# Danish Diabetes Register

**Bendix Carstensen** Steno Diabetes Center Copenhagen
Gentofte, Denmark
http://BendixCarstensen.com

EASD research course, SDCC, December 2019

From /home/bendix/teach/Epi/KU-reg/EASDcourseBxC.tex

Tuesday 19th November, 2019, 14:22

# Background for a diabetes register

## Population surveillance

- Monitor and describe:
  - Prevalence (no. and %)
  - Incidence (no. and rates)
  - Mortality and SMR

## Health care surveillance

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

Results up to 31.12.2006 reported in:

Carstensen *et al.*: The Danish National Diabetes Register: Trends in incidence, prevalence and mortality, Diabetologia, 2008.

# Danish Diabetes Register—how does it look?
# Ficticious sample from a diabetes register

| id | sex | doBth | doDth | doDM | doNDR | dpPod | doOAD | doIns | inc |
|---|---|---|---|---|---|---|---|---|---|
| 0C25D | W | 09NOV1935 | . | 12OCT2009 | . | . | 12OCT2009 | . | oad |
| 0CEC1 | M | 11SEP1919 | 22MAY1992 | 19APR1990 | 19APR1990 | . | . | . | lpr |
| 0CCE3 | M | 18MAR1936 | . | 01JUN2001 | 06JUN2007 | 23MAY2007 | 01JUN2001 | . | oad |
| 0C619 | M | 03JUL1944 | . | 09JAN2003 | . | . | 09JAN2003 | . | oad |
| 0CD42 | W | 29MAR1941 | . | 01OCT2009 | 01OCT2009 | . | 22OCT2009 | . | lpr |
| 0C42B | M | 01JUN1949 | . | 06OCT2005 | . | . | 06OCT2005 | . | oad |
| 0CBE4 | M | 15AUG1962 | . | 29SEP2009 | . | . | 29SEP2009 | . | oad |
| 0C2ED | W | 02APR1949 | . | 08SEP2007 | 21JAN2009 | 19MAR2008 | 08SEP2007 | . | oad |
| 0C5FA | W | 08OCT1901 | 20DEC1993 | 08AUG1992 | 08AUG1992 | . | . | . | lpr |
| 0CFB0 | W | 19APR1913 | 29AUG1992 | 23JAN1991 | . | 23JAN1991 | . | . | pod |
| 0C976 | W | 09MAR1913 | 20MAY1999 | 03APR1998 | . | . | 03APR1998 | . | oad |
| 0CB64 | M | 15APR1947 | . | 24APR2001 | 21MAY2001 | . | 24APR2001 | . | oad |
| 0CEE1 | W | 12DEC1940 | . | 16JUL2002 | 16JUL2002 | . | 13JAN2006 | 17JAN2006 | lpr |
| 0CB84 | M | 31DEC1916 | 28JUN1991 | 24MAY1991 | 24MAY1991 | . | . | . | lpr |
| 0CF20 | W | 21JUN1919 | 15NOV1993 | 16FEB1992 | 16FEB1992 | 20JAN1993 | . | . | lpr |
| 0CCB3 | W | 31DEC1944 | . | 05OCT1993 | 05OCT1993 | 21APR2004 | 05NOV1994 | . | lpr |
| 0C52A | W | 16MAY1965 | . | 23NOV2005 | 22MAY2006 | . | 23NOV2005 | . | oad |
| 0C758 | M | 26JAN1932 | . | 05MAR2008 | . | 21MAY2008 | 05MAR2008 | . | oad |
| 0CBB4 | M | 16JUN1932 | 24APR2006 | 25FEB1998 | 25FEB1998 | 18NOV1998 | 03MAR2000 | 30JUL2002 | lpr |
| 0CA85 | M | 05MAR1957 | . | 27AUG2004 | 27AUG2004 | . | 11SEP2004 | . | lpr |

# Danish Diabetes Registers—short history

- **NDR** — established 2006, last year of update 2012
  no T1D/T2D distinction
- **RUKS** — Started 2015, initially not available for linkage
  has T1D/T2D distinction, based **only** on NPR & RMPS
- **DMreg** — established 2018 by SDCC Clinical Epidemiology
  using Statistics Denmark, has T1D/T2D distinction, based on DADD, NPR, NHSR, DiaBase & RMPS.
  Covers **1996–2016** incl.

| | |
|---|---|
| DADD: | Danish Adult Diabetes Database - quality register updated annually |
| NPR: | Nation Patient Register |
| NHSR: | National Health Services Register |
| RMPS: | Register of Medicinal Products Statistics - Prescription register |
| DiaBase: | Quality database for eye-screening of diabetes patients |

