Seminar in cooperation with University of Tartu, University of Southern Denmark, WHO PATH CC Krakow and Estonian Health Insurance Fund

Quality of Health Care

Tallinn, 28-30 August 2013

The Danish Diabetes Registries

Medical Director Paul D. Bartels

the danish clinical registers

a national quality improvement programme

DK-Clinical Quality registries criteria for selection

- Disease severity, incidence/prevalence, quality problems….. Improvement possibility?
- Resources – and appropriateness?
- Coupling to implementation of national clinical guidelines/ cancer plan/cardiovascular plan/diabetes plan/chronic care model?
- Political and patient preferences?

Diabetes – Denmark/Estonia

Diabetes at a glance, 2012
Europe (EUR)

Diabetes in Denmark

AT A GLANCE	2012
Total adult population (thousands)	4,013.25
Prevalence (%)	7.54
Number of adults with diabetes (thousands)	302.74
Number of adults with undiagnosed diabetes (thousands)	21.51
Number of deaths due to diabetes	2,781.00
Mean healthcare expenditures per person with diabetes (USD)	6,964.61

Diabetes in Estonia

AT A GLANCE	2012
Total adult population (thousands)	999.19
Prevalence (%)	9.21
Number of adults with diabetes (thousands)	92.05
Number of adults with undiagnosed diabetes (thousands)	1,145.50
Number of deaths due to diabetes	1,285.00
Mean healthcare expenditures per person with diabetes (USD)	1,220.66

