



Perspectives from the Swedish National Diabetes Register

*Trends in Mortality and
Cardiovascular Disease in Diabetes*

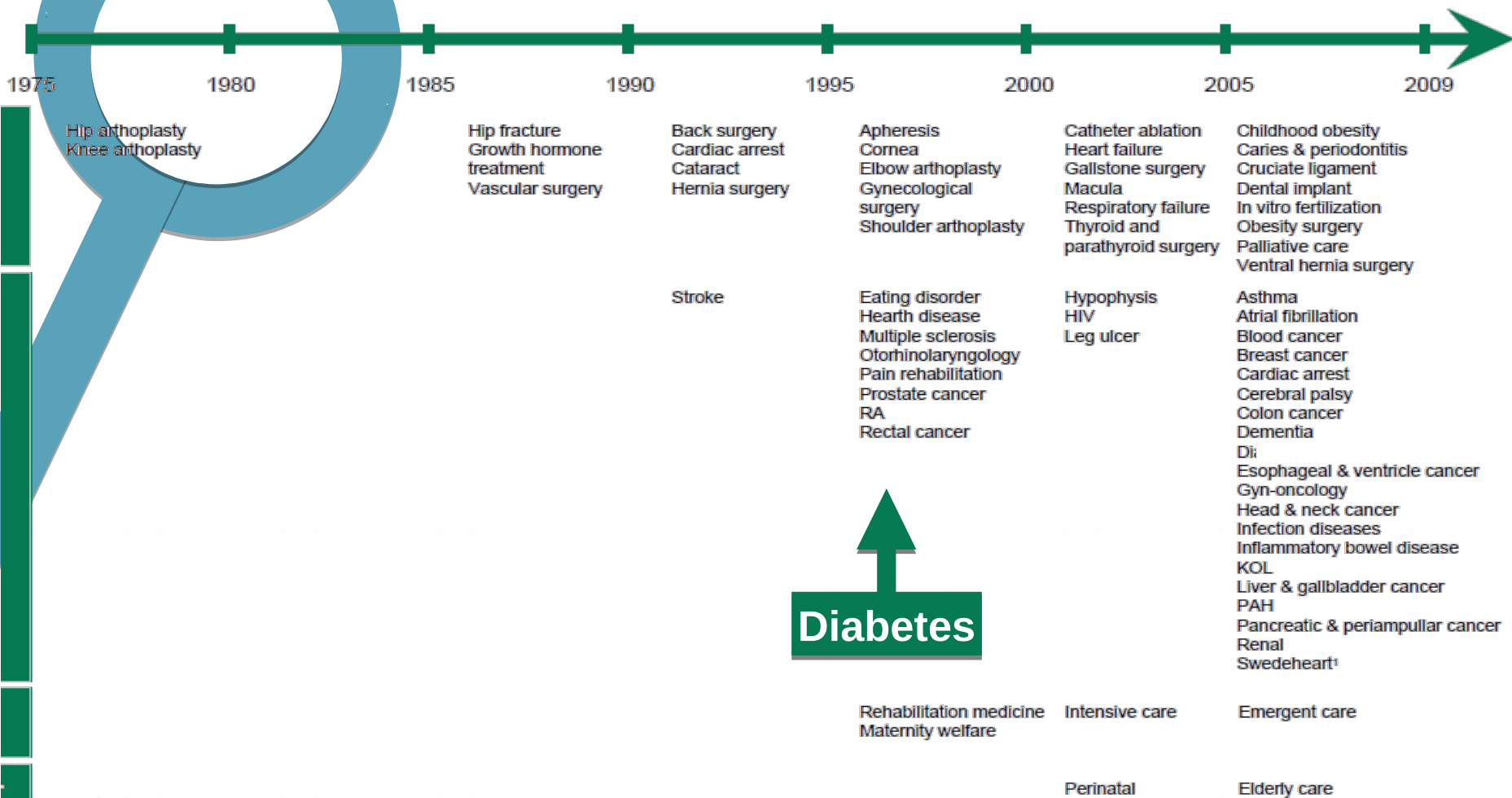
Professor Sofia Gudbjörnsdottir



Quality assurance

31 § The quality of health care should be developed and assured systematically and continually. Law (1996:787).