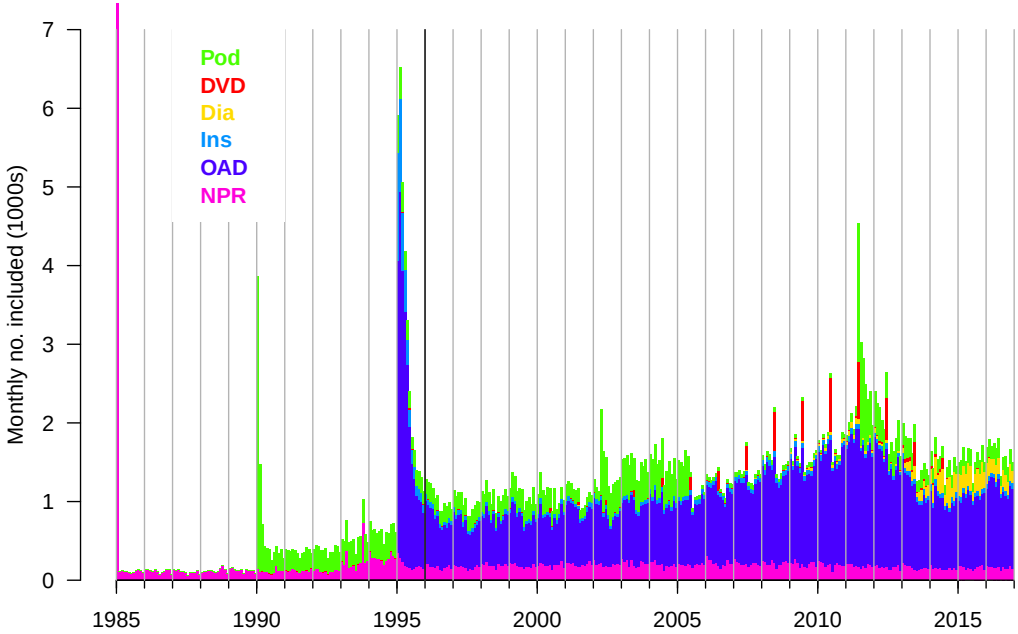
# Danish Diabetes Register — sources

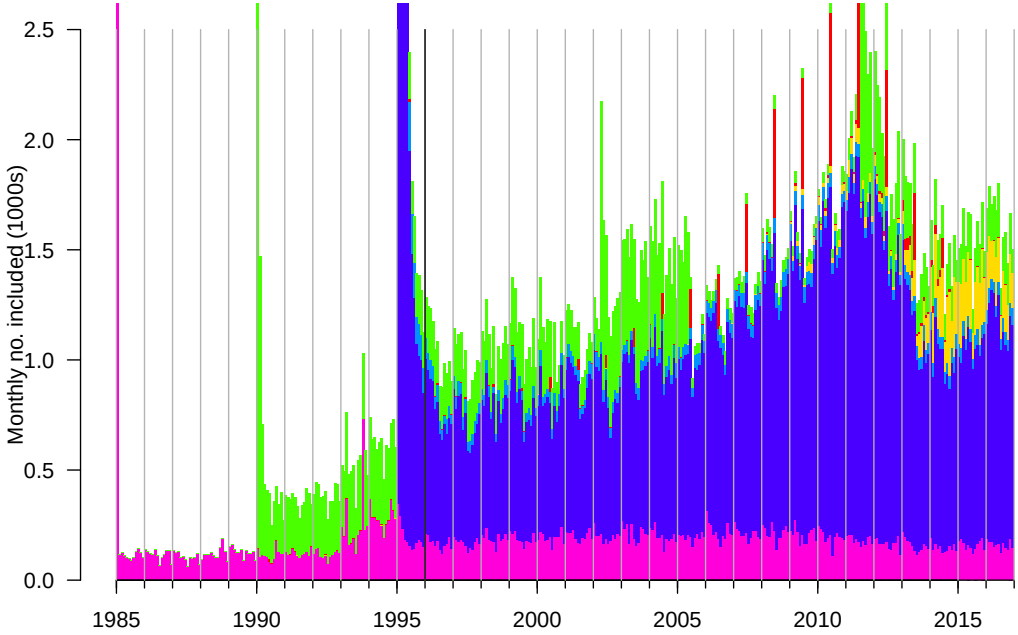
A side effect of a project at Statistics Denmark (DST), available inside the project at DST — Clinical Epidemiology at SDCC

