established in 1996 and covers all new cases of diabetes in the ages 0–14 years, that is the age-range covered by the pediatric wards in Denmark. By the end of 2005 this register contained 2900 patients, and the annual incidence rate was found to be 0.25 per 1000 person-years. The register collects clinical information on the registrees annually, and has a

biobank associated with it, where DNA and serum samples (conditional on consent) are collected from new cases and first-degree relatives. It is considered 100% valid and is therefore a valuable source for epidemiological studies but also for clinical and biological studies [4] because of the biobank material available. As the register is clinically based there is no link to the NDR.

Validity and coverage

The National Diabetes Register covers the entire Danish population, i.e. all persons with a CPR-number. Because of the coverage of the DNPR, incident cases of diabetes are only reliably recorded after 1 January 1995. Anyone with an inclusion date prior to this can only be said to be a prevalent case as of 1 January 1995 (provided death is not before this).

Prior to the establishment of the register, a pilot study was conducted in which patients with diabetes residing in Aarhus County on 31 December 2003 were identified by data from NDR, NHSR, and the prescription database and the laboratory database in Aarhus County. A total of 8,802 patients with a diagnosis of diabetes confirmed by the patients' general practitioners (GP) were included. The algorithm not using the laboratory database found 91% of the diabetes population while supplementation by laboratory data increased this to 96%. The positive predictive value was 89% for both, using the GPs' recorded status as the reference [1]. Details of the component criteria are given in Table I.

However, these figures are for diagnosis of diabetes defined as presence of a diagnosis in the health care system, which by no means is implied by formally meeting the diagnostic criteria. The Inter99 study [5,6] indicated that more than half of the persons with diabetes according to the diagnostic criteria are undiagnosed. Further details of the pilot study can be found in [1].

The first criterion that patients have met is indicated in Figure 1 (the inclusion criterion). Changes in the agreement between chiropodists and the National Health Service have changed the frequency of chiro-dates in the register over the period, but this is not likely to influence the validity of the register, as persons in the register quickly meet more than one criterion; the fraction of patients still only meeting one criterion 1 year after first inclusion is 55%, and after 5 years 35%. The fraction meeting only one criterion is decreasing with time since inclusion in the register, and in the long term the fraction meeting only one criterion is about 20%.

Table I. Sensitivity and positive predictive value of each criterion in relation to GP registrations (Aarhus County).

Criterion	Se	PPV
Registration in NPR with a diagnosis of diabetes, defined as ICD-10: DE10-14, DH36.0, DO24 excluding DO24.4), and ICD-8 (prior to 1994): 249, 250	64	97
Registration of chiropody (as diabetic patient) in NHSR	40	97
Five blood-glucose measurements in a 1-year period in NHSR	38	86
Two blood-glucose measurements per year in 5 consecutive years	13	95
All criteria combined	86	89
Prescription of OAD or insulin	72	95

Values are %.

Adapted from [1]. The study was done prior to the availability of prescription data for the nationwide algorithm, hence the prescription criterion is not included in the combined.

NHSR, National Health Service Register; NPR, National Patient Register; OAD, oral anti-diabetic drugs; PPV, positive predictive value; Se, sensitivity.

From Figure 1 it is also seen that the fraction of those that are included on the basis of OAD purchase has increased in recent years, while those included based on recordings from the NPR has decreased. This would be consistent with an earlier date of diagnosis of patients in general practice, combined with an increasing medication of patients early in the course of the disease.

Clinical diabetes is a condition that very well may go undiagnosed for years, so the register is not complete in the clinical sense that the vast majority of persons with diabetes are likely to be included.

Diabetes occurrence

A comprehensive analysis of incidence, prevalence, and mortality based on the register is published in *Diabetologia* in 2008 [7]. The register contains 410,882 cases (199,270 men and 211,612 women), of which 259,201 were alive at the end of 2008 and 125,626 had a date of inclusion prior to 1995, and of these 98,610 were alive on 1 January 1995.

As an example of a demographic measure we computed the prevalences by age and sex based on the most recent version of the register (1 January 1995–31 December 2007) at 1 January in the period. We found that prevalence increased faster among men than among women and that the age of peak prevalence moved from 85 to 75 for men, but remained at 85 for women. For further details, see the companion paper [8].

Conclusion

The National Diabetes Register is a source of demographic information (i.e. distribution of cases and deaths by sex, age, calendar time etc.) and a tool for monitoring trends in prevalence, incidence, and mortality among Danish diabetes patients. Also the

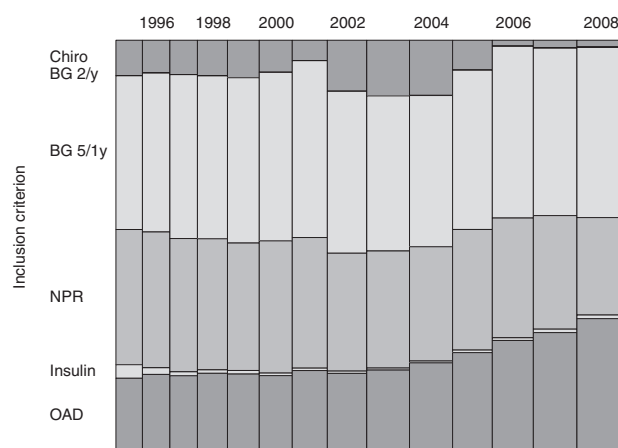


Figure 1. The distribution of the inclusion criteria for each year of inclusion in the register. The widths of the columns are proportional to the total included number of persons each of the years 1995–2008. The gray scale colours correspond to inclusion criteria as in the Content section. Note that the criterion BG 2/y (2 blood-glucose measurements per year in 5 consecutive years) contribute so few cases that it hardly shows up in the figure.

register is a valuable source in linkage with other registers, not only when studying diabetes as an outcome, but also when presence of diabetes is considered a determinant for other outcomes such as CVD and cancer.

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