National Quality Registries in Sweden



Diabetes



SVENSK FÖRENING FÖR DIABETOLOGI
SWEDISH SOCIETY FOR DIABETOLOGY

- NDR started 1996
- Negotiations with GP:s, endocrinologists, internists and patients



The Swedish National
Diabetes Registry

Original aim of NDR

- Benchmarking tool for the health centers
 - ... since improvement requires measurement

NDR today

- Improve care!
- 100 % of hospital-based diabetes centers
- > 90% of primary care/general practice
- Direct transfer of patient or cohort files
- **ndr.nu**
 - by nurses, mostly
- Results are public!
- Funding
 - Swedish Association of Local Authorities and Regions
 - Region Western Sweden



The Swedish National
Diabetes Registry

Easy and uncontroversial to monitor the results in Sweden

- Unique personal identifier
- Allows linkage of official databases
- Health care providers pay the bills
- Political climate
- No fear of integrity issues

NDR platform

- Registercentrum.se created 2009
 - One technical platform and IT staff
- 23 quality registries today
 - Orthopaedic
 - Ear-nose-throat
 - Psychiatry
 - Airways
 - ... and other



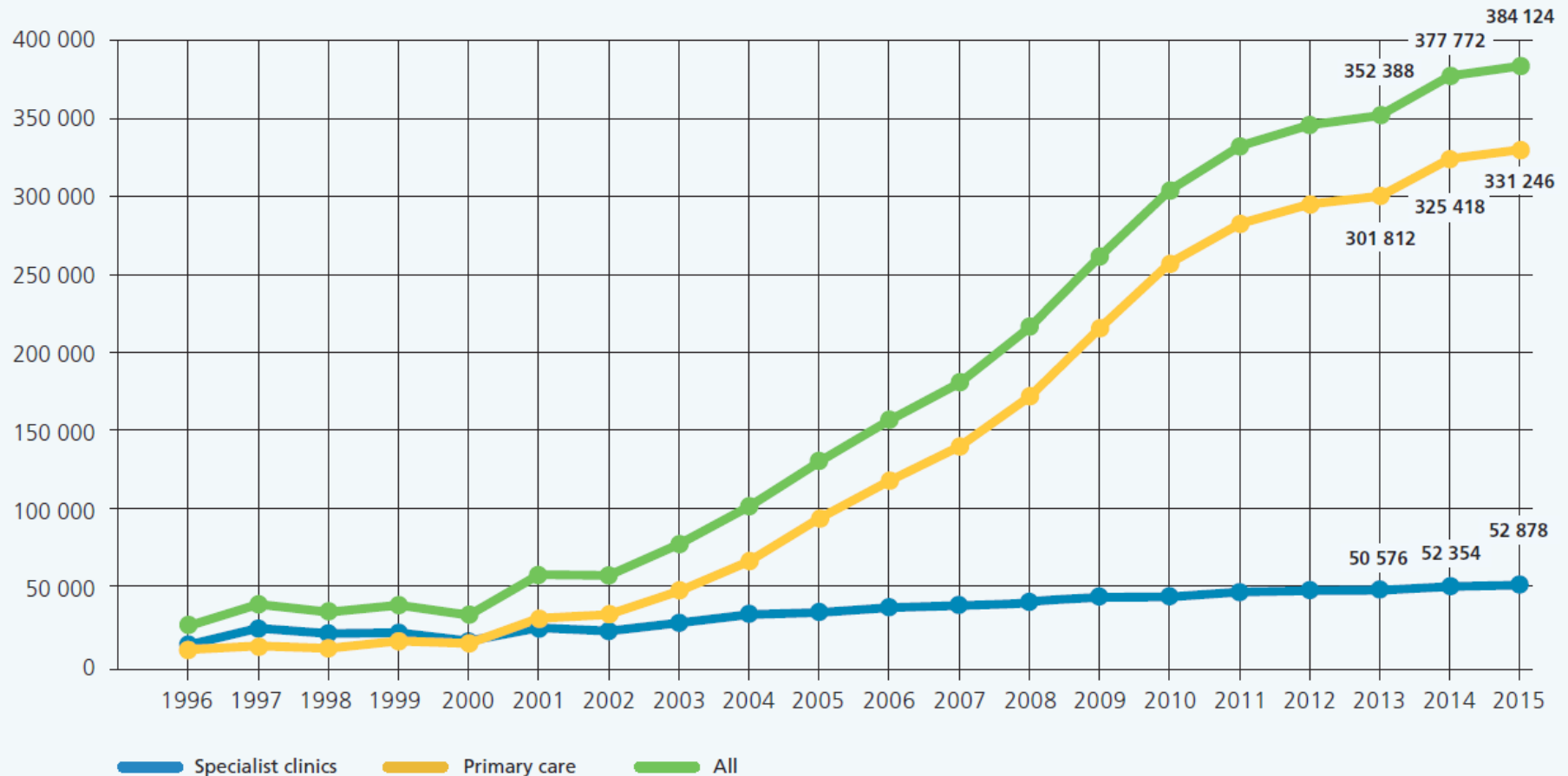
NDR Organization

- Manager, Soffia Gudbjörnsdottir
- Secretary, project leaders
- Database managers, biostatisticians
- Steering committee
- Scientific advisory board
- Working group (results, reports)
- Multiple collaborations

