

The Swedish National Diabetes Register

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Director

The Swedish National Diabetes Register

- To improve diabetes care
- Launched 1996
- Internet-based quality registry
- Interactive statistical reports
- Immediate access own results and comparative national statistics
- Local quality control
- Benchmarking-public results
- Ideally, all persons with diabetes should be registered once every year
- Not yet mandatory, but high ascertainment

The Swedish National Diabetes Register

- The NDR is maintained by the Swedish Society for Diabetology on behalf, and with the financial support, of the Swedish National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions.
- The Swedish Diabetes Association, a patient advocacy group, actively uses the NDR as well.

The Swedish National Diabetes Register



NDR- A natural part of diabetes care

online feedback has been of great importance!

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



Patient profile

19851003-XXXX

Print

New visit

Profile

Table

Kvinna, 29 år gammal
Typ 2 diabetes (inkl MODY)
Debutår: 2006
Diabetesbehandling: Tabl. och Insulin

Vikt: 90 kg
Längd: 182 cm
BMI: 27.1 kg/m²
Midjemått: 104 cm



Blood lipids

Kolesterol Triglycerid LDL HDL



Behandlas med lipidsänkande läkemedel: Ja

Blood pressure

135/55 mm Hg



Behandlas med blodtryckssänkande läkemedel: Ja

Coronary/Vascular Disease

Ischemic heart disease No

Cerebrovascular disease No

Aspirin No

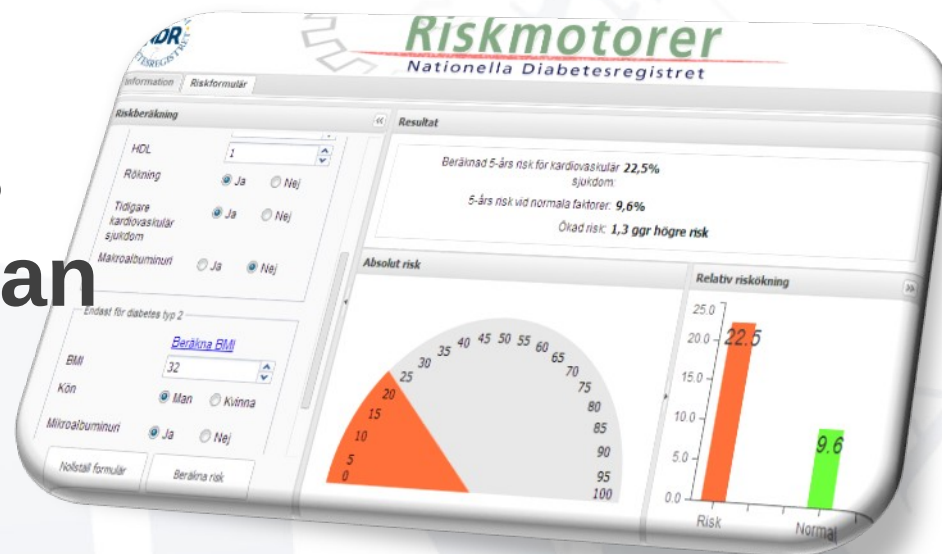
Physical activity

Aldrig <1 1-2 3-5 Dagligen

Smoking

Never smoked

NDR's risk engines adopted by European guidelines



European Heart Journal (2013) 34, 3035–3087
doi:10.1093/eurheartj/ehs108

ESC GUIDELINES



ESC Guidelines on diabetes, pre-diabetes, and cardiovascular diseases developed in collaboration with the EASD

The Task Force on diabetes, pre-diabetes, and cardiovascular diseases of the European Society of Cardiology (ESC) and developed in collaboration with the European Association for the Study of Diabetes (EASD).

5.3 Risk engines developed for people with diabetes

The United Kingdom Prospective Diabetes Study (UKPDS) risk score for CAD has a good sensitivity (90%) in a UK population,^{101,102} overestimated risk in a Spanish population,⁹⁴ and had moderate specificity in a Greek population.¹⁰³ Moreover, this risk score was developed before the advent of modern strategies for CVD prevention.