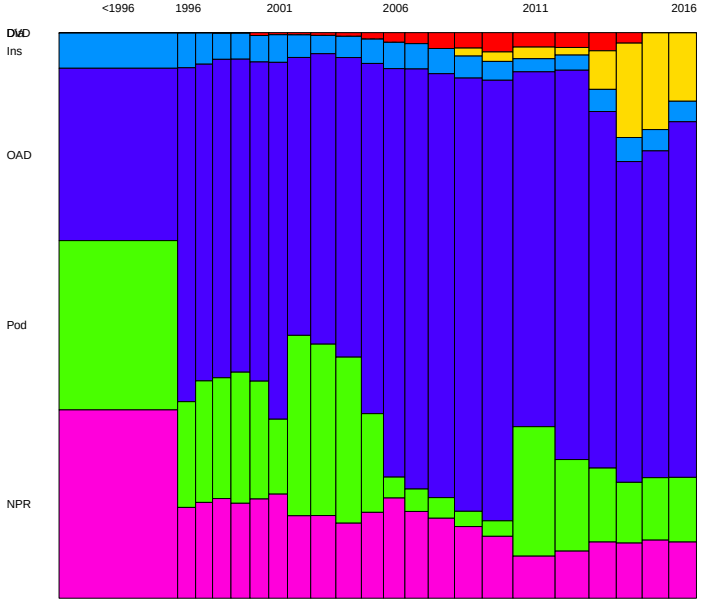
- NPR, National Patient Register
- RMPS, Register of Medicinal Product Statistics (prescription reg.)
- NHSR, National Health Services Register
- DADD, Danish Adult Diabetes Database
  — annual clinical status since 2005
  — complete for T1D, not for T2D
- diaBase, Eye-screening database for diabetes patients
- Inclusion data is the first occurrence in any of these as a diabetes patient

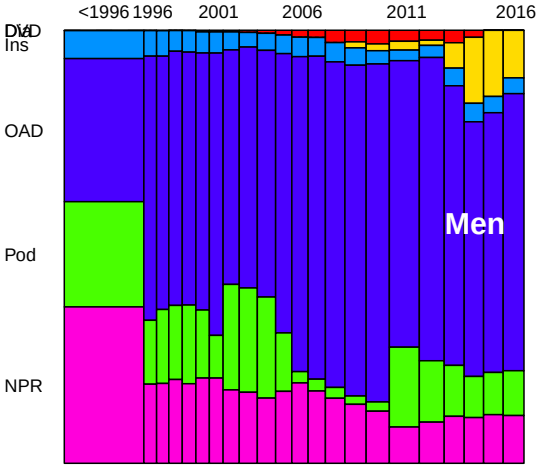
# Reconstructed Diabetes Register

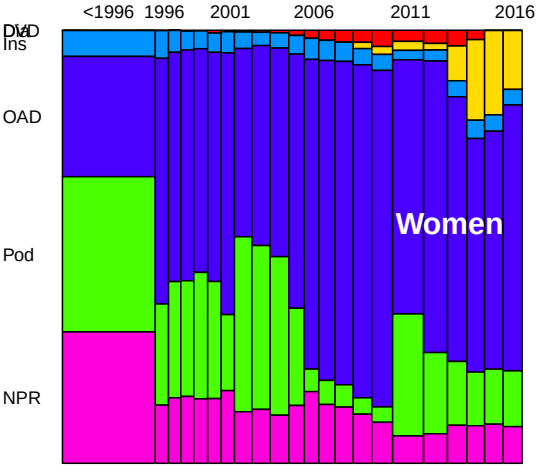
- No blood glucose criteria used
- Podiatry (foot therapy) for DM patients (NHSR)
- GDM window $-30$ to $365$ days
- PCOS: $-30$ days from NPR diagnosis or only metformin in the age-range 20–40 years — excluded
- T1/T2 classification:
  - Based on DVDD (Danish Adult Diabetes Database)
  - Subsequently on NPR
  - Any OAD before age 15 $\rightarrow$ T1D
  - Any insulin before age 30 $\rightarrow$ T1D
  - Non-classifiable coded as T2D


Pod
DVD
Dia
Ins
OAD
NPR
Monthly no. included (1000s)
0
1
2
3
4
5
6
7
1985
1990
1995
2000
2005
2010
2015