Number of patients

9.5 million inhabitants, < 5% diabetes prevalence

Number of patients entered in NDR, 1996–2015



Date of registration

Microalbuminuria

Caregiver

Social s

Year of

Type of

Diabeto

HbA1c

Height

Blood p

Antihyp

Blood l

Lipid-l

Aspirin treatment

Severe hypoglycaemia

Patient ID

Clinical characteristics

Risk factor control

Treatments

Complications

Processes

PROM

NDR today

- 100 % of hospital-based diabetes centers
- > 90% of primary care/general practice
- Direct transfer of patient data or cohort files
- **www.ndr.nu** - by nurses, mostly
- Real-time results online, down to clinical level, public

LISA
Country of birth, marital status,
education level, profession,
employment status, income

**Prescribed Drug
Register**

Cause of Death Register

**In-patient and
Out-patient registers**

**Personal
Identity
Number**

The Birth Register

The Cancer Register

+ many more

DATA

706,331 patients!

A myriad of variables!

- Demographics
- Socioeconomic status
- Ethnicity, profession
- Biomarkers, Risk factors
- Treatments, Management
- Complications, Other disease
- PROM

ASCERTAINMENT

- >95% typ 1 DM
- >90% typ 2 DM

OPPORTUNITIES

- Improve care
- Observational studies
- RRCS

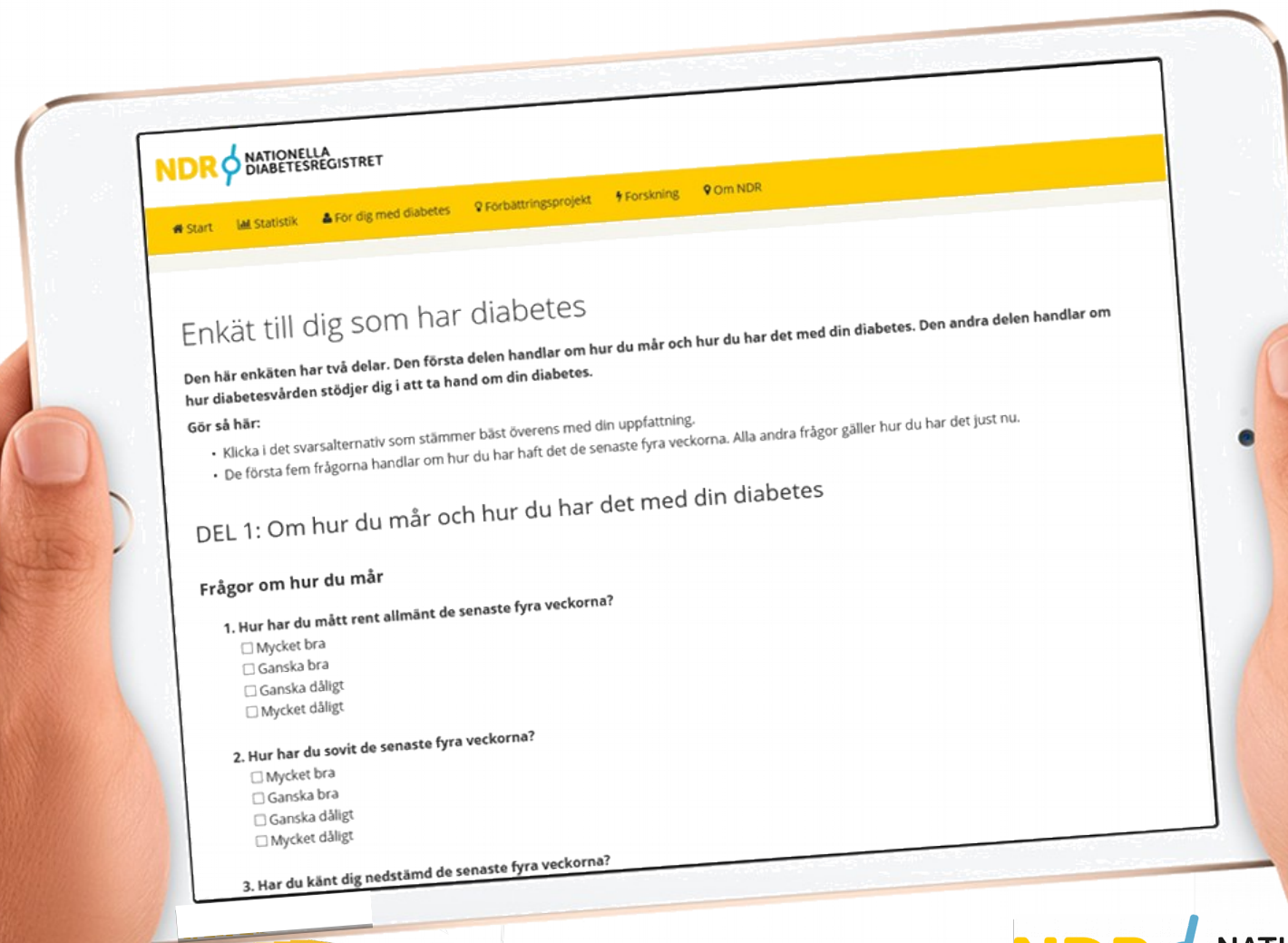
NDR - a natural part of diabetes care

online feedback has been of great importance!

- >1400 care units online
- >90% of all known patients with diabetes



Patient reported data (PROM) is now a part of NDR





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and Clinical Practice

journal homepage: www.elsevier.com/locate/diabres



International
Diabetes
Federation



Diabetes care – improvement through measurement

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ABSTRACT

The National Diabetes Register (NDR) of Sweden was initiated in response to *The Saint Vincent Declaration* (published 1990), to provide a tool for continuous quality assurance in diabetes care. The original purpose, to monitor the results of health centres from year to year and to compare these with national and regional means, is still the most important one, while continuous follow-up of guidelines, treatments and complications are as important on a national level.



The Swedish National
Diabetes Registry

PROM

- To develop and evaluate a diabetes-specific questionnaire
- For future systematic collection of patient reported outcomes within the Swedish National Diabetes Register
- Identify individuals or groups of individuals with a potential to increase their quality of life

Who wants to see the results?

- National Board of Health and Welfare and other national bodies
- Regional health care providers