The Swedish National Diabetes Register (NDR) was applied in a homogeneous Swedish population and reported a good calibration.¹⁰⁴

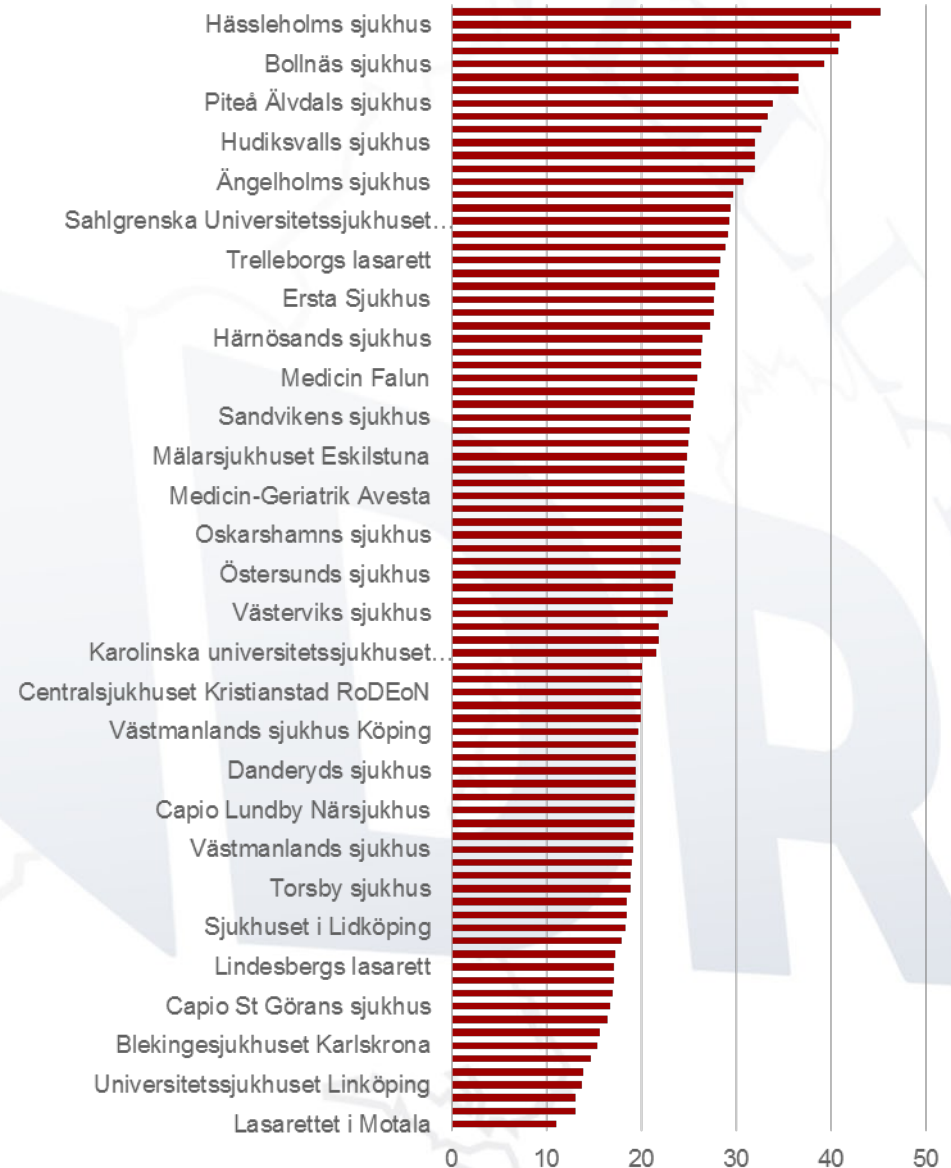
The Framingham Study. Stroke has only undergone validation in a Spanish group of 178 patients and overestimated the risk.^{105,106}

The UKPDS for stroke underestimated the risk of fatal stroke in a US population.¹⁰⁷



