What have we learned from Scandinavian Diabetes Registers?

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http://BendixCarstensen.com/DMreg

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Disclosure

- Employee at Steno Diabetes Center,
  a Research Institution and Diabetes hospital/clinic,
  owned by NovoNordisk

- Own shares in NovoNordisk,
  worth approx. half my annual salary.

Two examples used in this talk

- **Danish** National Diabetes Register

    - established 2006
    - covers entire Danish population 1995–2012 incl.
    - 450,000 persons with DM, 300,000 alive 2012

- **Swedish** National Diabetes Register

    - established 1996
    - coverage:

            2000: 50,000 ptt
            2005: 150,000 ptt
            2010: 300,000 ptt
            2015: 350,000 ptt $\approx$ 88% of all

What is a diabetes register?

Two different types of registers:

1. Demographic surveillance register (DK)
   - All cases of DM in the population
   - Only dates of:
     birth, diagnosis, death
2. Clinical quality register (SE)
   - Not complete w.r.t. cases of DM
   - Clinical information is collected regularly (*e.g.* annually)
     HbA1c, HDL, BMI, . . .

Different registers — different purposes

- Demographic register:
  - Surveillance of the diabetes occurrence in the entire **population**
  - Size of and changes in:
    - prevalence
    - incidence
    - mortality
    - co-morbidity
- Clinical register:
  - Surveillance of **treatment quality**
    (for those in the register)
  - Size of and changes in:
    - Proportion of patients treated according to guidelines
    - Distribution of and changes in clinical parameters:
      HbA1c, Blood pressure, Cholesterol . . .

Practical issues

- Linking information from different sources:
  - Cause of death register
  - Health care usage register
  - Medicine purchase register

- Denmark & Sweden (+N+FI+IS) have unique person-id used for this

- . . . including data-bases from primary care

- Clinical registers requires data-collection from primary care

- . . . by web or by automated data transfer

Current situation

- Denmark:
  - a demographic register updated till 2012
    based on existing registers:
    - Health services
    - Prescriptions
    - Hospitalizations
  - a rudimentary clinical register (resembling the Swedish)

- Sweden:
  - no comprehensive demographic register
  - an almost complete clinical register

- Examples of results from both registers

Swedish NDR: Quality assurance

Swedish law no. 787 (1996):

§**31** The quality of health care should be developed and assured systematically and continually.

Patient record systems (PRS) / Quality registers

- PRS not facilitated for analysis of quality improvement
- Quality registers has been developed to fill this gap
- Useful for multiple purposes:
  - quality control at local level
  - comparisons
  - general health planning and management
  - clinical research
- Open report to meet the public demand for transparency
- Developed and managed by the professional groups using them
- All registers contain individual-based data on problems or diagnoses, treatment interventions and outcomes
- Protected with same standards as medical records regarding confidentiality and data handling

Key points for success:

- ▸ (small country)
- ▸ uniform health care system
- ▸ long tradition of nation-wide registries
- ▸ personal identification number
- ▸ reporting to/for data providers
- ▸ reporting to/for patients
- ▸ reporting to/for policy makers

Swedish NDR: Registered items

Date of registration	Caregiver code	Person id
Year of diabetes diagnosis	HbA1c	Micro- & macro albuminuria
Type of diabetes	Diabetes treatment	S-creatinine
Height & weight	Blood pressure	IHD (date)
Waist circumference	Anti-hypertensive treatment	Stroke (date)
Smoking habits	Blood lipid level	Retinal image (date)
Physical activity	Lipid-lowering treatment	Visual impairment
Severe hypoglycaemia	Aspirin treatment	Foot examination
		Amputation