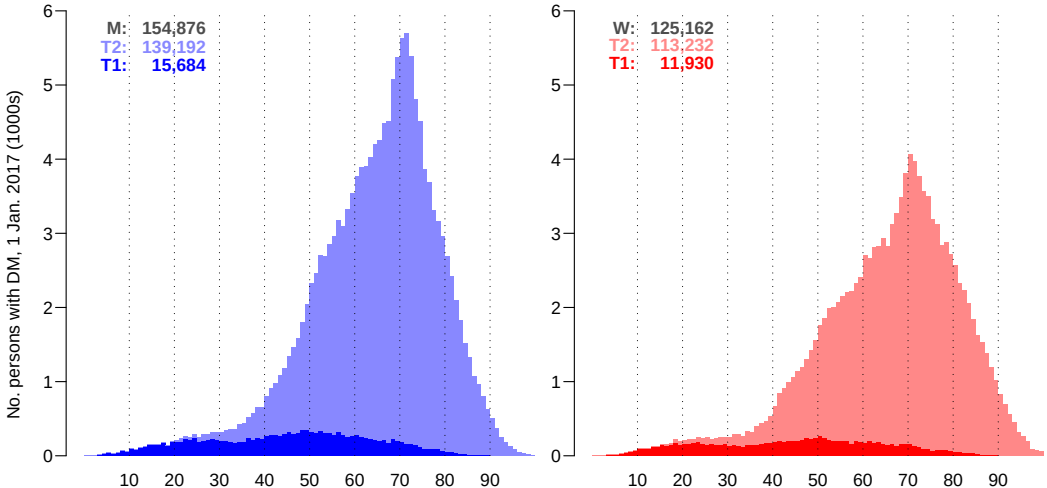

Monthly no. included (1000s)
2.5
2.0
1.5
1.0
0.5
0.0
1985
1990
1995
2000
2005
2010
2015


<1996
1996
2001
2006
2011
2016
DVD
Ins
OAD
Pod
NPR


<1996
1996
2001
2006
2011
2016
DVd
Ins
OAD
Pod
NPR
Men


<1996
1996
2001
2006
2011
2016
DVd
Ins
OAD
Pod
NPR
Women

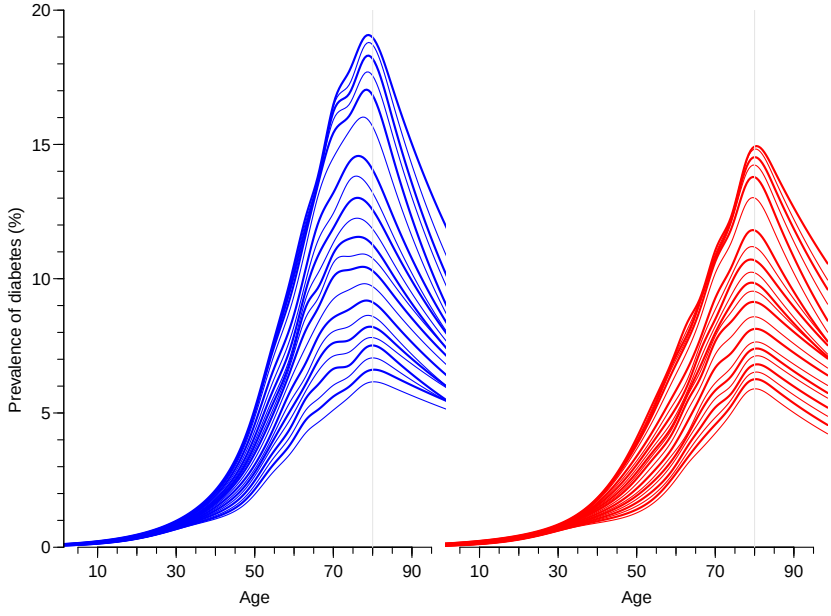
# Number of diabetes patients 2017-01-01



# Prevalence: Methods

- Prevalent cases by 1 Jan 1995,. . . ,2017 tabulated by sex and 1-year age.
- Corresponding population figures from Statistics Denmark.
- Prevalence analysed by a binomial model with log-link and the population size as denominator.
- Separate parametric terms used for each sex and date.
- One age-specific prevalence curve for each sex and year.

Age-specific prevalences of DM according to the reconstructed register.