**Real-time statistics
publicly available**

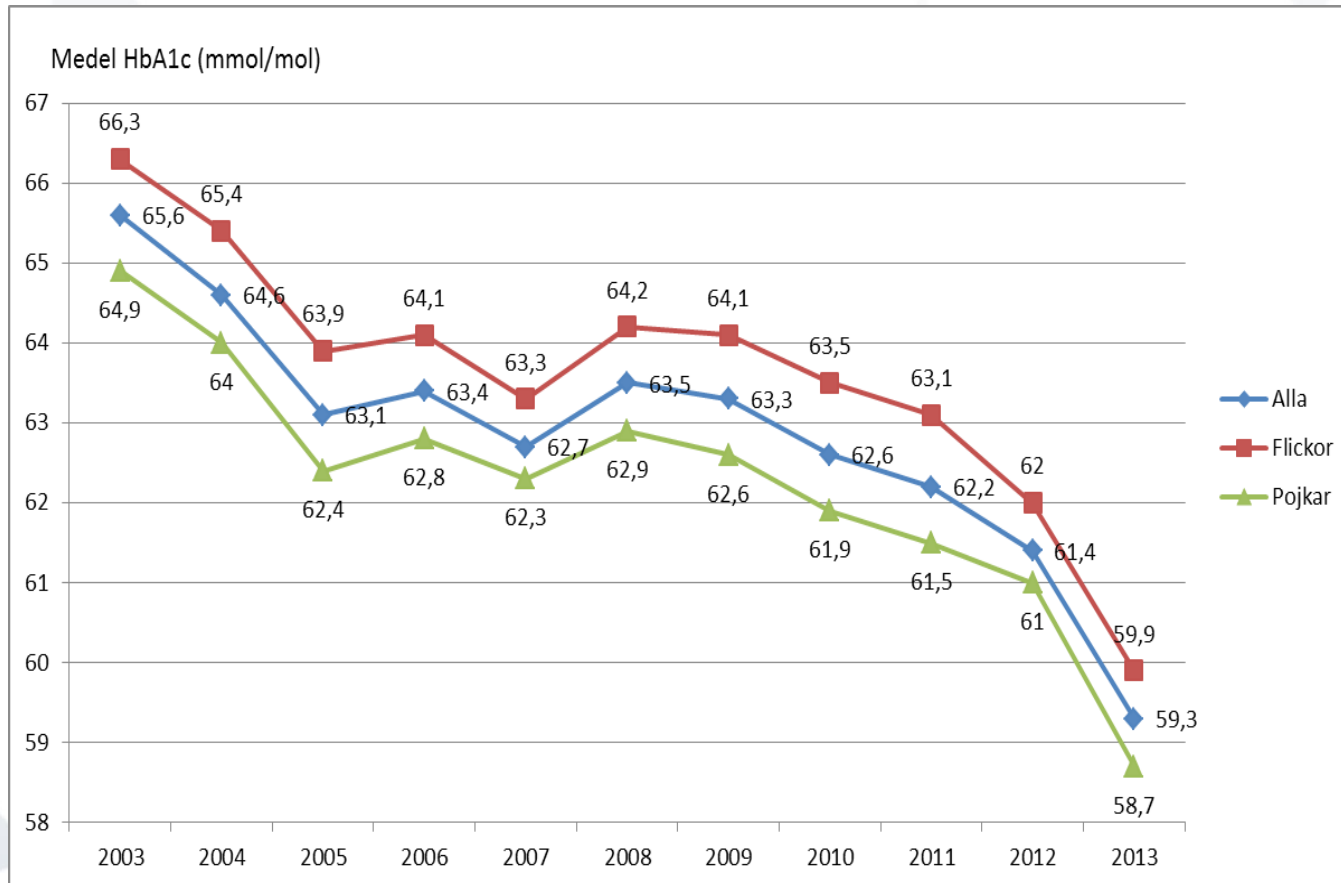
% of persons with diabetes type 1, treated with insulinpump



Quality improvement projects

- The critical factors for success are that measuring results is integral to the overall clinical process, as well as training the entire team to participate in the improvement effort

Proven quality improvement projects, kids





ELSEVIER

Contents available at [ScienceDirect](#)

Diabetes Research
and Clinical Practice

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



International
Diabetes
Federation



Diabetes care – improvement through measurement

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ARTICLE INFO

Keywords:

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Epidemiology

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.

