

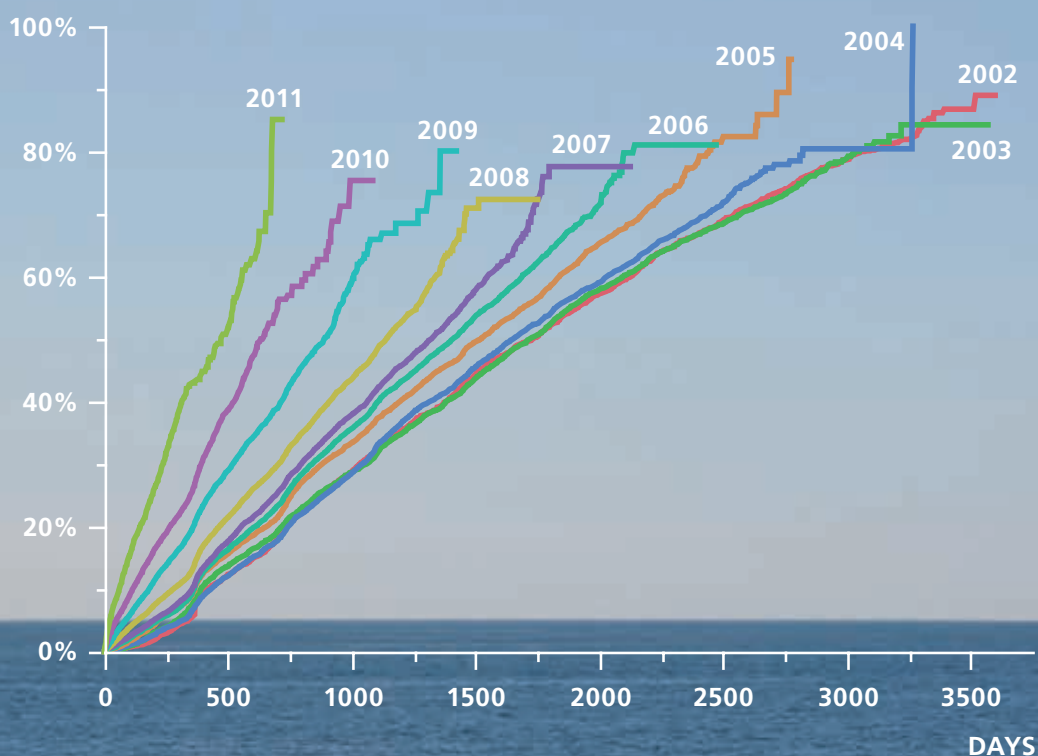


Swedish National Diabetes Register

# Annual report 2013

Time to pharmacological treatment has been reduced from year 2002 to 2011.

PATIENTS



# Annual Report 2013: Results

Swedish National Diabetes Register (NDR) – Centre of Registers, Region Västra Götaland  
[www.ndr.nu](http://www.ndr.nu)

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# The Swedish National Diabetes Register (NDR) serves as a useful tool for providers of everyday care

Chronic diseases place a heavy burden not only on patients and their families, but on healthcare systems around the world. Such pressure on the infrastructure and organisation of the systems often leads to poor management of chronic conditions. The resulting complications reduce quality of life and dramatically increase healthcare costs. The personal and social repercussions are enormous. Diabetes management has a number of dimensions, each of which is multifaceted in itself. Thus, patients should receive advice from a wide range of skilled professionals who are working together. A diabetes centre is an important resource that permits a multidisciplinary team to communicate effectively while providing consistent, reliable counselling. In addition, an individual care plan should be set up on the basis of the patient's particular needs and circumstances.

A clinical, practice-based population register can be used to support structural care and identify patients who may not be complying with their medication regimen, exposing them to risk of inadequate diabetes control.

The NDR was launched in 1996 for the purpose of promoting evidence-based development of diabetes care by offering up-to-date information about changes in the treatment of glycaemia and other risk factors, as well as diabetic complications. Another aim is to support improvement in the quality of care provided by participating units at hospitals and primary care clinics. The overall objective is to reduce morbidity and mortality, as well as to maximise the cost-effectiveness of diabetes care. The NDR is maintained by the Swedish Society for Diabetology on behalf, and with the financial support, and the Swedish Association of Local Authorities and Regions. The Swedish Diabetes Association, a patient advocacy group, actively uses the NDR as well.

The NDR has been online since April 2002 ([www.ndr.nu](http://www.ndr.nu)), allowing individual clinics to quickly monitor their activities on a regular basis by virtue of immediate access to their own results, as well as national statistics for purposes of comparison.

The NDR, which has been an integral part of Swedish diabetes care for the past 18 years, has engaged the participation of both hospitals and primary care clinics. The register offers a unique opportunity to monitor the quality of care in terms of risk factors and the potential complications of diabetes, as well as the evolution of treatment methods. The results generated by the register have been presented at many international meetings and conferences. To our knowledge, the NDR is the largest diabetes register in the world.

Because the course of diabetes is complex and lifelong, both clinical practice and quality control of treatment measures must reflect systematic adherence to various guidelines. The NDR is an instrument to facilitate such monitoring and to disseminate findings in an accessible, transparent, comparable and timely manner. The register is both a repository of results and an educational tool for improving local quality assessment efforts. The register enables a focus on national quality indicators while following various process measures that are important at the local level. Diabetes care is largely self-managed. The NDR also promotes and facilitates the influence and participation of patients in their care and treatment. For example, patients can actively monitor data about their interactions with healthcare providers.

Improved diabetes care minimises risk factors and the incidence of complications. The result is less human suffering and greater social cost benefits. The findings of the proposed projects may prove highly useful during an implementation process that involves continuous monitoring of the performance of an individual diabetes care unit.

The NDR has established itself as a well-functioning tool to promote improvement efforts in the field of diabetes care. Documented evidence suggests that use of the register leads to better long-term outcomes. The critical factors for success are the emergence of healthcare systems in which measuring results is integral to the overall process, as well as training the entire team to participate in the improvement effort. Another factor that is crucial to the effectiveness of the project is the commitment of providers to measuring results, collecting data and discussing what they have learned.

The NDR is used extensively throughout the country. NDR-IQ and other ongoing improvement projects ensure the promulgation of new working methods, along with evidence-based approaches to ensuring progress and improvement.