- The clinics
- The patients
- Big pharma

Glycemic Control and Excess Mortality in Type 1 Diabetes

N Engl J Med
Volume 371(21):1972-1982
November 20, 2014

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Glycemic Control and Excess Mortality in Type 1 Diabetes

Marcus Lind, M.D., Ph.D., Ann-Marie Svensson, Ph.D., Mikhail Kosiborod, M.D.,
Soffia Gudbjörnsdottir, M.D., Ph.D., Aldina Pivodic, M.Sc., Hans Wedel, Ph.D.,
Sofia Dahlqvist, Mark Clements, M.D., Ph.D., and Annika Rosengren, M.D., Ph.D.

ABSTRACT

BACKGROUND

The excess risk of death from any cause and of death from cardiovascular causes is unknown among patients with type 1 diabetes and various levels of glycemic control. We conducted a registry-based observational study to determine the excess risk of death according to the level of glycemic control in a Swedish population of patients with diabetes.

Excess Mortality among Persons with Type 2 Diabetes

N Engl J Med 2015;373:1720-32.

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Excess Mortality among Persons with Type 2 Diabetes

Mauro Tancredi, M.D., Annika Rosengren, M.D., Ann-Marie Svensson, Ph.D., Mikhail Kosiborod, M.D., Aldina Pivodic, M.Sc., Soffia Gudbjörnsdottir, M.D., Ph.D., Hans Wedel, Ph.D., Mark Clements, M.D., Ph.D., Sofia Dahlqvist, and Marcus Lind, M.D., Ph.D.

ABSTRACT

BACKGROUND

The excess risks of death from any cause and death from cardiovascular causes among persons with type 2 diabetes and various levels of glycemic control and renal complications are unknown. In this registry-based study, we assessed these risks according to glycemic control and renal complications among persons with type 2 diabetes.

METHODS

We included patients with type 2 diabetes who were registered in the Swedish National Diabetes Register on or after January 1, 1998. For each patient, five controls were randomly selected from the general population and matched according to age, sex, and county. All the participants were followed until December 31, 2011, in the Swedish Registry for Cause-Specific Mortality.

RESULTS

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Mortality and Cardiovascular Disease in Type 1 and Type 2 Diabetes

Aidin Rawshani, M.D., Araz Rawshani, M.D., Ph.D., Stefan Franzén, Ph.D., Björn Eliasson, M.D., Ph.D.,
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Circulation



Range of Risk Factor Levels/Control, Mortality and Cardiovascular Outcomes in Type 1 Diabetes

Aidin Rawshani, Araz Rawshani, Stefan Franzén, Björn Eliasson, Ann-Marie Svensson, Mervete Miftaraj, Darren K. McGuire, Naveed Sattar, Annika Rosengren and Soffia Gudbjörnsdottir

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