Registry-based research

- Excellent opportunities for long-term studies of a large (and increasing) patient population;
- > 80 original scientific papers –

Causes
of Death
Register

Other
Quality
Register

Education
Register
(Statistics Sweden)

National
Patient
Register

Medical
Birth
Register

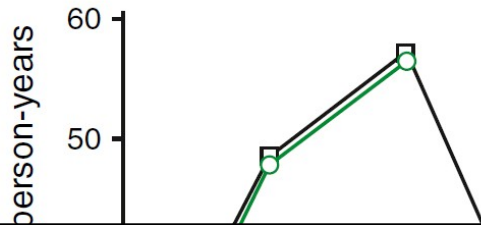
Cancer
Register

Prescribed
Drug
Register



Personal
Identity Number

The incidence of type 1 diabetes in 0–34 year olds



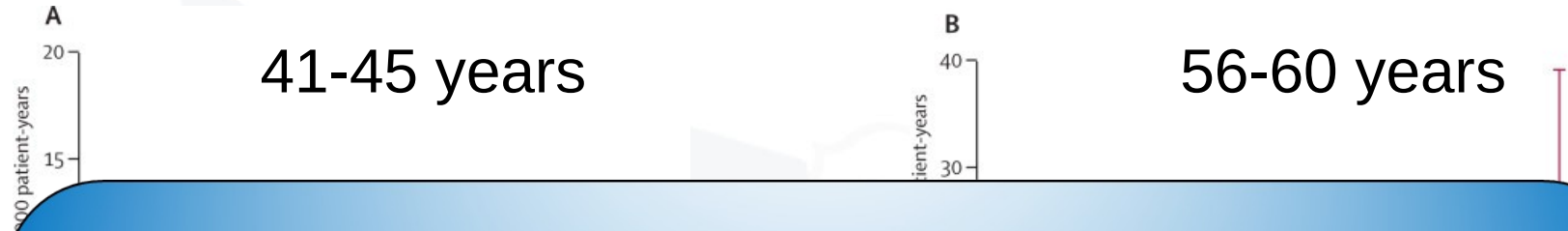
CONCLUSIONS:

The incidence of type 1 diabetes in patients aged 34 and younger was two to three times higher than previously reported. The registries can be used to reliably assess incidence rates in this age group.

ARTICLE

The incidence of diabetes among 0–34 year olds in Sweden: new data and better methods

Araz Rawshani • Mona Landin-Olsson •
Ann-Marie Svensson • Lennarth Nyström •
Hans J. Arnqvist • Jan Bolinder • Soffia Gudbjörnsdóttir



Conclusion:

Heart failure should be considered a major diabetic complication in type 1.

Good glycaemic control could potentially prevent hospitalisation for heart failure

The Lancet 2011; 378: 140-6



**Glycaemic control and incidence of heart failure in
20 985 patients with type 1 diabetes: an observational study**

Marcus Lind, Ioannis Bounias, Marita Olsson, Soffia Gudbjörnsdottir, Ann-Marie Svensson, Annika Rosenqren



Registry-based observational study to determine the excess risk of death according to the level of glycemic control in Swedish population of persons with type 1 diabetes

For each patient, five controls were selected from the general population and matched according to age, sex and county.