http://www.idf.org/sites/default/files/IDF_WP_5E_Update_FactSheet.pdf

T1 Diabetes – Denmark-Estonia

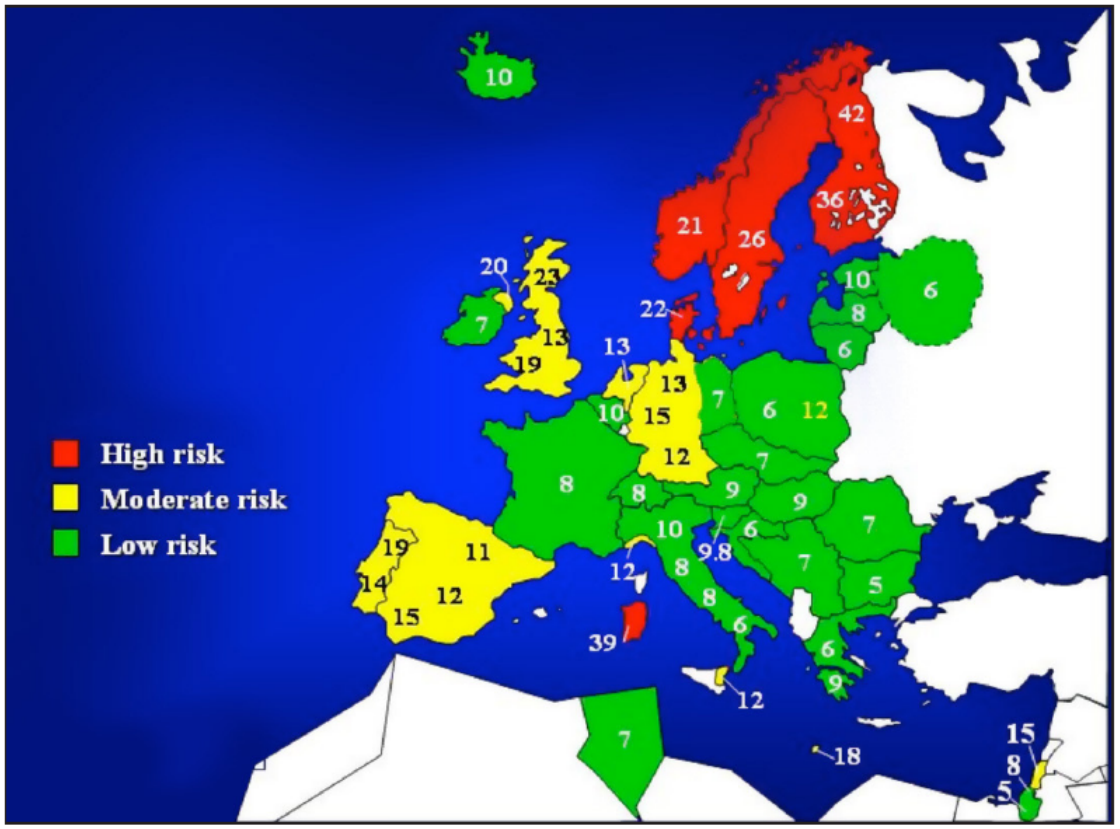


Figure 1. The T1DM incidence among children aged 0–14 years in Europe and in some Mediterranean countries based on EURODIAB data.

Songini M, Lombardo C. The Sardinian way to type 1 diabetes. J Diabetes Sci Technol 2010; 4(5):1248-1255.

Supports the need for

- Monitoring and improving quality of DM care
- Clinical management information
- Transparency of DM QoC

Diabetes care: Two diseases, all ages, several organ systems – therefore we have to have

4½ Clinical Registries for Diabetes in Denmark

(The location of NOVO-Nordisk may have contributed)

The National Diabetes Register

- Health authority register initiated 2007 within the framework of the national diabetes plan
- Based on existing administrative registers – not direct reporting
- Provide information on prevalence, incidence and mortality rates of the complete (+/- 5%) diabetes population in DK
-

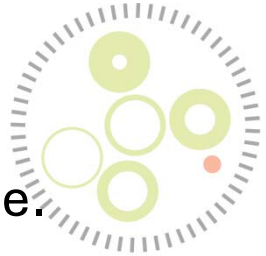
(Carstensen B. et al Scand. J. Public Health, 2011; 39 (suppl 7):58-61

3+ National Quality Registers

- **The DK Register for Childhood Diabetes:** Covers the complete population with incident diabetes, age 0-18, All treated in pediatric dpts. Initiated 1996 as a combined national quality and research registry with biobank.

- **The DK register for adult diabetes (DDDA)** covers adult patients with diabetes treated in Hospital Diabetes Clinics and integrated with the Diabetes quality module for GP surgeries. Initiated 2008 within the framework of the NIP

- **The Register for screening of DM ophthalmopathy** initiated 2003. Covers hospital and specialist practice.



Diabetes DK: Why clinical registries are in special demand

- Surveillance of the prevalence and incidence of diabetes
- Demand for quality improvement and guideline adherence in prevention of late diabetic complications (national niabetes plan)
- Demand for coordination between hospitals, GPs, and municipalities
- Planned transfer of major part of diabetes care from specialised hospital clinics to GPs
- New role for hospital diabetologists as consultants for the GP and municipal services
- Demanded by patient organisations

Elements of medical scientific foundations in the diabetes quality registers

- Clinically/epidemiologically defined population criteria (ADDB: ICD10 codes, age, clinical unit)
- Clinically/epidemiologically selected variables with definitions (ADDB: demographic data, case history, risk factors: BMI, smoking, blood pressure, biochemistry, drug treatment)
- Clinically/epidemiologically selected measures of quality = indicators, with algoritms for calculation