# Participation and reporting in 2013

## Participation rate

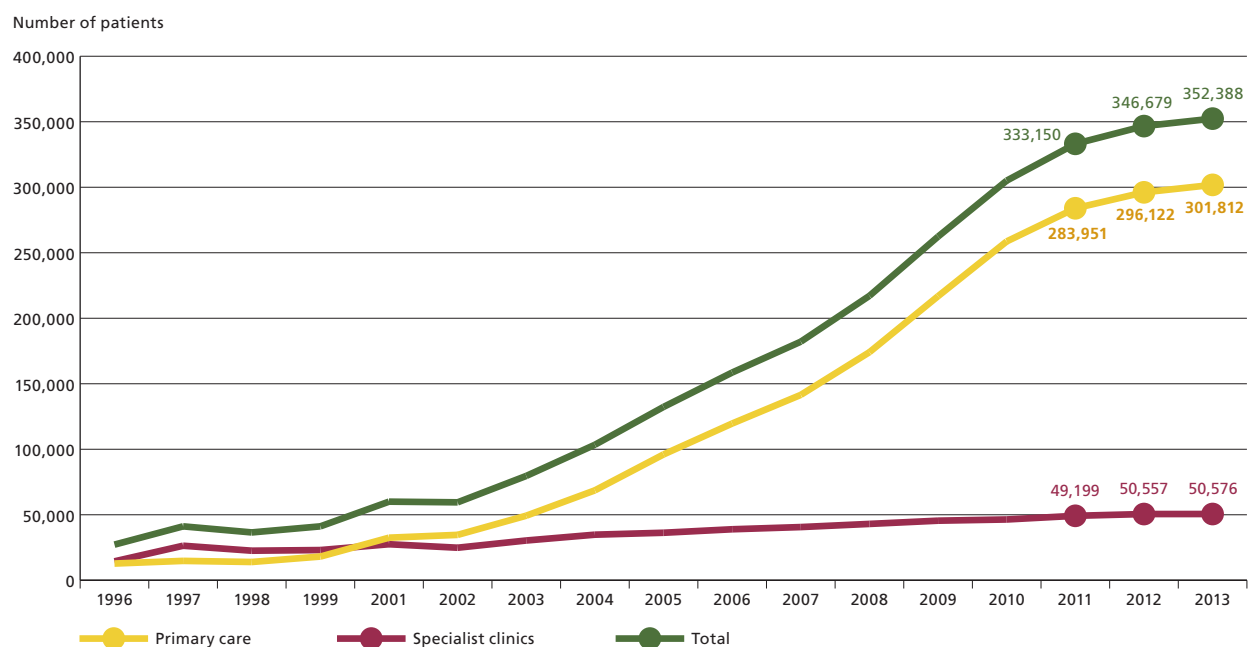
Population-based data were obtained from the Swedish National Diabetes Register (NDR). The Swedish NDR was initiated in 1996 as a tool for quality assurance in diabetes care. National results are published in yearly reports and the register is administrated from Centre of Registers in Region Västra Götaland, Gothenburg, Sweden ([www.NDR.nu](http://www.NDR.nu)). Reporting to the register is not mandatory, but all specialist clinics and primary healthcare centres are encouraged to do so. Today 100% of specialist clinics and 95% of primary health care centres participate. More than 352,000 patients were reported to the register in 2013, representing approximately 88% of adult patients with diabetes in Sweden. Annual reporting to the NDR is carried out by trained physicians and nurses via the Internet or via clinical records databases, with information collected during patient visits at specialist clinics and primary health care centres nationwide. All included patients have agreed by informed consent to register before inclusion. In Sweden almost all patients with type 1 diabetes receive their treatment at specialist clinics. We estimate that approximately 90% of all adult patients with type 1 diabetes, were reported to the NDR in 2013. Furthermore, a recent study showed the prescribed drug register (PDR), which contains data on every prescription filled in Sweden since 1 July 2005 was matched with the NDR amongst the type 1 diabetes 18–34 age group with 91% precision for 2007–2009. (Rashwani et al. 2014. The incidence of diabetes among 0–34 year olds in Sweden: new data and better methods. *Diabetologia*. Apr 9.

Approximately 4% of Swedes have diabetes, though the prevalence varies from one county to another. Type 2 diabetes represents approximately 90% of all cases. On average men are younger when they develop the disease than women. Figure 1 shows the number of patients who participated in 1996–2013, broken down by primary care and specialist clinics. The total increased again in 2013 to 352,388. The register received reports in 2013 from all counties, all 90 specialist clinics and 1,246 primary care clinics (better than 90% altogether).

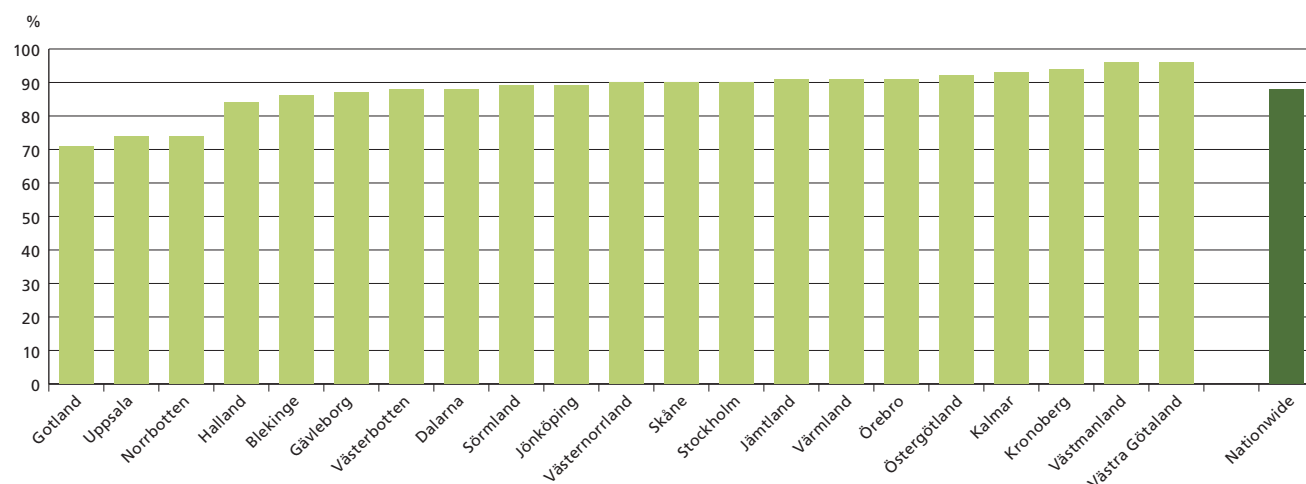
Thus, approximately 90% of all Swedish people with diabetes were entered in the register in 2013, allowing for highly representative data in general, though varying from county to county (see Figure 2). A number of diabetics in each county do not appear in the Prescribed Drug Register because they receive dietary treatment only.