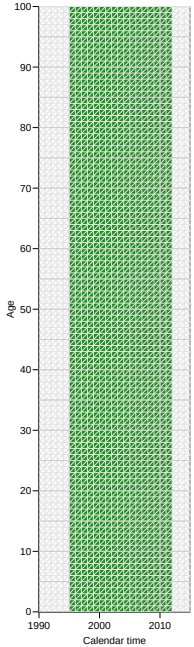


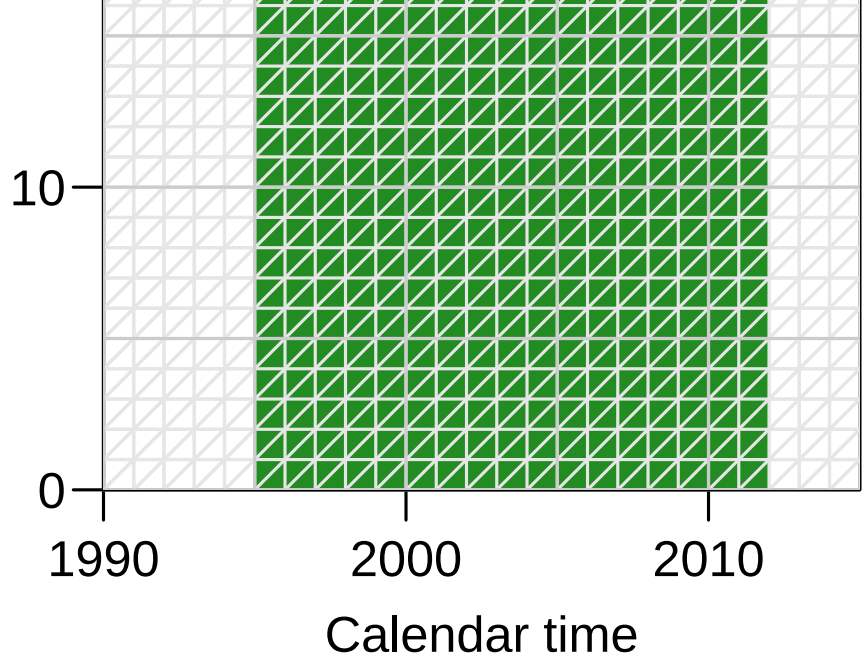
# Incidence: New cases included

| | T1D | | T2D | | All DM | | |
|---|---|---|---|---|---|---|---|
| Period | M | W | M | W | M | W | M+W |
| 1996 | 725 | 527 | 6,269 | 5,345 | 6,994 | 5,872 | 12,866 |
| 1997 | 649 | 528 | 6,192 | 5,264 | 6,841 | 5,792 | 12,633 |
| 1998 | 714 | 503 | 7,019 | 5,844 | 7,733 | 6,347 | 14,080 |
| 1999 | 654 | 451 | 7,415 | 6,203 | 8,069 | 6,654 | 14,723 |
| 2000 | 692 | 479 | 8,450 | 7,005 | 9,142 | 7,484 | 16,626 |
| 2001 | 655 | 455 | 7,391 | 6,090 | 8,046 | 6,545 | 14,591 |
| 2002 | 621 | 423 | 8,410 | 7,474 | 9,031 | 7,897 | 16,928 |
| 2003 | 588 | 412 | 9,468 | 8,140 | 10,056 | 8,552 | 18,608 |
| 2004 | 583 | 453 | 9,782 | 8,288 | 10,365 | 8,741 | 19,106 |
| 2005 | 585 | 427 | 9,163 | 7,621 | 9,748 | 8,048 | 17,796 |
| 2006 | 584 | 440 | 9,050 | 7,193 | 9,634 | 7,633 | 17,267 |
| 2007 | 585 | 450 | 9,636 | 7,966 | 10,221 | 8,416 | 18,637 |
| 2008 | 603 | 438 | 10,831 | 8,792 | 11,434 | 9,230 | 20,664 |
| 2009 | 596 | 392 | 10,962 | 8,509 | 11,558 | 8,901 | 20,459 |
| 2010 | 587 | 405 | 11,876 | 9,333 | 12,463 | 9,738 | 22,201 |
| 2011 | 537 | 401 | 13,363 | 11,084 | 13,900 | 11,485 | 25,385 |
| 2012 | 517 | 347 | 10,981 | 9,013 | 11,498 | 9,360 | 20,858 |
| 2013 | 495 | 398 | 8,650 | 6,829 | 9,145 | 7,227 | 16,372 |
| 2014 | 495 | 398 | 8,637 | 6,443 | 9,132 | 6,841 | 15,973 |
| 2015 | 520 | 406 | 9,569 | 7,354 | 10,089 | 7,760 | 17,849 |
| 2016 | 518 | 363 | 10,404 | 7,819 | 10,922 | 8,182 | 19,104 |
| Sum | 12,503 | 9,096 | 193,518 | 157,609 | 206,021 | 166,705 | 372,726 |

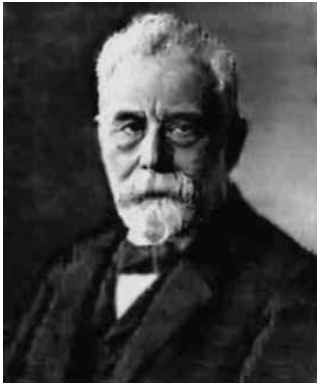
# Incidence: Methods

- New cases tabulated by age and date of diagnosis (1996-2016) and date of birth, in 1-year classes.
- Corresponding person-years figures from Statistics Denmark — person-years in the diabetes register subtracted.
- Incidence rates analysed by Poisson-regression with smooth parametric terms in age and date of diagnosis and date of birth, using log-person-years as offset.

