

Diabetes Register(s)

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Danish Registers, University of Copenhagen, 26 November 2024

<http://BendixCarstensen.com/DMreg>

Background for a diabetes register

Population surveillance

- ▶ Monitor and describe:
 - ▶ Prevalence (no. and %)
 - ▶ Incidence (no. and rates)
 - ▶ Mortality and SMR
 - ▶ Predictions of likely future developments

Health care surveillance

- ▶ Keep track of diabetes patients
- ▶ Match patients to treatment indicators (GPs)
- ▶ ...improve accuracy of treatment information
- ▶ Predictions of likely future developments

Danish Diabetes Registers - a short history

- ▶ **NDR** — established 2006, last year of update 2012
no T1D/T2D distinction (1996-2012), defunct
- ▶ **RUKS** — Started 2015, initially not available for linkage
has T1D/T2D distinction, based **only** on NPR & RMPS
(1996-2022)
- ▶ **DMreg** — established 2018 by SDCC Clinical Epidemiology
using Statistics Denmark, has T1D/T2D distinction, based on
DADD, NPR, NHSR, RMPS, DiaBase & LABKA
Covers **1996–2022** (soon 2023) incl.

RUKS sources

- ▶ NPR - national patient register — only E10, E11
- ▶ RMPS - prescription register — Insulines / non-Insulines
- ▶ A new register of prevalent cases each 1 January
- ▶ Tables etc. available at the SDS website
- ▶ Available at the SDS research server

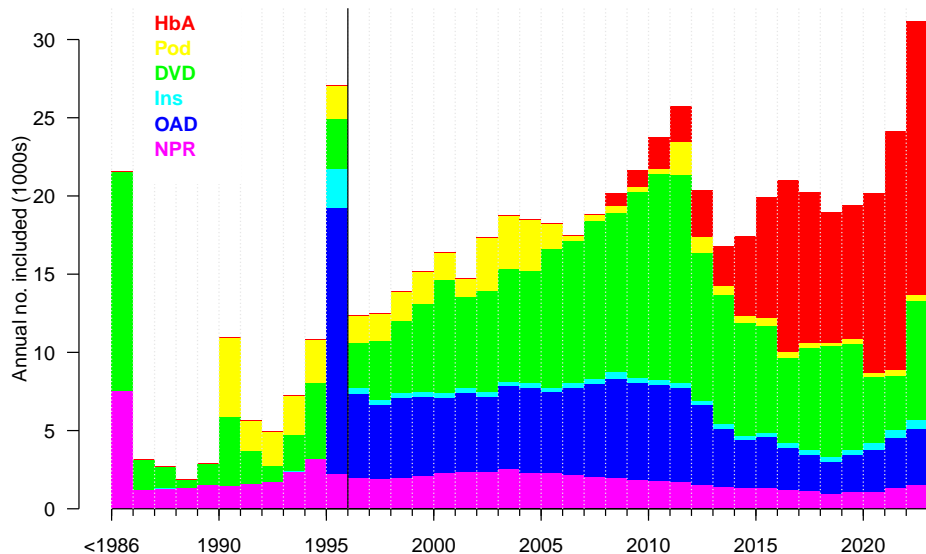
DMreg sources

- DADD Danish Adult Diabetes Database - quality register
updated annually from 2022-7-1 replaced by
DiD — Dansk Diabetes Database (DDiD)
 - NPR National Patient Register
 - NHSR National Health Services Register
 - RMPS Register of Medicinal Products Statistics
— “Prescription register”
 - DiaBase Quality database for eye-screening of diabetes patients
 - LABKA National laboratory data base - clinical measurements, HbA_{1c}
 - MFR Medical Birth Register, used to exclude possible GDM
- Inclusion date is the first occurrence in any of these as a diabetes patient. Once included the person remains in the register.