### **Participation rate among people with diabetes receiving medication – comparison between the NDR and Prescribed Drug Register**

To obtain an even more accurate estimate of the participation rate, we performed a comparison with the Prescribed Drug Register of the National Board of Health and Welfare. Figure 2 compares Swedes age 50–80 who picked up prescriptions for diabetes medications (tablets or insulin) in 2012 with the NDR for 2012 and 2013). The NDR contains more than 88% of patients nationwide and more than 90% in many counties.

**Figure 1.** Number of patients entered in NDR, 1996–2013.

Source: NDR – Swedish National Diabetes Register.

**Figure 2.** Comparison between the NDR and the Prescribed Drug Register. People age 50–80 entered in the Prescribed Drug Register on 1 January–31 December 2012 and in the NDR in 2012–2013. Matching based on unique Swedish personal identity numbers.

Source: NDR – Swedish National Diabetes Register.

# Observations by the Patient Advocacy Group

From the earliest days of the NDR, the Swedish Diabetes Association has been an active participant and vigorously promoted the inclusion of as many patients as possible. We are gratified to note that the participation rate has steadily grown to a very impressive level. We now have a means of verifying the quality of Swedish diabetes care and identifying areas for improvement at both the county and clinic level. The register serves as a solid foundation for setting priorities and designing various programmes. The results are useful not only for clinics and county councils, but for individual patients as a tool for evaluating the care and treatment they receive.

The traditional focus of the NDR on medical care is wholly understandable. While relatively unknown at one time, concepts such as empowerment and patient influence are now mandatory items on the healthcare agenda. Diabetes is a quintessential example of that trend, given that is predominantly a matter of self-care and individual decision making on both everyday and special occasions when it comes to diet, medication, exercise, social activities and the full gamut of modern life. The NDR have done a number of patient reported outcome measure (PROM) projects. For that we can only be thankful, but the process is evolving much too slowly. The time has come to graduate from projects to the real world. From our point of view, the issue isn't the best way to ask patients what they think of their caregivers, but to explore the treatment options and tools they have at their disposal to manage their condition and maximise their quality of life. Such considerations determine not only the ultimate well-being and outcomes of each patient, but the successes and failures of diabetes care as a whole.

Another area that requires urgent attention is reporting of data about the use of insulin pumps, continuous glucose monitoring (CGM) systems and other medical devices. Entering such data will quickly generate facts about the impact of the devices on such variables as HbA1c levels and quality of life. There is no doubt in our minds that this information would re-channel public discussion from the current overemphasis on short-term economic gain to the long-term benefits for patients, the healthcare system and the community at large. Above all, more Swedes would have the opportunity to share the fruits of technological progress.

The Diabetes Association wholeheartedly supports this year's decision to publish register results online and present them at the clinic level. At long last we will have access to hard data. In fact, the association would like to take the next step and publish the names of the individual clinics. We believe the fear that patients will switch clinics is considerably overblown. As is the case with all statistics, the challenge is to use common sense without losing sight of possible sources of error. The great majority of diabetics will continue to choose the primary care and specialist clinic closest to home. Ensuring that all patients have access to the same information is a democratic imperative. It goes without saying that we want to maximise our options for lobbying and advocacy, but protecting the right of individual patients to make choices and affect the care they receive is equally important. We have no interest in witch hunting or blacklisting clinics that report inferior results but rather in making a positive contribution to quality assessment efforts. The Diabetes Association is fully aware that the Swedish healthcare system is unaccustomed to the publication of data at the clinic level. Nevertheless, clear communication about the true import of the information should allay any concerns and fears that either we or the media may have.



Fredrik Löndahl, President  
Swedish Diabetes Association

# Nationwide results for 2009–2013

This section presents nationwide results over time. We have selected a number of indicators – additional results appear on our website. For the first time, we have included a life expectancy analysis for type 1 diabetics, including a comparison with the general population.

The annual report of the NDR evaluates diabetes care in relation to the guidelines of the National Board of Health and Welfare while shedding light on patient populations, treatments, results and processes. The objectives of diabetes treatment should be individualised on the basis of each patient's circumstances.

Instead of a single target level, the following discussion often presents averages, proportions and several different targets. Particular patient populations are highlighted.




## Number of patients and classification of diabetes

The results are presented for specialist clinics broken down by clinical classification of diabetes. All diabetics in primary care are reported as one group. A total of 97% of patients treated at specialist clinics have been clinically classified. A total of 97% of patients in primary care have been classified as type 2 diabetics, while only 3% developed the disease when they were younger than 40 and are receiving insulin treatment. Thus, the annual report regards patients in primary care as synonymous with type 2 diabetics.

NDR's scientific reports define type 1 diabetics epidemiologically as patients with onset when they were younger than 30 and have insulin treatment only. Type 2 diabetics, on the other hand, are defined epidemiologically as patients age 40 or older who are receiving **1)** dietary treatment or taking tablets only, or **2)** insulin treatment, whether or not they are taking tablets. This breakdown has proven to coincide very well with the clinical classification in the NDR. However, a few percent of patients whom the register classifies epidemiologically as type 2 diabetics have latent autoimmune diabetes in adults (LADA).

In Sweden almost all patients with type 1 diabetes attend specialist clinics, i.e., outpatient clinics with specialists in diabetology/endocrinology. These clinics also care for patients with complicated type 2 diabetes or many patients with secondary diabetes. Most patients with type 2 diabetes attend primary care, and are seen by general practitioners and diabetes nurses/educators.

The three patient populations are:

-  All patients in primary care
-  Type 1 diabetics treated at specialist clinics
-  Type 2 diabetics treated at specialist clinics

Tables 1a–c describe the clinical characteristics of the three populations. Type 2 diabetics have a higher average age and shorter disease duration in primary care than at specialist clinics. The fact that specialist clinics are reporting fewer and fewer type 2 diabetics suggests that primary care is assuming increasing responsibility for this population.

**Table 1a.** Patients with diabetes in primary care: number, mean age, duration, men.

	2009	2010	2011	2012	2013
Number	219,588	259,560	281,729	296,835	303,403
Mean age (SD)	67.8 (11.9)	67.9 (12.1)	68 (12.1)	68.1 (12.1)	68.2 (11.9)
Mean duration, years (SD)	8.7 (7.9)	8,8 (7.9)	8,9 (8)	9.2 (8.1)	9,5 (8,1)
Men (%)	121,639 (55.4)	143,961 (55.5)	157,263 (55.8)	166,848 (56.2)	172,081 (56.7)

Source: NDR – Swedish National Diabetes Register.