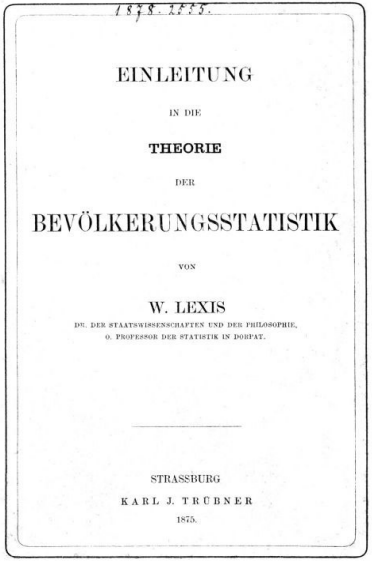



10
0
1990
2000
2010
Calendar time

# Digression: Lexis diagram



Wilhelm Lexis (1837–1914)
German demographer, statistician and economist.



1878. 2275.

EINLEITUNG

IN DIE

THEORIE

DER

BEVÖLKERUNGSSTATISTIK

VON

W. LEXIS

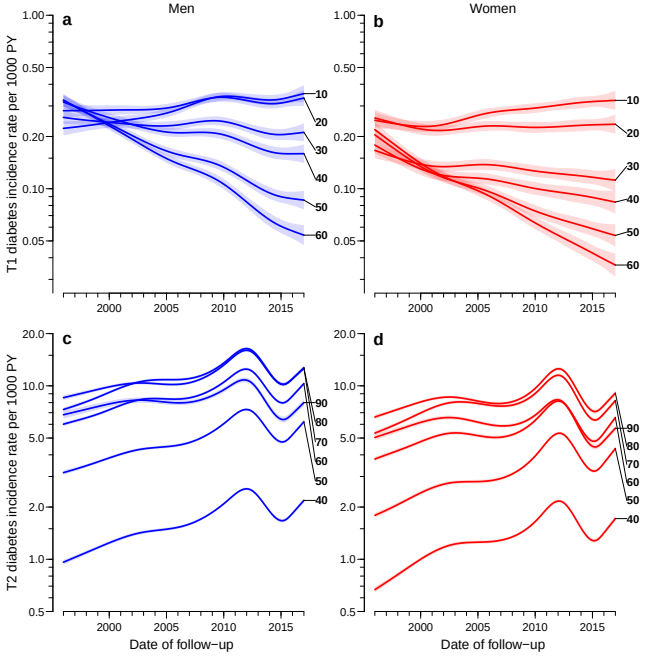
DR. DER STAATSWISSENSCHAFTEN UND DER PHILOSOPHIE,
O. PROFESSOR DER STATISTIK IN DORPAT.

STRASSBURG
KARL J. TRÜBNER
1875.

Incidence rates in different ages.

Note the different $y$-axes for T1D and T2D.

T2D is 10 times more common than T1D.



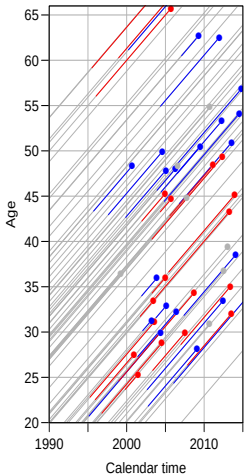
# Methods: Mortality and SMR

- Deaths and person-years of follow-up among diabetics tabulated by age and period at follow-up in 1-year classes.
- Corresponding mortality figures from Statistics Denmark. Deaths and person-years from the diabetes cohort subtracted.
- Mortality analysed by Poisson-regression of deaths with smooth parametric terms for current age, current date and current disease duration, using log-person-years as offset.
- SMR analysed using dataset amended by mortality among non-DM persons, using interaction between DM / non-DM and age / duration.