The NEW ENGLAND JOURNAL of MEDICINE

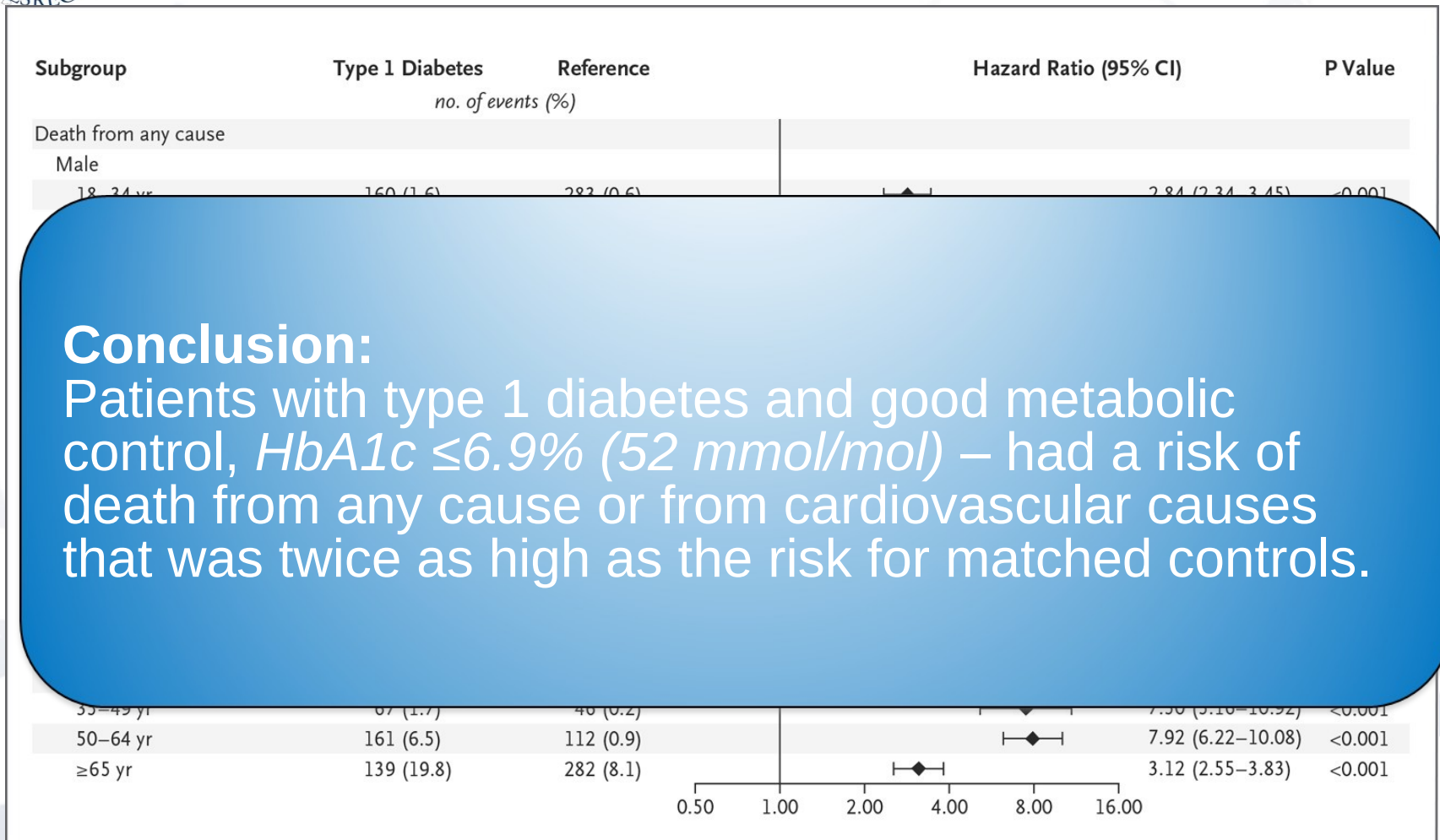
ORIGINAL ARTICLE

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

Relative risk for death (total and CVD) for Persons with typ-1 diabetes compared with controls



How does SES relate to CVD and death in type 1 diabetes?

Population:

24,947 patients,

No

M

M

>1

Risk of death (adjusted for 13 confounders)



Conclusion:

Low SES increases the risk of CVD and death by a factor of 2-3 in type 1 diabetes.



Impact of Socioeconomic Status on Cardiovascular Disease and Mortality in 24,947 Individuals With Type 1 Diabetes

DOI: 10.2337/dc15-0145

Insulin pump therapy - BMJ, June 22

thebmj

Research ▾

Education ▾

News & Views ▾

Campaigns

Research

Insulin pump therapy, multiple daily injections, and cardiovascular mortality in 18 168 people with type 1 diabetes: observational study

2015 ; 350 doi: <http://dx.doi.org/10.1136/bmj.h3234> (Published 22 June 2015)

Cite this as: 2015;350:h3234

Article

Related content

Metrics

Responses

Peer review

Isabelle Steineck, physician¹, Jan Cederholm, associate professor², Björn Eliasson, adjunct professor of medicine, senior consultant³, Araz Rawshani, physician⁴, Katarina Eeg-Olofsson, physician³, Ann-Marie Svensson, research nurse⁴, Björn Zethelius, associate professor⁵, scientific director⁶, Tarik Avdic, medical student⁴, Mona Landin-Olsson, adjunct professor of medicine, senior consultant⁷, Johan Jendle, associate professor, senior consultant⁸, Soffia Gudbjörnsdóttir, associate professor^{3,4} the Swedish National Diabetes Register

Conclusions

This nationwide observational study of individuals with type 1 diabetes shows that treatment with an insulin pump was associated with a considerable reduction in risk of fatal coronary heart disease, fatal cardiovascular disease, and all cause mortality. Whether the results reflect the physiological consequences of insulin pump treatment, the clinical management that pump users receive, or the educational aspects of having the pump remains elusive.