**Table 1b.** Patients with type 1 diabetes at specialist clinics: number, mean age, duration, men.

	2009	2010	2011	2012	2013
Number	30,683	31,291	33,399	34,776	36,126
Mean age (SD)	46 (15.8)	45.9 (16.0)	45.7 (16.3)	45.7 (16.5)	45.9 (16.7)
Mean duration, years (SD)	23.1 (14.7)	23.1 (14.8)	23.2 (14.9)	23.2 (15.0)	23.5 (15.2)
Men (%)	17,069 (55.6)	17,421 (55.7)	18,790 (56.3)	19,491 (56)	20,170 (55.8)

Source: NDR – Swedish National Diabetes Register.

**Table 1c.** Patients with type 2 diabetes at specialist clinics: number, mean age, duration, men.

	2009	2010	2011	2012	2013
Number	12,775	12,221	12,068	10,876	10,146
Mean age (SD)	62.4 (12.6)	62.6 (12.6)	62.5 (12.7)	62.6 (12.7)	62.6 (12.8)
Mean duration, years (SD)	13.9 (9.7)	14.2 (9.8)	14.5 (9.9)	15.2 (10.0)	15.4 (10.0)
Men (%)	8,216 (64.3)	7,922 (64.8)	7,757 (64.3)	7,062 (64.9)	6,505 (64.1)

Source: NDR – Swedish National Diabetes Register.

**Table 2a.** Recently diagnosed patients in primary care. Clinical characteristics at onset.

	2009	2010	2011	2012	2013
Number	13,391	16,676	16,964	16,614	14,416
Mean age (SD)	62.9 (12.5)	62.8 (12.6)	62.9 (12.5)	62.8 (12.5)	62.8 (12.7)
Number HbA1c	12,687	15,518	16,013	16,144	14,107
Mean HbA1c, mmol/mol (SD)	52.1 (14.9)	52.4 (14.9)	52.3 (15.5)	52.8 (15.7)	51.7 (15.5)
Number BMI	10,944	13,552	14,381	14,545	12,789
Mean BMI, kg/sq m (SD)	30.6 (5.7)	30.6 (5.7)	30.6 (5.6)	30.8 (5.7)	30.7 (5.7)

Source: NDR – Swedish National Diabetes Register.

**Table 2b.** Recently diagnosed adults with type 1 diabetes at specialist clinics. Clinical characteristics at onset.

	2009	2010	2011	2012	2013
Number	403	397	398	409	356
Mean age (SD)	37.4 (14.8)	36.6 (15.1)	37.1 (15.4)	35.6 (14.8)	33.8 (13.3)
Number HbA1c	380	366	382	386	343
Mean HbA1c, mmol/mol (SD)	54.9 (17.1)	57.4 (19.9)	56.6 (18.4)	55.5 (17.8)	53.4 (16.8)
Number BMI	329	341	344	337	298
Mean BMI, kg/sq m (SD)	24.5 (4.4)	24.6 (3.7)	24.6 (4.3)	24.3 (4)	24.1 (4)

Source: NDR – Swedish National Diabetes Register.

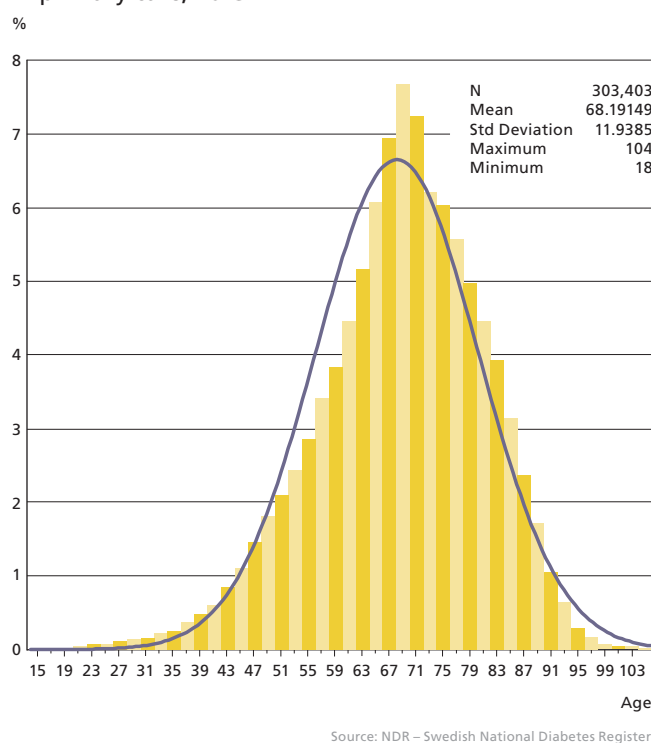
**Table 2c.** Recently diagnosed adults with type 2 diabetes at specialist clinics. Clinical characteristics at onset.

	2009	2010	2011	2012	2013
Number	339	347	307	229	214
Mean age (SD)	53.9 (13.3)	54.3 (14.1)	54.9 (14.1)	52.9 (14.4)	52.6 (15.8)
Number HbA1c	314	316	291	211	205
Mean HbA1c, mmol/mol (SD)	53.9 (15.2)	52.3 (15.3)	55.8 (19)	57 (20.9)	55.7 (18.8)
Number BMI	262	261	244	195	183
Mean BMI, kg/sq m (SD)	29.9 (5.4)	30 (5.7)	30 (5.4)	29.7 (5.9)	29.4 (5.6)

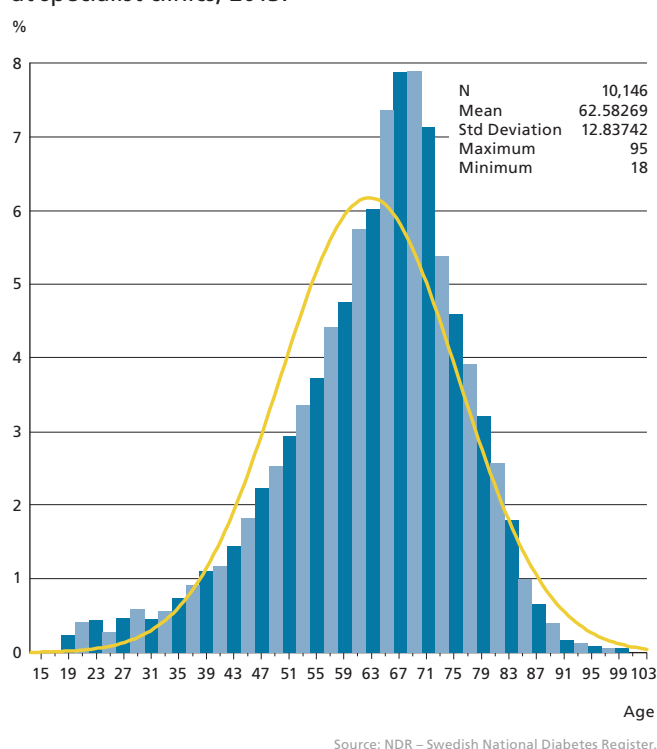
Source: NDR – Swedish National Diabetes Register.