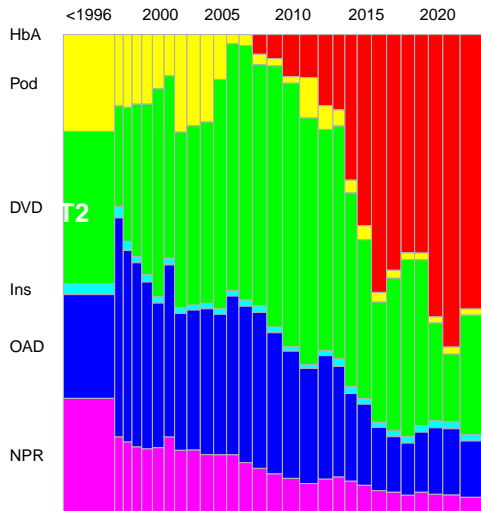
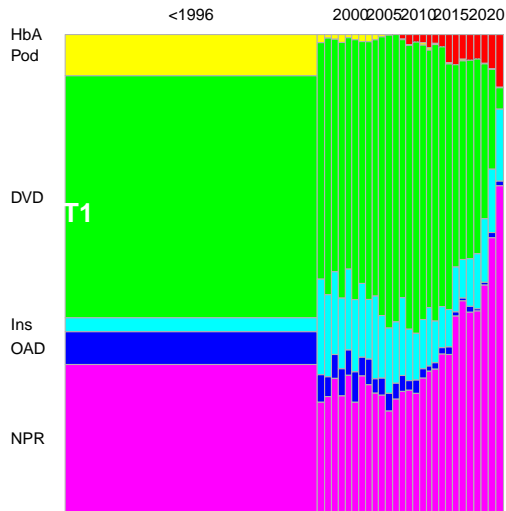
DMreg sources: Exclusions

- ▶ PCOS (PolyCystic Ovarian syndrome): metformin medication between 18 and 40 years for women disregarded.
- ▶ Gestational diabetes: — no inclusions during pregnancy (pregnancy periods derived from the birth register).

Inclusion criteria in DMreg



Inclusion criteria in DMreg by type of diabetes



What's in the register

One record per event (diagnosis) — three variables central:

- ▶ person-id
- ▶ date of diabetes
- ▶ type of diabetes (T1 / T2 / other)

Also:

- ▶ sex,
- ▶ date of birth,
- ▶ date of death,

to facilitate demographic analyses

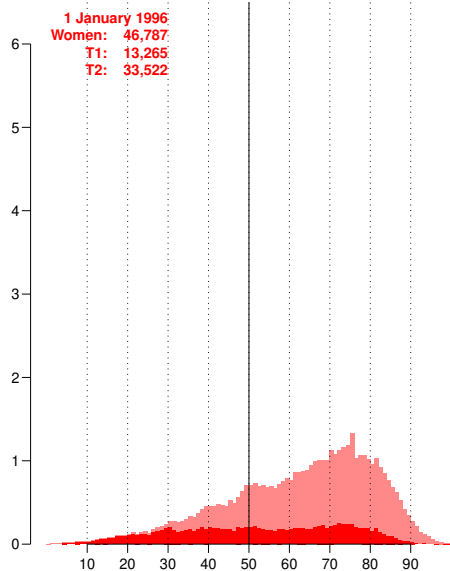
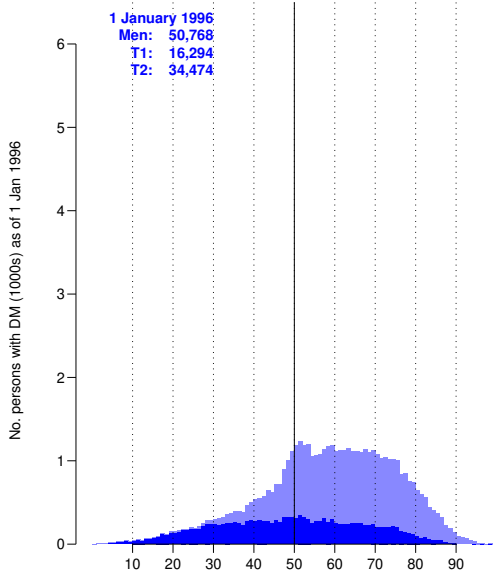
Persons in the register till 2011-12-31

- ▶ 613,971
- ▶ 51,316 T1; 544,965 T2; 16,690 other
- ▶ diagnosed < 1996 29,864 T1; 64,665 T2; 3,562 other