And documentation of it all in critical evidence-based review

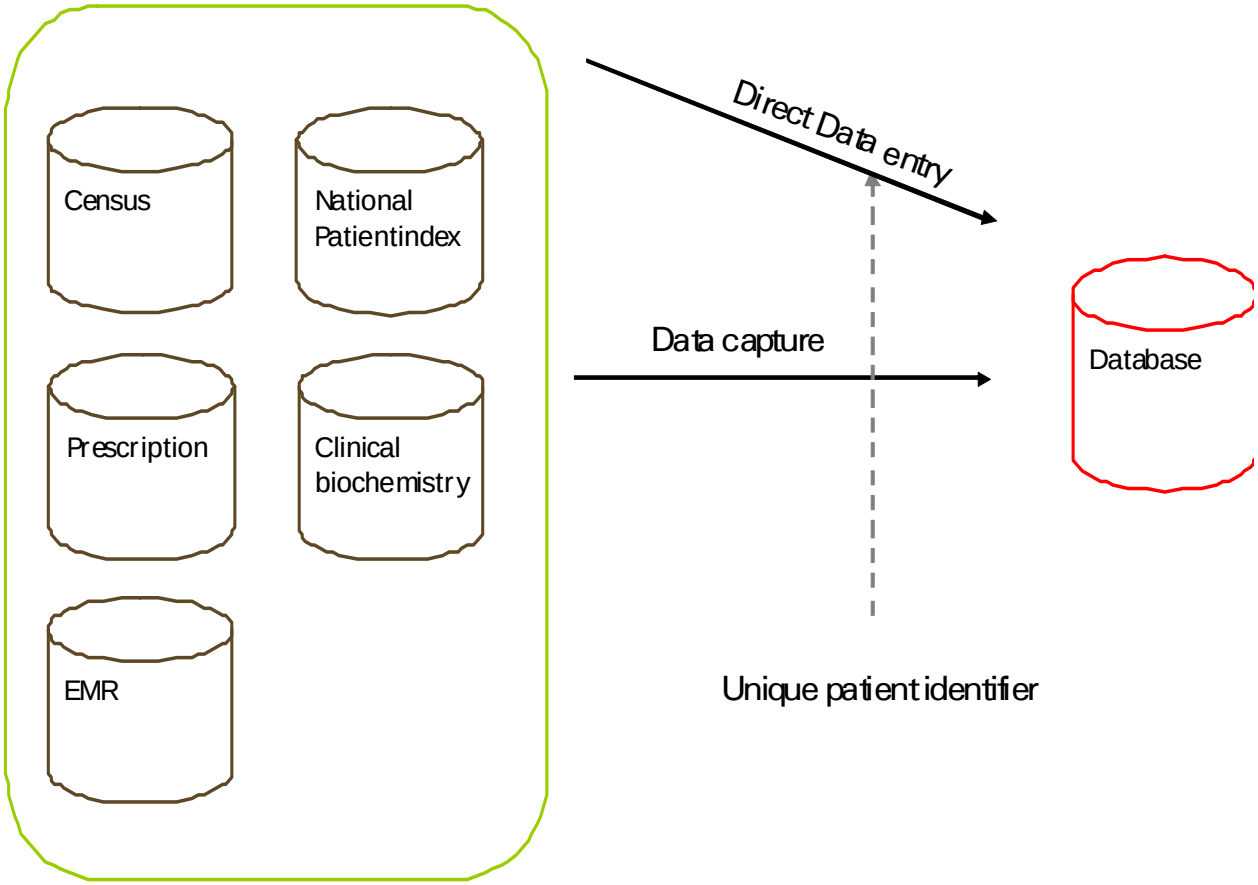
Indicator	Type	Standard	Time reference
Proportion of diabetics who have their HbA1C measured	Process	≥ 95%	At least once a Year
Distribution of the measured values for HbA1C	Result	No threshold value has been determined	The most recent values
Proportion of diabetics who have their blood pressure measured	Process	≥ 95%	At least once a year
Distribution of the measured values of systolic blood pressure	Result	No threshold value has been determined	The most recent values
Distribution of the measured values of diastolic blood pressure	Result	No threshold value has been determined	The most recent values
Proportion of diabetics for whom lipid status is checked	Process	≥ 90%	At least every second year
Distribution of the measured values of the total cholesterol	Result	No threshold value has been determined	The most recent values
Proportion of diabetics who are examined for albuminuria	Process	≥ 95%	At least every second year
Proportion of diabetics who have an eye examination	Process	≥ 90%	At least every second year
Proportion of diabetics who have an eye examination	Process	≥ 95%	At least every four years
Proportion of diabetics who have their feet examined	Process	≥ 95%	At least every second year

Indicator	Type	Standard	Time reference
Proportion of diabetics with HbA1C not treated with antidiabetics/insulin	Result-proces	No threshold value has been determined	The most recent values
Proportion of diabetics with hyperten-sion not in antihypertensive treatment pressure	Result-process	No threshold value has been determined	The most recent values
Proportion of diabetics with hyper-lipidemia not in cholesterol lowering treatment	Result-process	No threshold value has been determined	The most recent values
Proportion of diabetics with micro-albuminuria not treated with ACE-inhibitors	Result-Process	≥ 90%	The most recent values
Proportion of diabetics receiving all processes	Process	85%	1 y