Figure 3–5 shows the age breakdown for primary care, as well as type 1 and type 2 diabetics treated at specialist clinics, in 2013. As was the case in 2012, specialist clinics are treating many young adults with type 1 diabetes as a result of higher prevalence among children and adolescents.

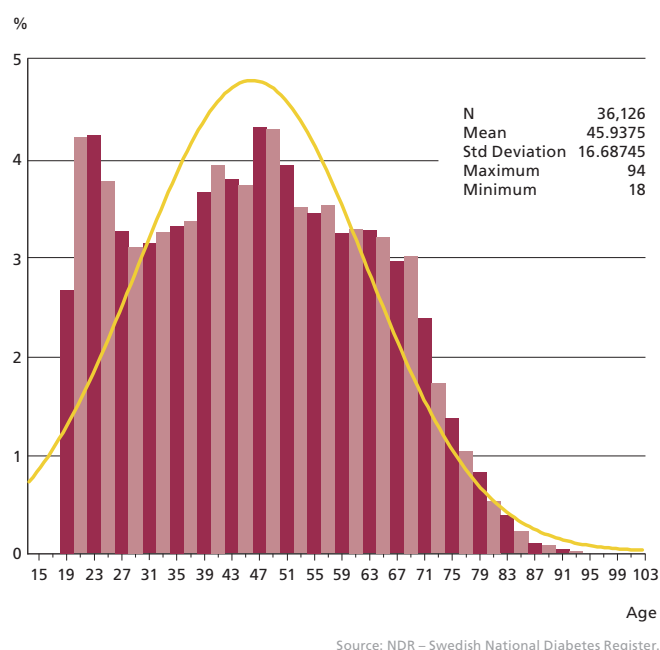
**Figure 3. Histogram by age. Patients with diabetes in primary care, 2013.**



**Figure 4. Histogram by age. Patients with type 2 diabetes at specialist clinics, 2013.**



**Figure 5. Histogram by age. Patients with type 1 diabetes at specialist clinics, 2013.**

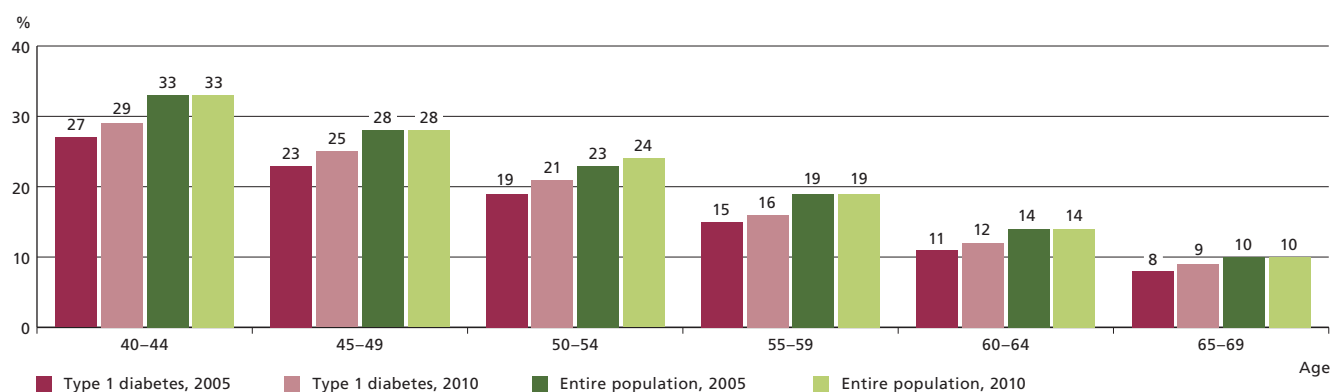


### Life expectancy of type 1 diabetics

The figure (Figure 6) shows the life expectancy among patients with type 1 diabetes (those who developed the disease before the age of 30 and are receiving insulin) for the six age groups between 40 to 69. Life expectancy increased for all groups from 2005 to 2010. For comparison purposes, the life expectancy of the general Swedish population, also broken down by age group, is presented for the same years. The greater increase in the life expectancy among patients with type 1 diabetes than of the general population was statistically significant.

One reason for the increased life expectancy among patients with type 1 diabetes may be improvements in the treatment of hypertension, high blood lipid levels and other risk factors for cardiovascular and kidney disease. Changes in BMI, physical activity and other lifestyle factors may also have played a role. Better control of HbA1c levels by means of injections or insulin pumps may also have contributed. The way that the healthcare system is structured to treat patients with type 1 diabetes is also important when it comes to both inpatient and outpatient care, including teams of professionals and specially trained diabetes nurses. The widespread use of the NDR by clinics since 2005 to report among patients with type 1 diabetes has created new opportunities for structured monitoring of the care provided at the local level.

Remaining life expectancy is based on actuarial tables. The basic variables are the size of the population and the number of deaths for various ages during the year in question.

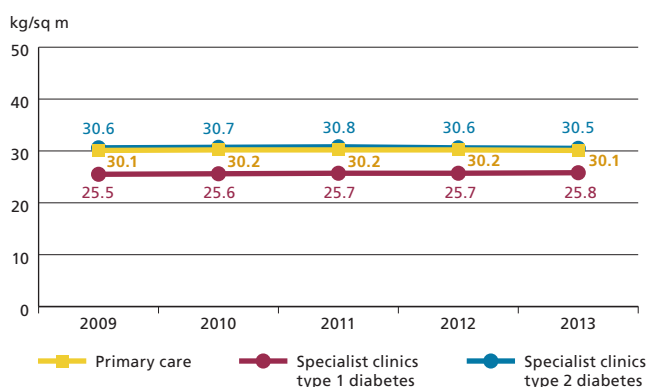
**Figure 6. Life expectancy, type 1 diabetes.**

Sources: Register Service, Swedish National Board of Health and Welfare, and NDR – Swedish National Diabetes Register.