SE-NDR: Trends in HbA1c
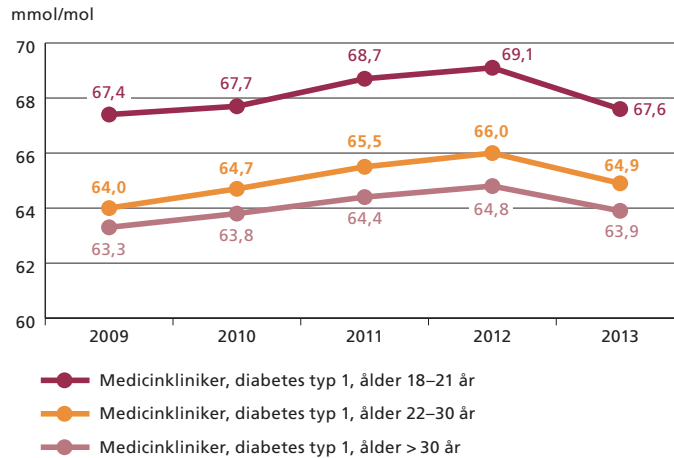
Figur 21. Medelvärde för HbA1c (mmol/mol).
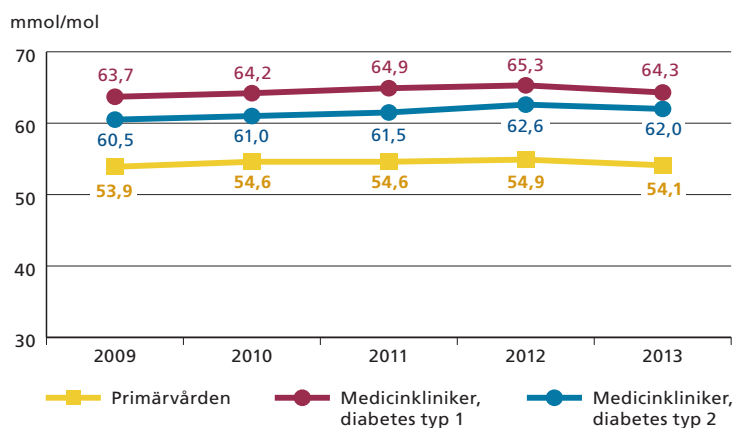
Källa: NDR – Nationella Diabetesregistret.

Yellow: Primary care   Blue: Clinics,T2   Brown: Clinics,T1

SE-NDR: Trends in HbA1c T1D by age

**Figur 25.** Medelvärde för HbA1c (mmol/mol) i olika åldersgrupper. Typ 1 diabetes vid medicinkliniker.

mmol/mol

Legend:
— Medicinkliniker, diabetes typ 1, ålder 18–21 år
— Medicinkliniker, diabetes typ 1, ålder 22–30 år
— Medicinkliniker, diabetes typ 1, ålder > 30 år

Källa: NDR – Nationella Diabetesregistret.