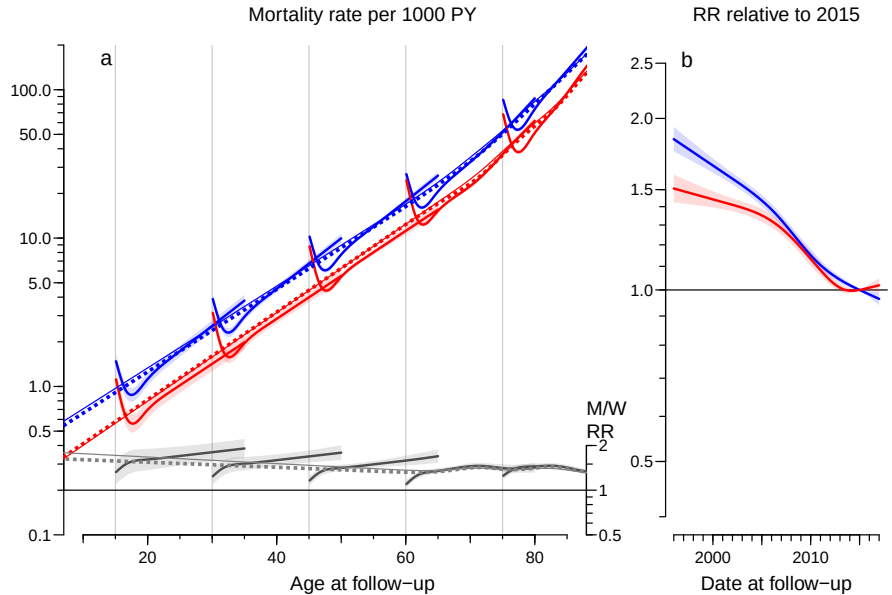
# Number of deaths — imbalance

| Year | New cases | Deaths | Surplus |
|---|---|---|---|
| 1996 | 12,866 | 6,116 | 6,750 |
| 1997 | 12,633 | 6,306 | 6,327 |
| 1998 | 14,080 | 6,397 | 7,683 |
| 1999 | 14,723 | 6,841 | 7,882 |
| 2000 | 16,626 | 6,947 | 9,679 |
| 2001 | 14,591 | 7,054 | 7,537 |
| 2002 | 16,928 | 7,406 | 9,522 |
| 2003 | 18,608 | 7,747 | 10,861 |
| 2004 | 19,106 | 7,609 | 11,497 |
| 2005 | 17,796 | 7,902 | 9,894 |
| 2006 | 17,267 | 8,000 | 9,267 |
| 2007 | 18,637 | 8,158 | 10,479 |
| 2008 | 20,664 | 8,034 | 12,630 |
| 2009 | 20,459 | 8,716 | 11,743 |
| 2010 | 22,201 | 8,808 | 13,393 |
| 2011 | 25,385 | 8,839 | 16,546 |
| 2012 | 20,858 | 9,158 | 11,700 |
| 2013 | 16,372 | 9,431 | 6,941 |
| 2014 | 15,973 | 9,746 | 6,227 |
| 2015 | 17,849 | 10,079 | 7,770 |
| 2016 | 19,104 | 10,259 | 8,845 |