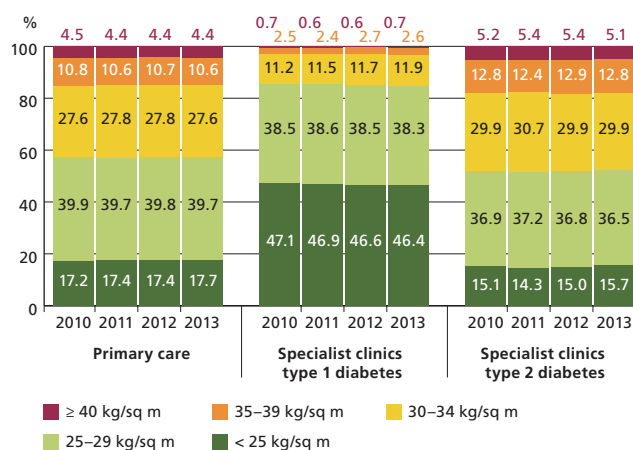
## Lifestyle

### Prevalence of overweight and obesity not rising but very high

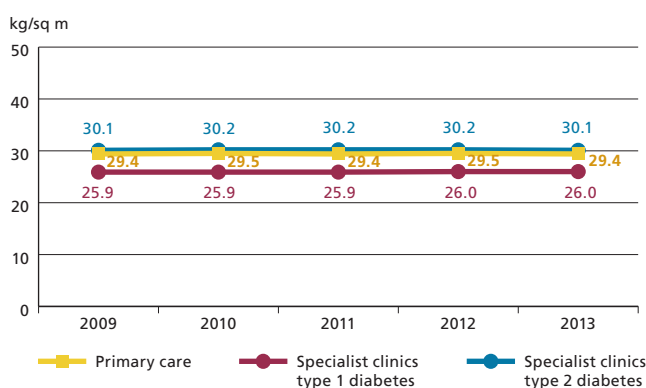
The proportion of women and men with type 2 diabetes who are overweight or obese has not risen significantly in recent years. Nevertheless, approximately 47% of women and 40.5% of men still suffer from obesity. Figures 7a–7b and Figure 8 show body mass index (BMI) trends in 2009–2013. Only 15.7% of type 2 diabetics treated at specialist clinics and 17.7% in primary care had normal weights (BMI < 25 kg/sq m).

**Figure 7a. Mean BMI, women.**

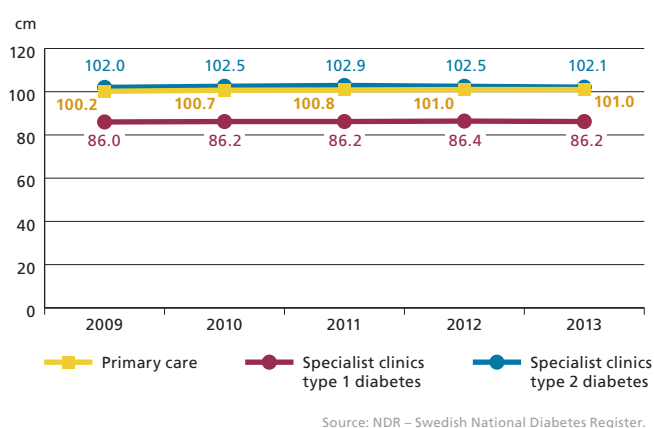
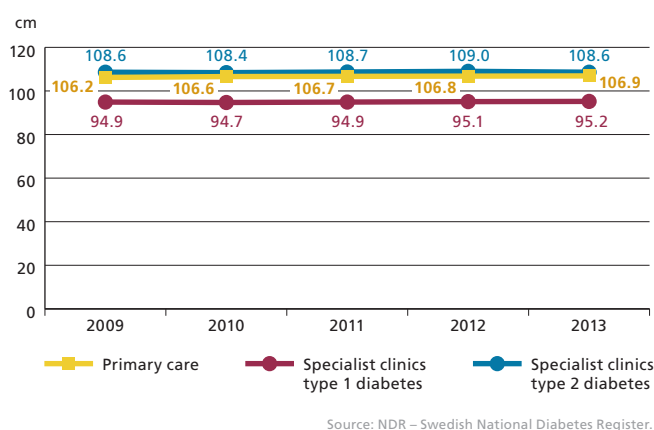
Source: NDR – Swedish National Diabetes Register.

**Figure 8. BMI by intervals.**

Source: NDR – Swedish National Diabetes Register.

**Figure 7b. Mean BMI, men.**

Source: NDR – Swedish National Diabetes Register.

**Figure 9a. Mean waist circumference, women.****Figure 9b. Mean waist circumference, men.**

## Many are physically inactive

The trend line in Figure 10 goes between patients who exercise regularly (at least three times a week) and those who do not. Patients with type 1 and type 2 diabetes at specialist clinics trended slightly downward.

**Figure 10. Physical leisure activities.**

## Physical activity protects against risk factors

The largest-ever observational study, conducted by the NDR, of physical activity among patients with type 2 diabetes found that both women and men can substantially reduce the risk of cardiovascular disease and premature death by exercising regularly.

The results clearly indicated that these patients have the power to improve their own prognoses by staying physically active and eliminating sedentary habits.

Type 2 diabetes increases the risk of cardiovascular disease. Medical research has established that physical activity reduces the risk of myocardial infarct, stroke and a number of other diseases in the general population. We launched a study to quantify the extent to which patients with type 2 diabetes, who by definition are at elevated risk of cardiovascular disease, can take advantage of these positive health effects.

The study was based on NDR data for more than 15,000 women and men with type 2 diabetes. Responses to questions about level of physical activity are entered in the NDR each year. None of the participants had cardiac infarct, stroke or another cardiovascular disease at baseline, but 750 of them developed one within the five-year follow-up period. A total of 427 participants died during the period, most of them at age 60–70.

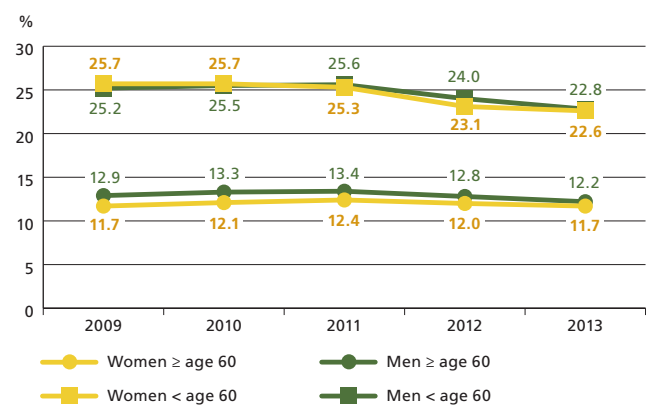
Both cardiovascular disease and premature death were much more common among participants who exercised no more than the equivalent of two 30-minute walks per week than those with higher levels of physical activity. The results of the study showed that it is never too late to adopt a healthier lifestyle. Participants who exercised very little at baseline and became more physically active during the follow-up period exhibited the most pronounced protection against the risk factors for cardiovascular disease and premature death.