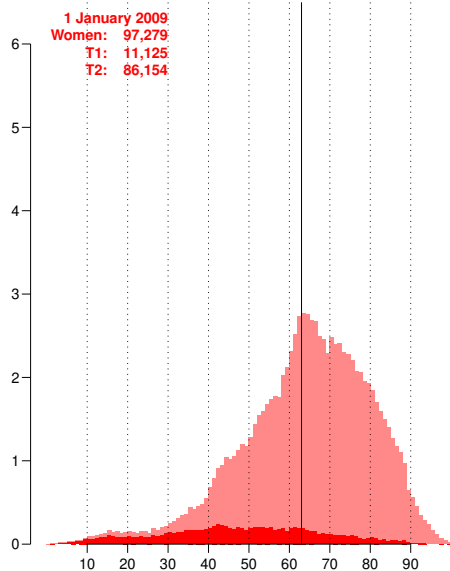
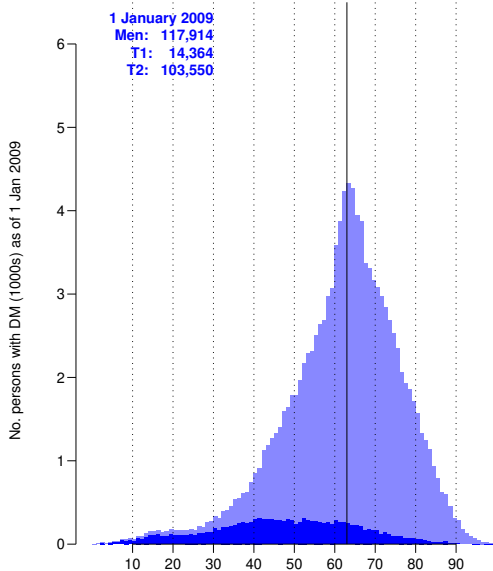
Prevalent cases

- ▶ Prevalent cases at date **D**:
 - ▶ inclusion (“diagnosis”) date $< D$
 - ▶ no date of death or date of death $> D$

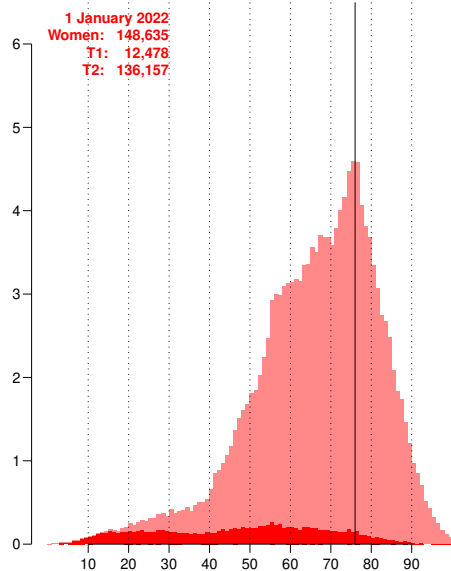
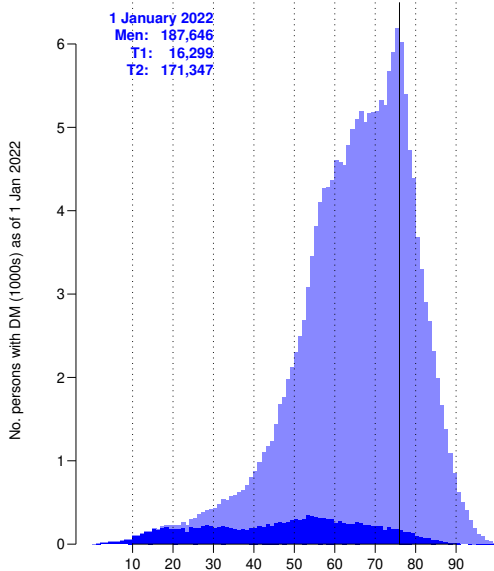
prevalent **number** of diabetes patients by age



prevalent **number** of diabetes patients by age



prevalent **number** of diabetes patients by age



Diabetes register use: Look-up

- ▶ Persons from some study cohort, such as a population survey or a clinical study—what is their:
 - ▶ **diabetes status** (noDM/T1/T2) at a given date
 - ▶ **diabetes date** (T1 / T2)
- ▶ by exclusion we also know if a person does **not** have diabetes (completeness assumption)
- ▶ \Rightarrow data input to existing (cohort) studies where follow-up is already known
 - ▶ diabetes as **explanatory** variable for some known outcome
 - ▶ **outcome** event in an existing cohort

Diabetes register use: Demography

Demographic **analysis** of **population**

- ▶ prevalence
 - ▶ incidence and
 - ▶ mortality rates,
 - ▶ —and derivatives of basic demographic measures:
 - ▶ state probabilities
 - ▶ lifetime risk
 - ▶ expected lifetime in noDM / T1 / T1
 - ▶ lifetime lost to diabetes
- ... but note that these measures need further assumptions
- ▶ register events are outcome **events**,
FU-time in population is outcome **risk time**

Diabetes demography

Demographic analyses of register event rates requires knowledge of **events** as well as **population time** covered by the register:

1. population size (number or risk time) by sex, age, date and other variables available both in the register and population. This will be **tabular** data, such as that available from Statistikbanken at DST.
2. **individual level** follow-up for **all** persons in the population — basically knowledge of entry (birth or immigration) and exit (death or emigration).