SE-NDR: Trends in pharmacological treatment of T2D

PATIENTER

DAGAR
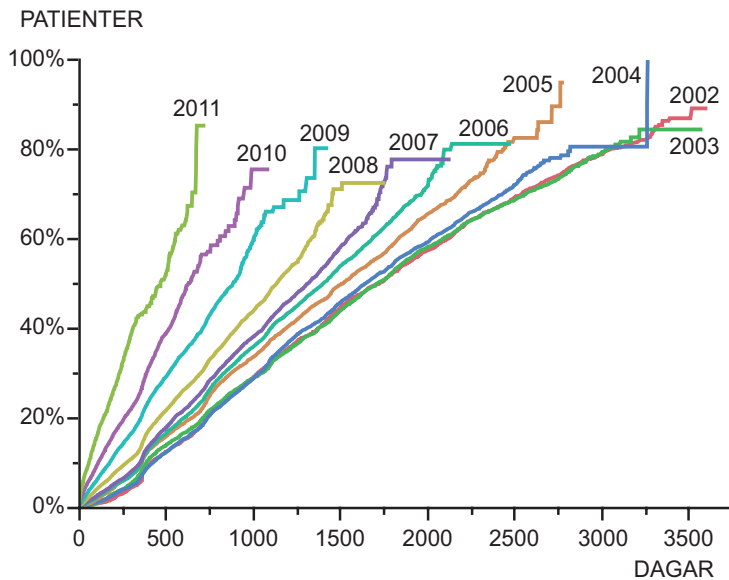
DK-NDR: Changes in prevalence 1995–2012
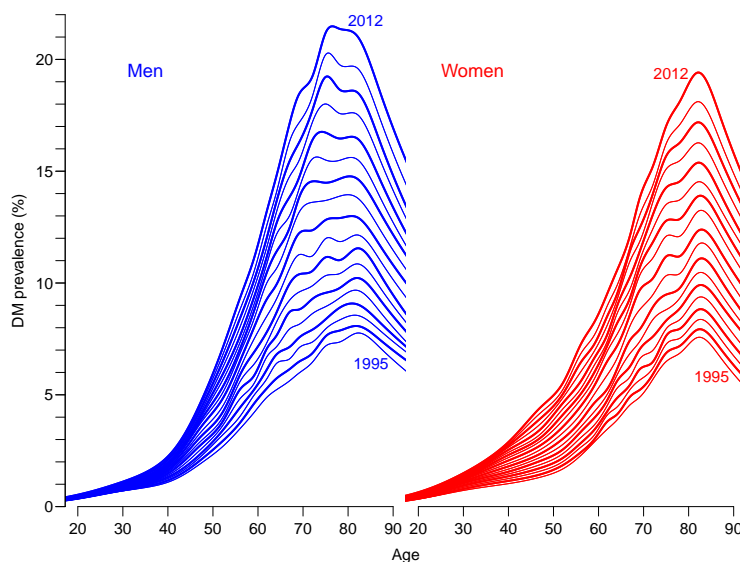
What drives the increasing prevalence in DK?
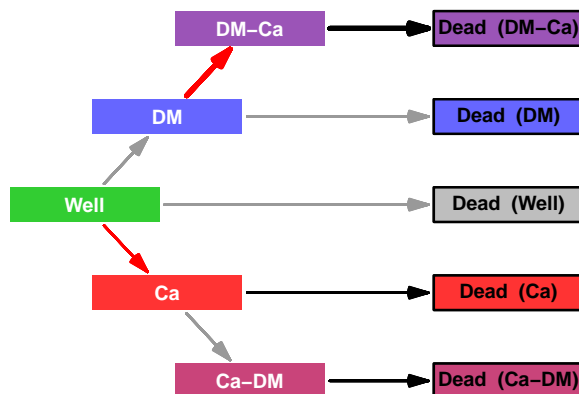
- Changing **rates** in period 1995–2012:

|	
Diabetes incidence	**3.5%**/year
Mortality (DM)	**−4.5%**/year
Mortality (no DM)	**−3.5%**/year