Their risk decreased by 50% compared with participants who remained physically inactive. In addition to a healthy diet, elimination of sedentary habits and regular physical activity are among the cornerstones of non-pharmacological treatment for type 2 diabetes. Because the disease is so common, greater awareness in this respect benefits public health as well. A number of international media, as well as the website of the European Society of Cardiology ([www.escardio.org](http://www.escardio.org)), featured the study.

## Patients with diabetes are smoking less

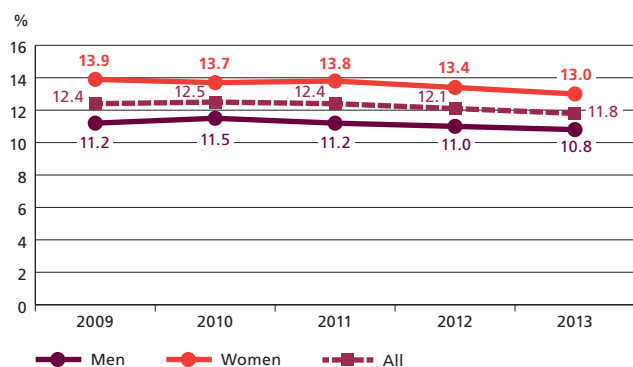
The percentage of smokers in primary care declined again in 2013 (Figures 11–12), regardless of gender or age (60, younger or older). Patients with diabetes are smoking less as well, but 13% of women and 10.8% of men have not quit yet.

**Figure 11.** Women and men in primary care < age 60 and ≥ age 60 who smoke.



Source: NDR – Swedish National Diabetes Register.

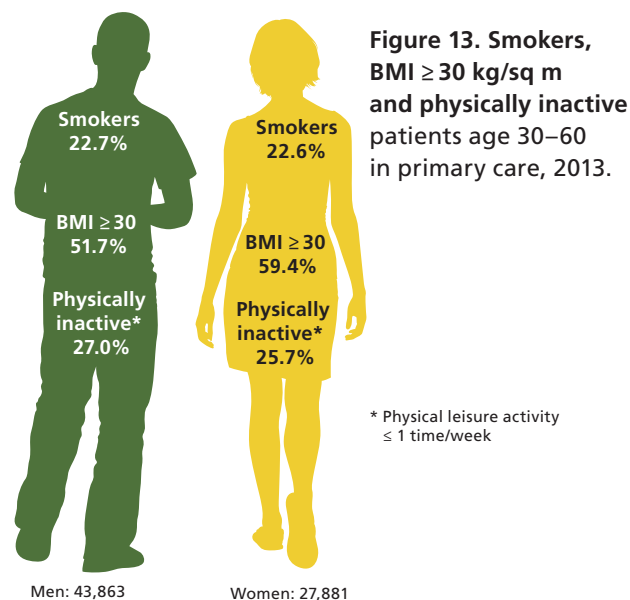
**Figure 12.** Type 1 diabetes patients at specialist clinics who smoke.



Source: NDR – Swedish National Diabetes Register.

## Patients with type 2 diabetes who are relatively young

More than one in five 30–60 year-olds smoke and one in four are physically inactive (Figure 13). A total of 51.7% of men and 59.4% of women have BMI ≥ 30 kg/sq m.



\* Physical leisure activity ≤ 1 time/week

Source: NDR – Swedish National Diabetes Register.

Distribution of HbA1c levels

Figures 14–15 contain distribution curves and histograms for the most recent HbA1c levels among patients with type 1 and type 2 respectively.

Figure 14. Histogram for HbA1c (mmol/mol). All patients with type 1 diabetes, 2013.

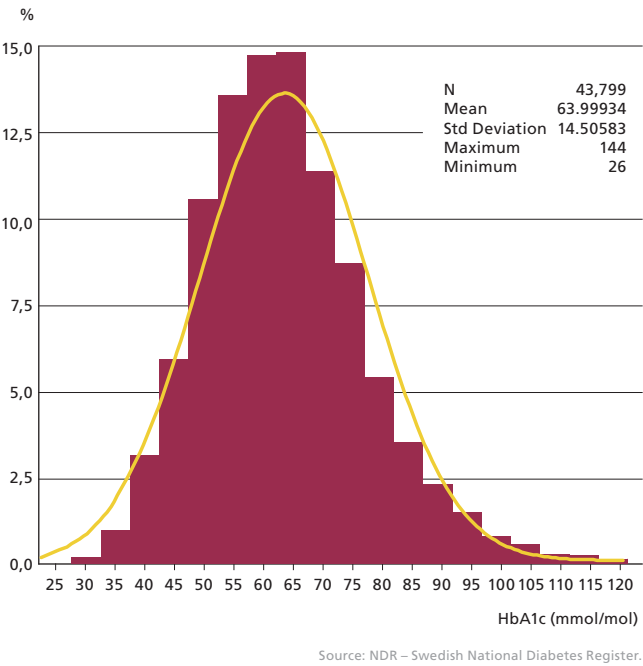
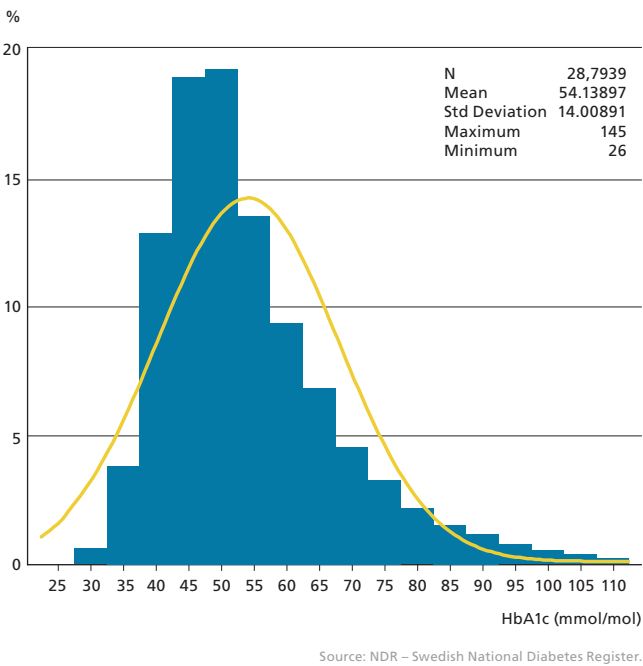


Figure 15. Histogram for HbA1c (mmol/mol). All patients with type 2 diabetes, 2013.