Elements in Diabetes quality registers - Technical/ scientific

- IT support for data collection, storage and processing for analysis
- Epidemiological support for analysis
- IT support for feed- of results to clinical and other stakeholders

DDDA – IT based dataflow



Elements in Diabetes quality registers – clinical and organisational support functions

Scientific measurement and statistics is not enough

- Direct clinical involvement: National and local level
- Experts in improvement science – to stimulate clinical and organisational change
- Strong leadership involvement

Activation of all stakeholders

Computerized data reporting by responsible clinicians at clinical departments

Data transmission via Internet

Data analyses by clinical epidemiologists

Clinical NIP-Registry/ National Patient Registry

Clinical activities and data registration

Weekly/Monthly/quarterly feedback to all clinical departments

Feedback of risk adjusted data once a year

Action Plan: Quality improvement

Regional clinical audit

National clinical audit

Public release

Diabetes Registries: Output to clinicians and organisations -

- Quarterly feed-back to local clinical level (on the road to real-time) - Supporting data formats (SPC)
- Standard yearly report with results published at departmental level, and whole system level together with clinical interpretations and recommendations for improvement - used by professionals, management, government – and the newspapers
- Ad-hoc analysis – supporting clinical research

Did you notice the expansion of perspective in the diabetes registries?

The classical objective for professionals and managers

'Do this clinical team do the right things to the right patients at the right time ?'

Is expanded to include statement of whole system functionality – seen from the patients perspective:

Does GPs, Hospitals, Ophtalmologists, social services work together towards optimal quality

Diabetes DK:
Why clinical registries are in special demand

- Surveillance of the prevalence and incidence of diabetes
- Demand for quality improvement and guideline adherence in prevention of late diabetic complications (national niabetes plan)
- Demand for coordination between hospitals, GPs, and municipalities
- Planned transfer of major part of diabetes care from specialised hospital clinics to GPs
- New role for hospital diabetologists as consultants for the GP and municipal services
- Demanded by patient organisations

Indicator	Type	Standard	Time reference
Proportion of diabetics with HbA1C not treated with antidiabetics/insulin	Result-proces	No threshold value has been determined	The most recent values
Proportion of diabetics with hyperten-sion not in antihypertensive treatment pressure	Result-process	No threshold value has been determined	The most recent values
Proportion of diabetics with hyper-lipidemia not in cholesterol lowering treatment	Result-process	No threshold value has been determined	The most recent values
Proportion of diabetics with micro-albuminuria not treated with ACE-inhibitors	Result-Process	≥ 90%	The most recent values
Proportion of diabetics receiving all processes	Process	85%	1 y

The National DM Quality register

- ***Sector for* Childhood Diabetes:** Covers the complete population with incident diabetes, age 0-18, All treated in pediatric dpts.

- ***Sector for* adult diabetes (DDDA)** covers adult patients with diabetes treated in Hospital Diabetes Clinics and integrated with the *Sector for* GP surgeries.

- ***Sector for* screening of DM ophthalmopathy**

How to start a national diabetes register

1. Simple start – at clinical – not system level/at regional not national level
2. Integrate and use the register in daily clinical work
3. Use own existing organisations (medical societies, university departments)
4. Use own IT-infrastructures and existing databases (e.g. from research projects) Use international experiences and documentation
5. Use international experiences and documentation
6. Include patient organisations

Cost of national diabetes quality registries ?

- **Direct/central costs:** Budget 2014 0.3 mio €
- **Clinical costs ???** – part of contract between GPs and regions
- **Earnings:** Reduced incidence of high cost late diabetic complications as kidney failure, blindness,amputations, heart disease ?