Available as the **LifeLines** register at DST:

individual follow-up of the entire DK population

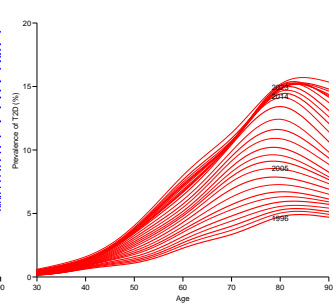
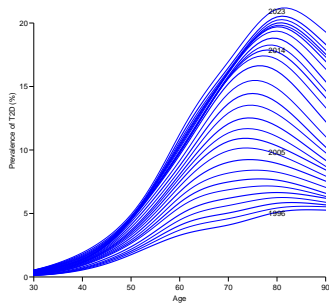
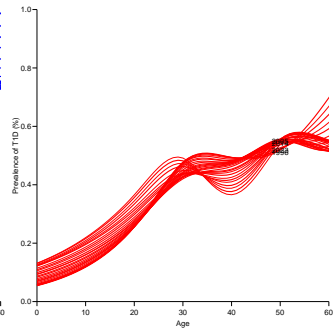
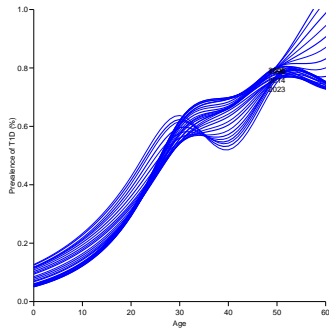
Prevalence of diabetes

What fraction of the population have diabetes (T1 / T2) at a given time?

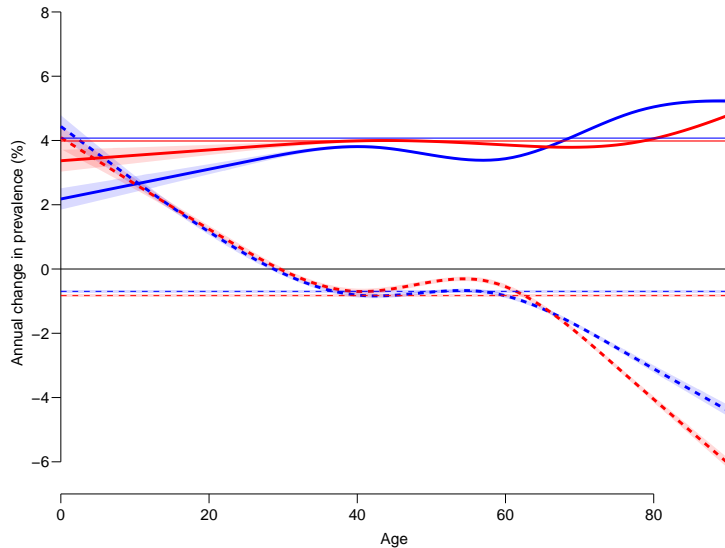
... the probability that a randomly chosen person has diabetes at a given date