What is already known on this topic

- In patients with diabetes, both hyperglycaemia and hypoglycaemia are risk factors for cardiovascular disease (coronary heart disease or stroke)
- Continuous subcutaneous infusion of insulin with a pump could result in fewer episodes of hyperglycaemia and hypoglycaemia than multiple daily injections and provide better glycaemic control

What this study adds

- Treatment of type 1 diabetes with an insulin pump is associated with significantly lower adjusted hazard ratios for fatal coronary heart disease, fatal cardiovascular disease, and all cause mortality, as well as non-significant reduction in hazard ratios for non-fatal or fatal cardiovascular disease
- Patient education and frequency of blood glucose monitoring might have influenced the observed association

What does NDR give us?

Organizational gains

- Almost complete nationwide monitoring of one of the most important chronic conditions
- Publically available real time data
- Tool for improvement and online feedback
- Benchmarking against guidelines
- Assessing patient reported outcomes

-

Trends in Swedish diabetes care 1996-2015

- Risk factor control is improving
- Much less variation between units
- NDR is an important tool for improvement
- Real-time statistics, publicly available
- Focus on PROM



Euro Diabetes Index

<http://www.healthpowerhouse.com/files/EDI-2014/EDI-2014-report.pdf>



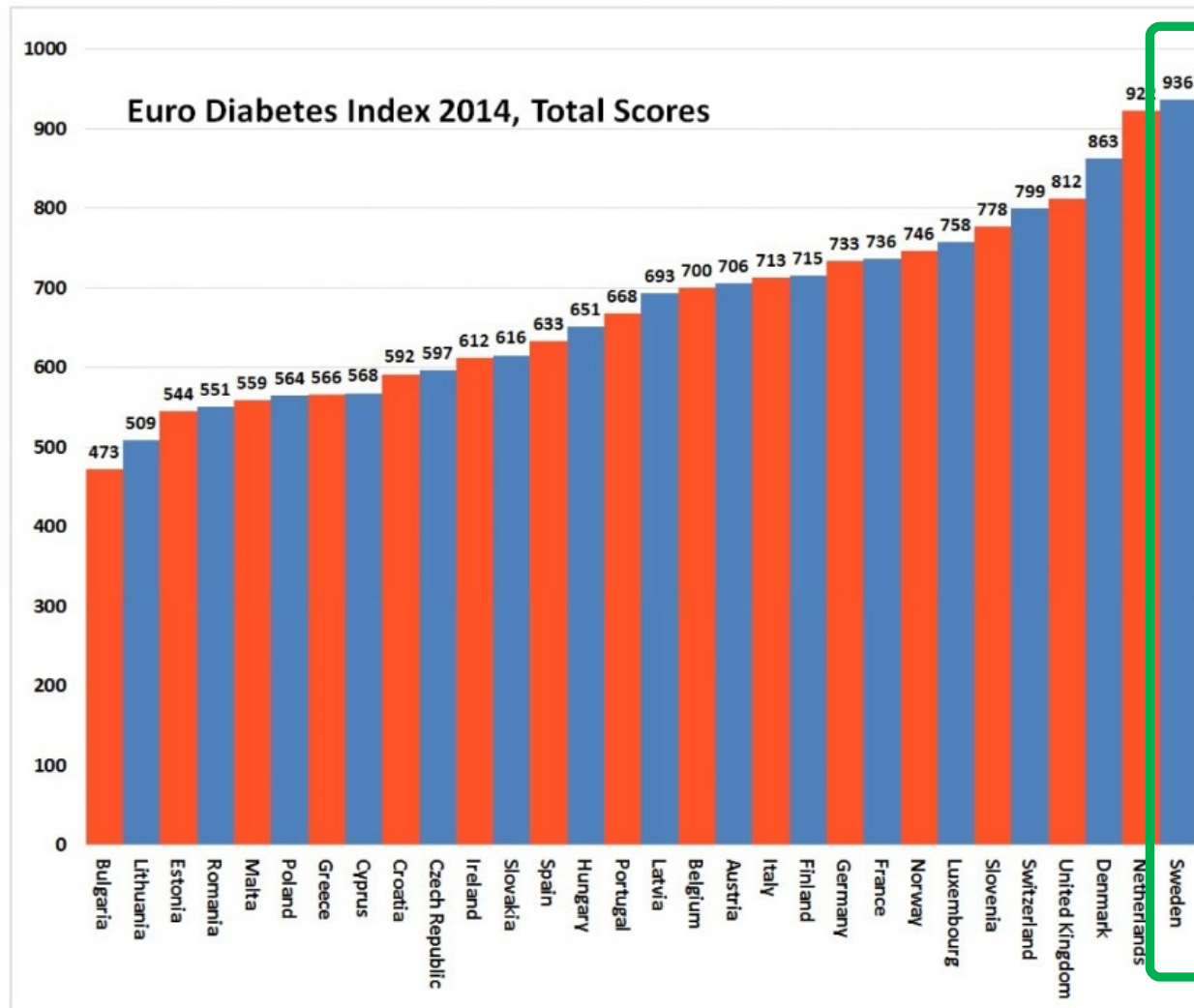
1.3 Top performers in the Index. What are they doing well?