- Increasing incidence increases prevalence
- Decreasing mortality among DM ptt. increases prevalence
- There is not balance between incidence and mortality in 1995 — so stability in rates will also increase rates.
- Which is the more important force?
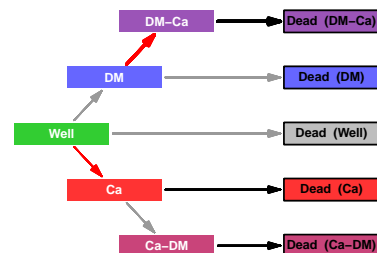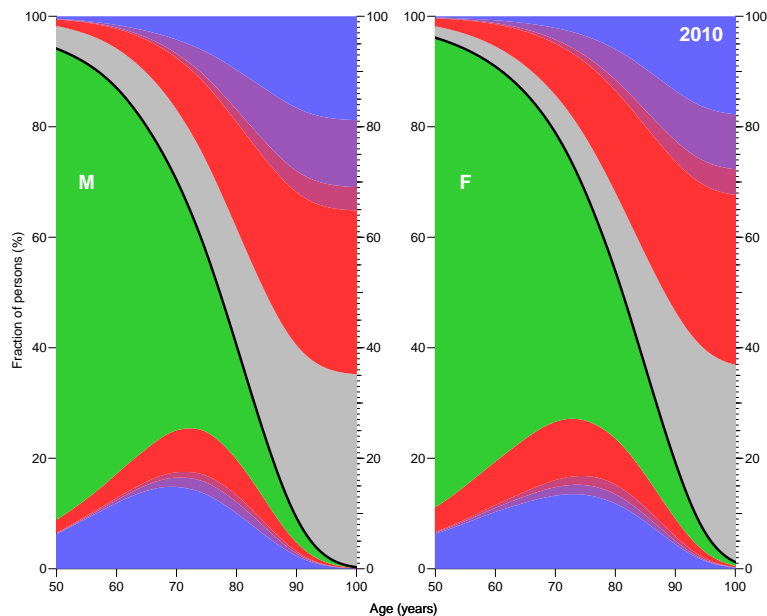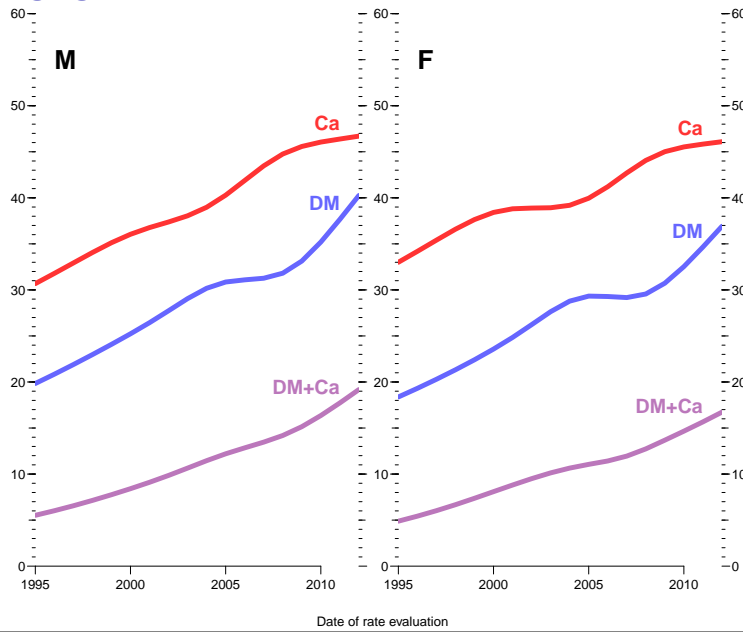- Use rates from the register and predict using different scenarios.