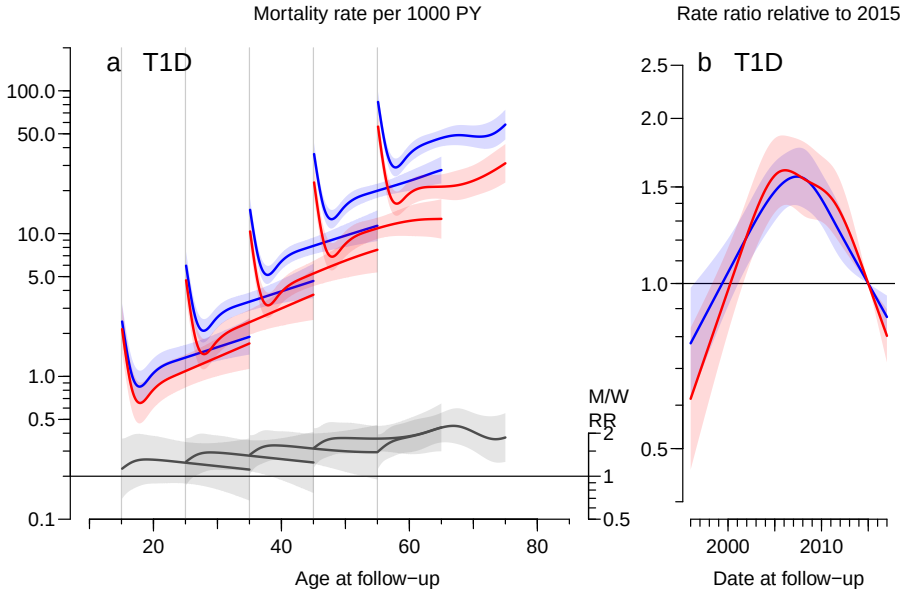
Incident cases Mortality



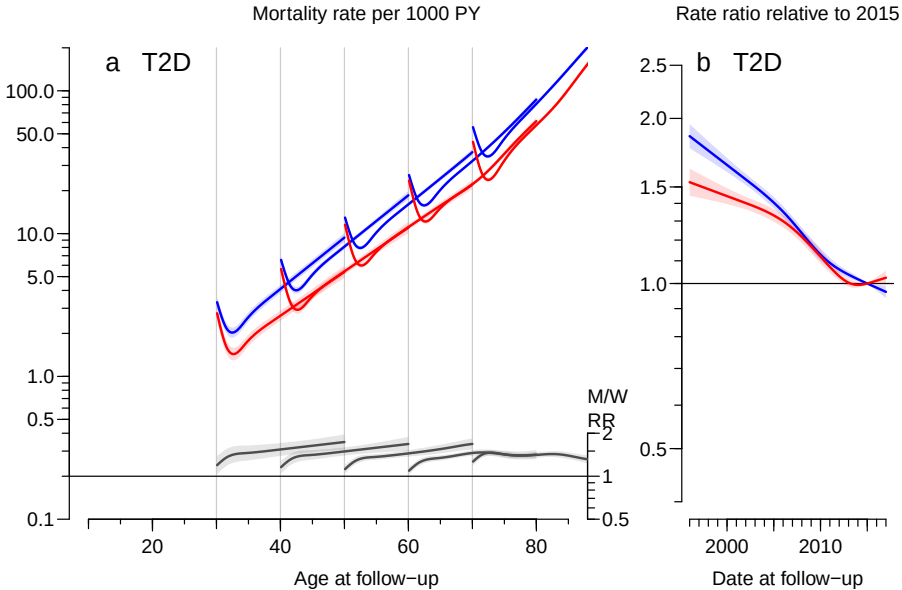
# Mortality among DM patients



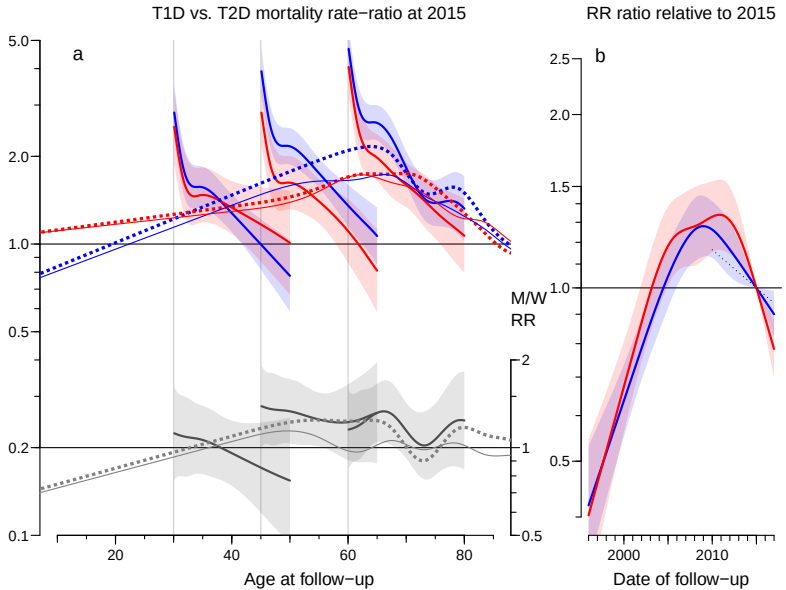
# Mortality among T1D patients



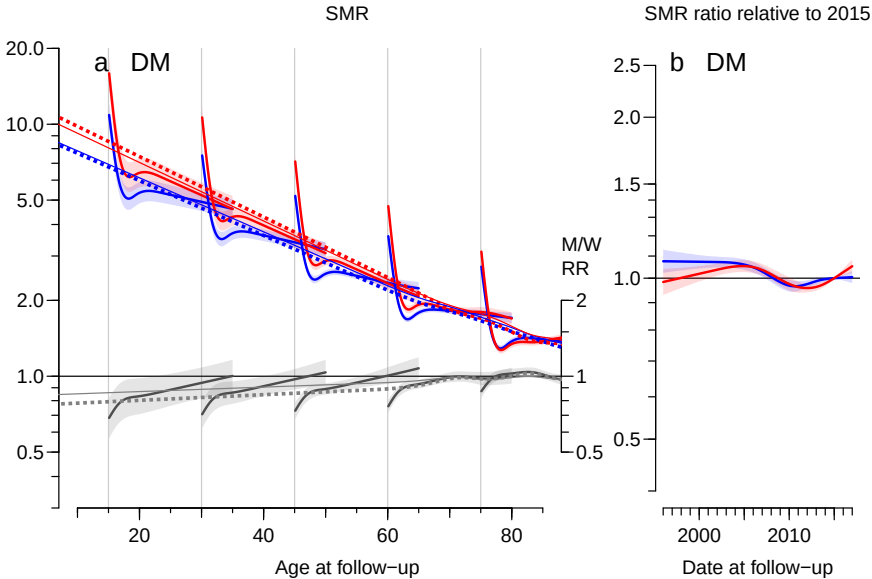
# Mortality among T2D patients



# Mortality RR between T1D/T2D



# SMR relative to persons without DM



# Mortality summary

- Mortality in DM patients increases exponentially by age.
- Decreasing by time: 4.0/3.8%/year
  (non-DM: 2.8/2.4 )
- Duration effects differs between T1D and T2D:
  - T1D: smaller mortality for longer duration
  - T2D: larger mortality for longer duration
- SMR is (almost) the same for men and women.
- SMR is 3 at age 45, 1.5 at 80

# Register is for surveillance

- How many persons have diabetes (age/sex/time. . . )
- How is the prognosis of diabetes patients
- How large is the population burden
- How do these develop over time

## Thanks for your attention