1.3.1 Sweden

The Diabetes Index 2014 shows Sweden (936 points out of a maximum possible of 1000; the highest score ever observed in a HCP Index) as the country with the best diabetes care delivery in Europe.

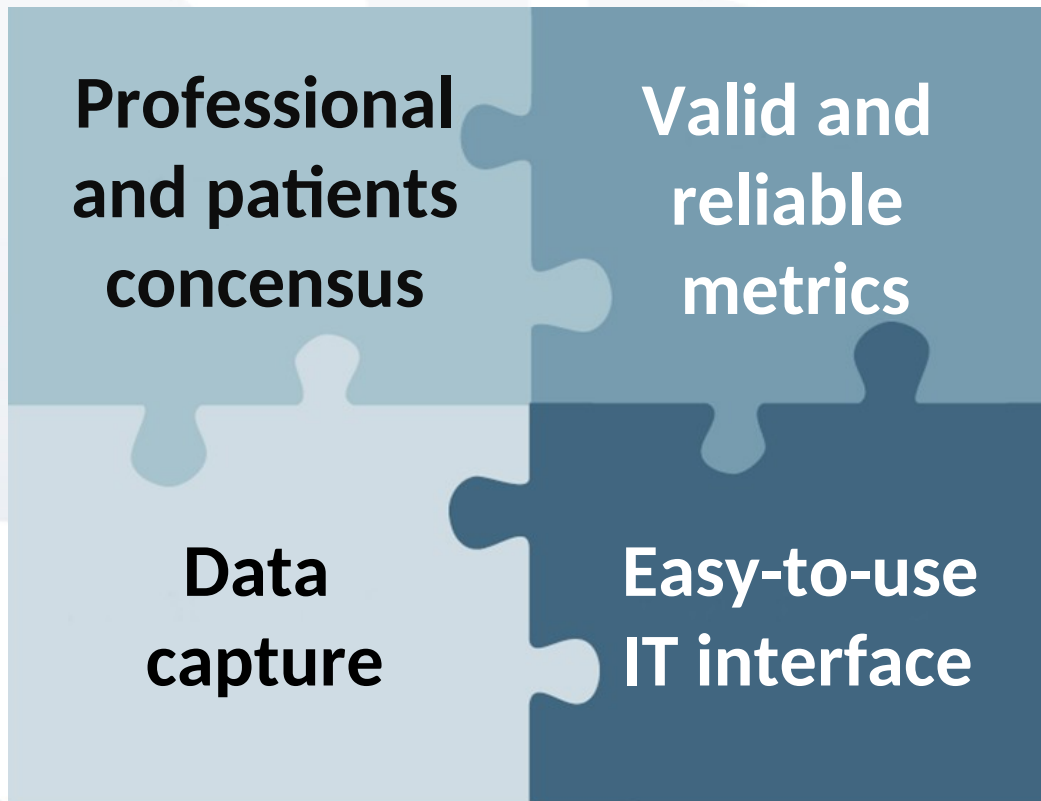
The secret of Swedish high performance is probably "The art of knowing what you are doing". It is the only country out of 30 countries assessed that could provide data on all 28 indicators.

3.1 Total scores and ranking in Euro Diabetes Index 2014



Graph 3.1 Total scores and country ranks in EDI 2014.

Strategic building blocks for National Registries



Strategic building blocks for National Registries