Lot of International Experience with diabetes registers

- Kaiser Permanente
- Joslin Diabetes Centre
- VA
- NHS (general Practice)

International experience EU

- EU-projects: EUBIROD – everything in terms of variables needed for quality registry
- EU- Joint action for quality and patient safety: possibility of sharing experiences and material with S, DK……

Results

– from newest yearly report from the Adult Diabetes Registry

Proportion of patients tested for micro-albuminuria every 2d year hospital outpatients

Indicator xx	Standard		
	95% fulfilled	Result - %	No. patients
Danmark	Yes	96	36666
Region 1	Yes	95	13198
Region 2	Yes	95	4391
Region 3	Yes	98	9542
Region 4	Yes	98	5928
Region 5	No	93	3024

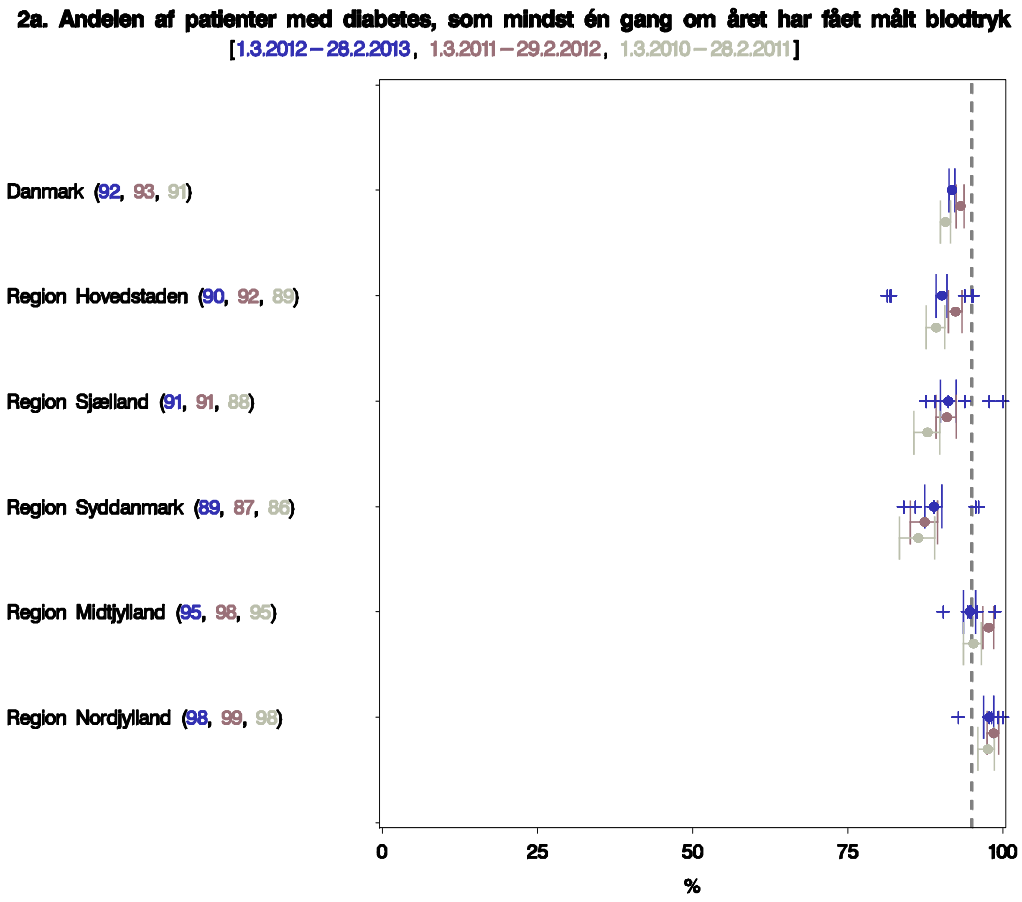
Proportion of patients tested for microalbuminuria every 2d year, hospital outpatients vs GP surgeries

	Standard		
	95% fulfilled	**Result - %**	**No. patients**
Denmark Hospitals	Yes	96	36666
Denmark GP-surgeries	No	77	12501