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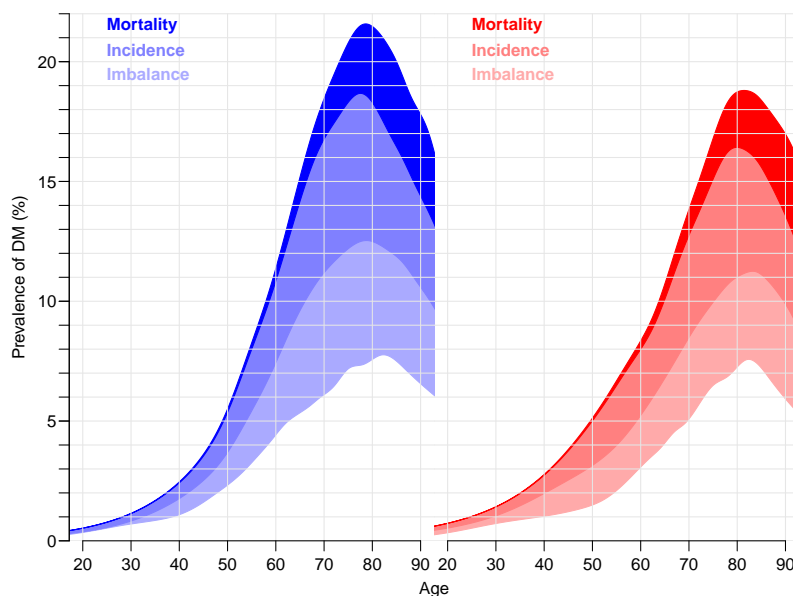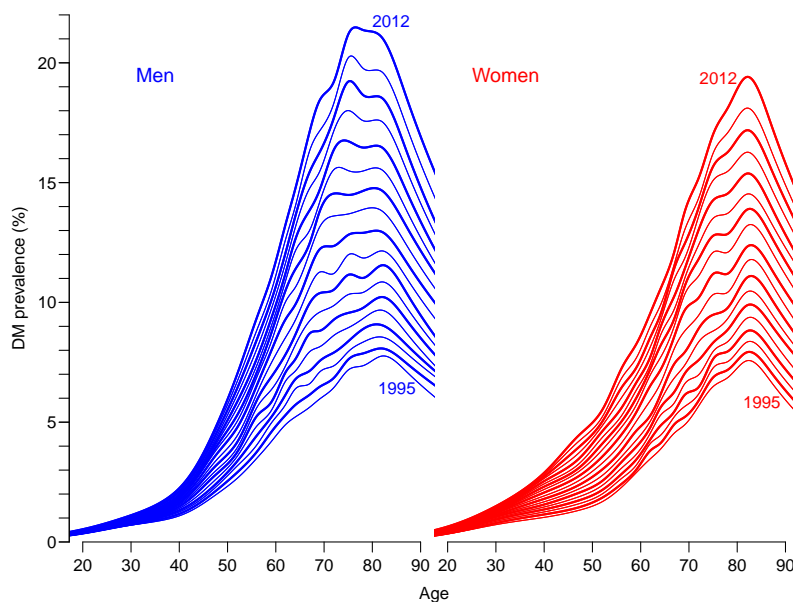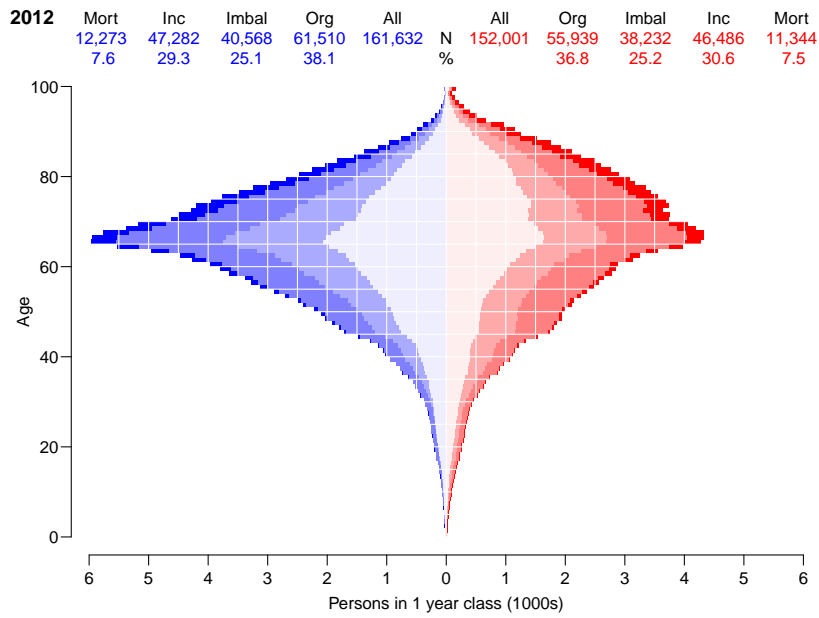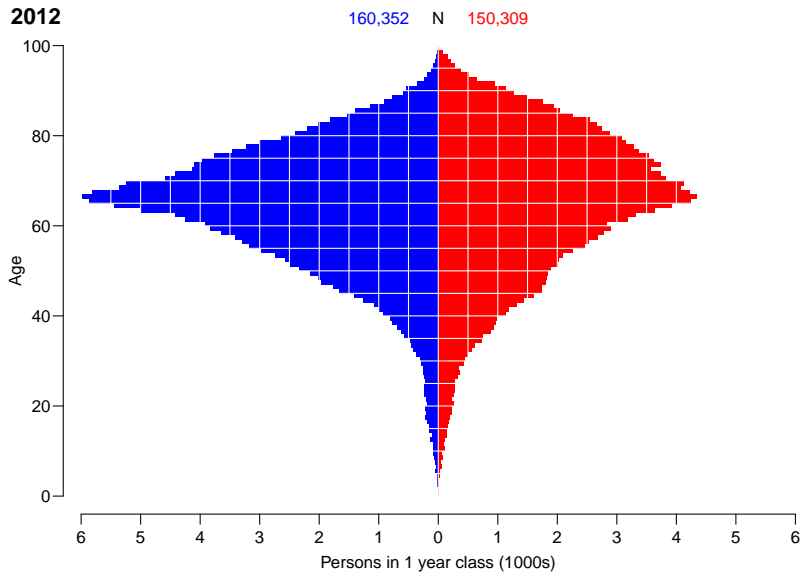
DK-NDR: Lifetime risk of diabetes and cancer
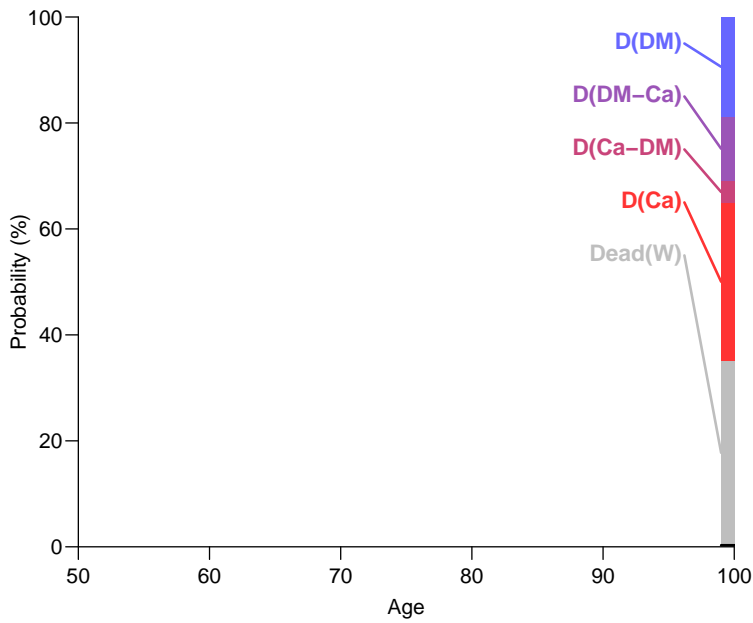
Lifetime risks

Cancer rates among DM-ptt inflated 20% 50%

Demographic changes in DM & Cancer 1995–2012

- Changing **rates** in period 1995–2012:

Diabetes incidence	**4%**/year
Cancer incidence	**2%**/year
Mortality	**–4%**/year

- Changing **life-time risk** 1995–2012:

		+20% Ca | DM	+50% Ca | DM
Diabetes	**19%** to **38%**	19% to 38%	19% to 38%
Cancer	**32%** to **46%**	33% to 48%	34% to 50%
DM + Ca	**6%** to **18%**	6% to 20%	7% to 22%

What have we learned?

- **DK**: about the demographic aspects of diabetes:
  - prevalence
  - incidence
  - mortality among DM patients
- **SE**: about the clinical features of diabetes patients
  - HbA1c - trends
  - Coverage of pharmacological treatment
  - . . .
- **Recording** of how **numbers** and **status** of diabetes patients develop is the key to:
  - population surveillance of DM
  - treatment improvement for patients

Thanks for your attention