as a function of sex, type of diabetes, calendar time

Prevalence



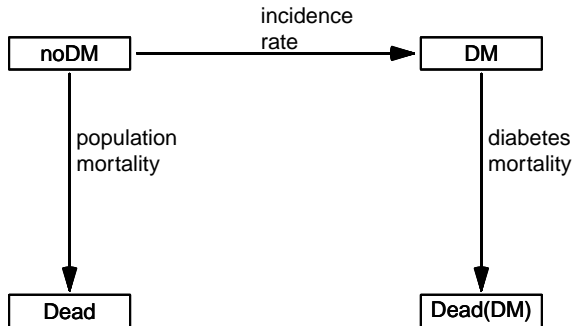
Prevalence trends



Incidence, mortality, SMR

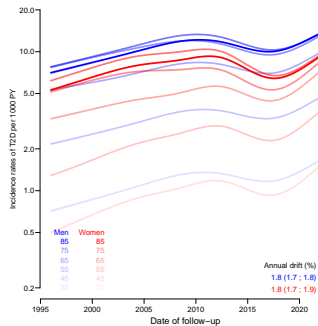
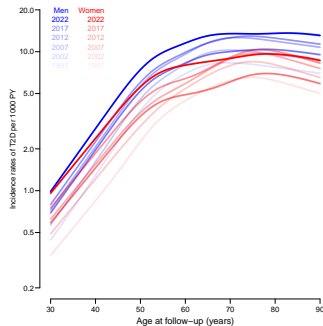
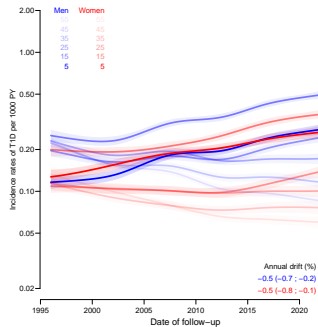
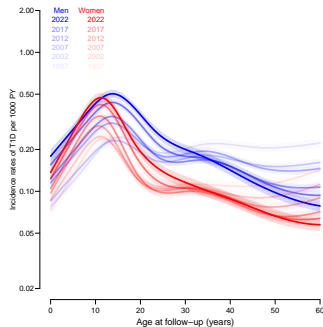
- ▶ **Incidence rate:**
no. new cases of diabetes relative to
person-years among persons without diabetes
- ▶ (diabetes) **Mortality rate:**
no. deaths relative to
person-years among persons with diabetes
- ▶ (population) **Mortality rate:**
no. deaths relative to
person-years among persons without diabetes
- ▶ **SMR** (standardized mortality ratio):
ratio of diabetes mortality to population mortality

Demography of diabetes

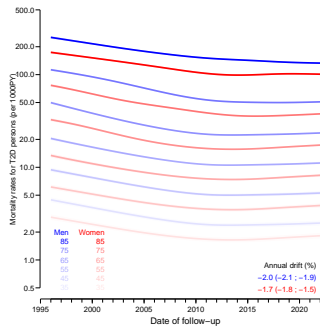
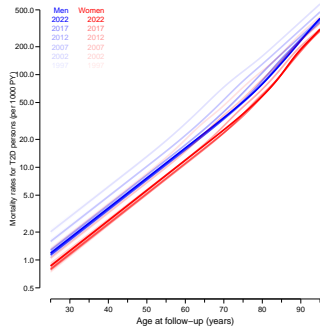
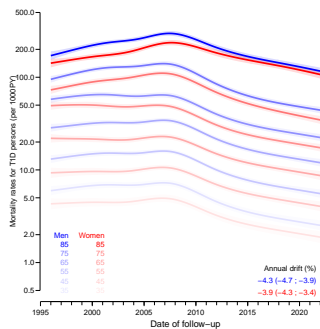
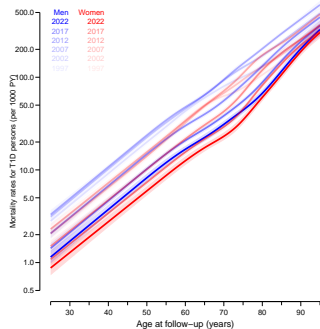


... as a function of sex, age, calendar time

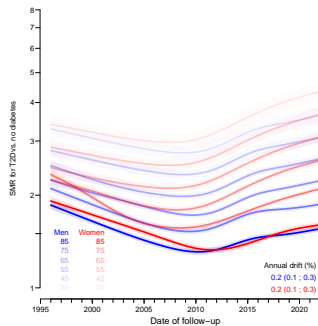
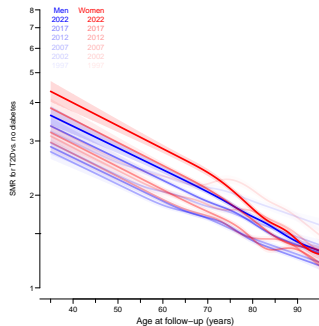
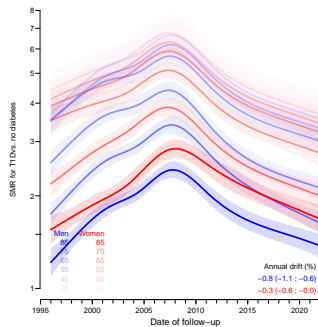
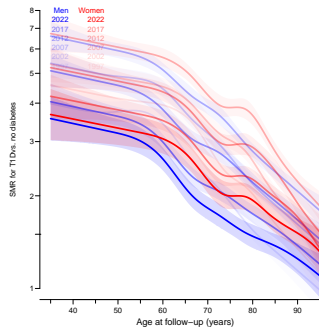
Incidence



Mortality



SMR



Diabetes register

- ▶ List of patients:
 - ▶ id
 - ▶ date of DM
 - ▶ type of DM
 - ▶ demographic variables
- ▶ based on existing registers