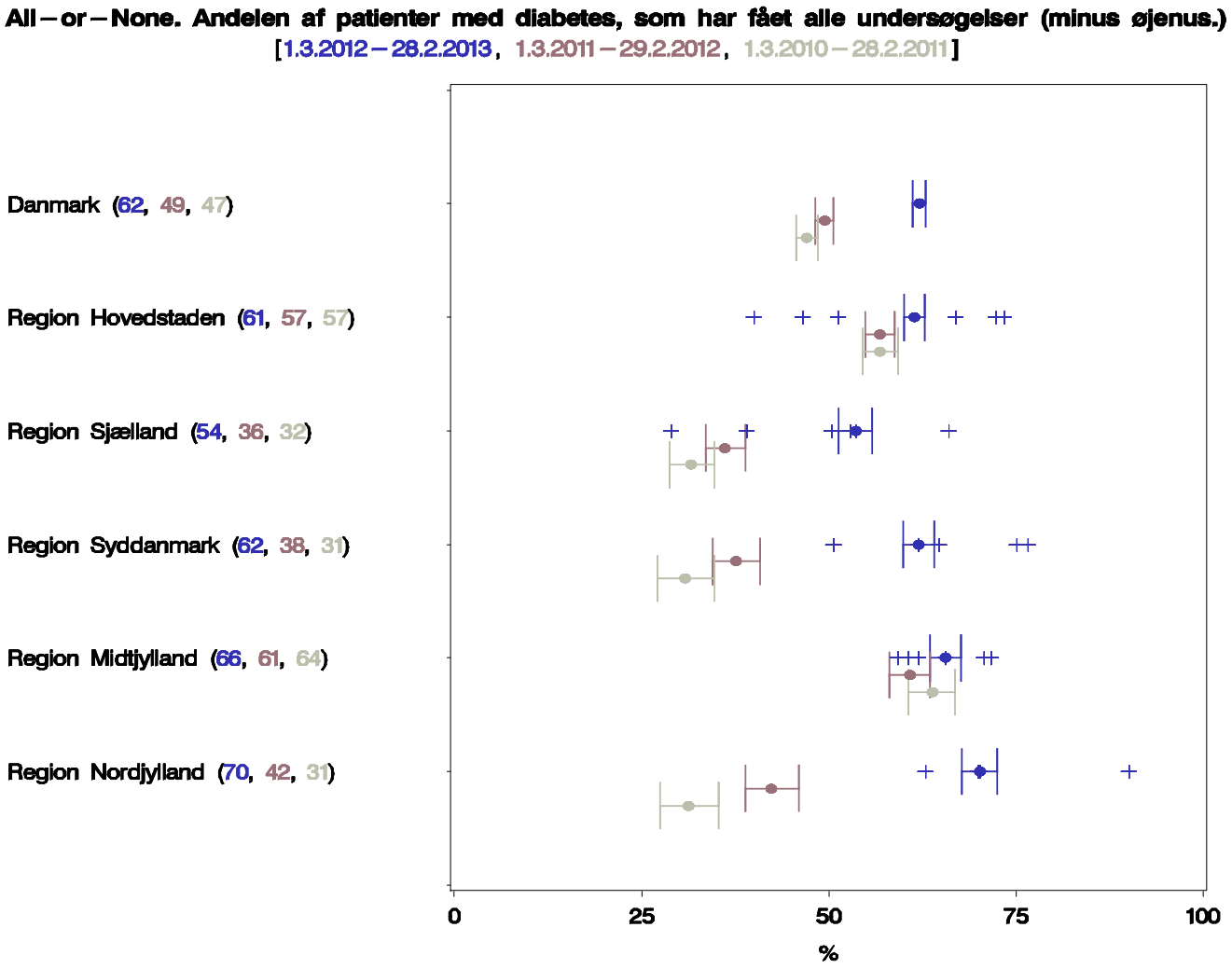
Proportion of diabetics with hyperlipidemia (LDL-Chol greatér than 2.5 mmol/l) not in lipid-lowering treatment, hospital outpatients vs GP surgeries

	Result - %	No. patients	Missing data
Denmark Hospitals	33	3923	30%
Denmark GP-surgeries	45	2999	3%

Not quite there BP-control in hospitals



Evolution and improvement : 2010 – 2013 Hospitals: Proportion of diabetics receiving all processes (hospitals)



Everything OK – Measurement of HbA1c