HbA1c trend

HbA1c levels have held steady or shown a negative trend in recent years. The negative trend reversed in 2013 (Figures 16–20) for all populations – with the exception of patients with type 2 diabetes treated at medical clinics who have had the disease for a short period of time, possibly reflecting the fact that their numbers have declined and that the ones who have remained have more severe cases. Thus, the trend has been positive both for patients with type 1 diabetes and for primary care as a whole.

Figure 16. Mean for HbA1c (mmol/mol).

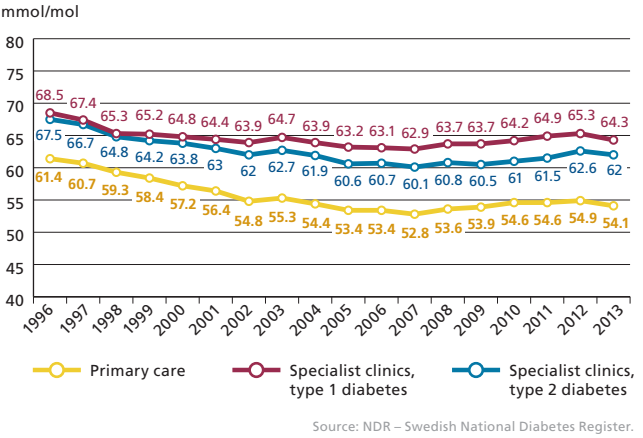
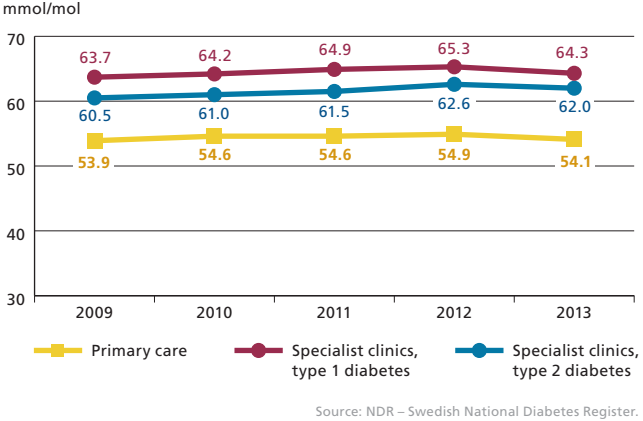
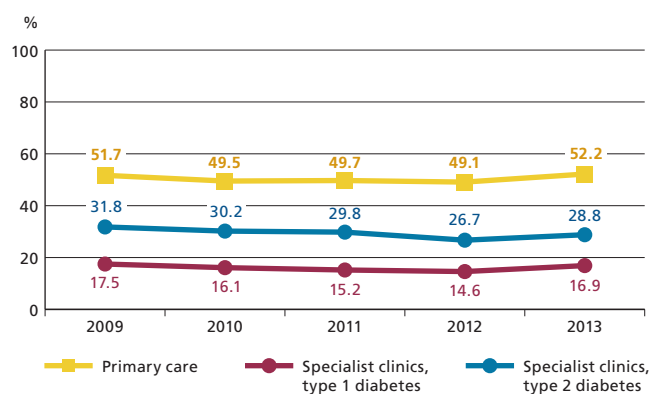
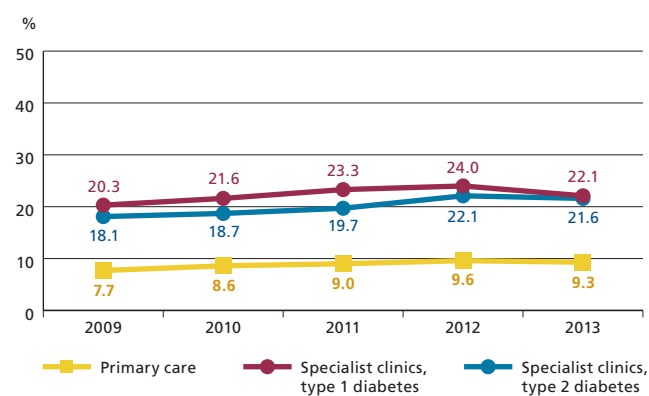


Figure 17. Mean for HbA1c (mmol/mol).

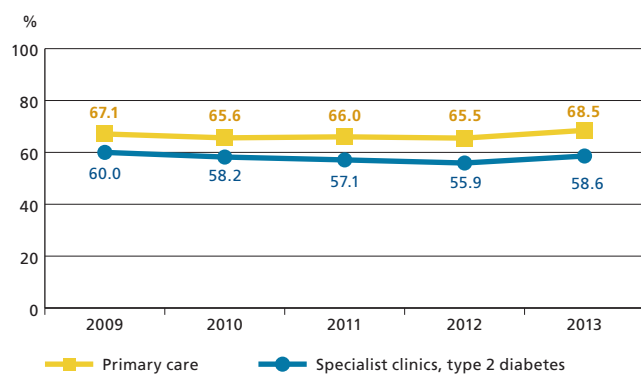


**Figure 18. HbA1c < 52 (mmol/mol).**

Source: NDR – Swedish National Diabetes Register.

**Figure 19. HbA1c > 73 (mmol/mol).**

Source: NDR – Swedish National Diabetes Register.

**Figure 20. HbA1c < 52 (mmol/mol) among patients < age 70 and diabetes duration ≤ 3 years.**

Source: NDR – Swedish National Diabetes Register.

## Patients with HbA1c levels above 73 mmol/mol

Tables 3a-c show the clinical characteristics of this population.

**Table 3a. Patients with HbA1c > 73 (mmol/mol). Primary care.**

	2009	2010	2011	2012	2013
Number	16,079	21,158	24,067	27,376	27,139
Mean age (SD)	64.3 (13.1)	64.8 (13.4)	65 (13.3)	65.4 (13.4)	65.5 (13.3)
Number (HbA1c)	16,079	21,158	24,067	27,376	27,139
Mean HbA1c, mmol/mol (SD)	85.3 (11.6)	85.6 (11.8)	85.9 (11.7)	86 (11.9)	86.2 (12.0)
Number (systolic blood pressure mm Hg) (SD)	14,942	19,613	22,282	25,488	25,420
Mean systolic blood pressure	137.5 (17.6)	137.1 (17.5)	136.6 (17.2)	136.1 (17.0)	135.7 (16.6)
Number (LDL)	9,646	13,204	15,688	17,769	17,372
Mean LDL, mmol/l (SD)	2.8 (1.0)	2.8 (1.0)	2.8 (1.0)	2.7 (1.0)	2.7 (1.0)
Number (BMI)	13,409	17,574	20,671	23,708	23,712
Mean BMI, kg/sq m (SD)	31.2 (5.9)	31.2 (6.0)	31.1 (5.9)	31 (5.8)	31 (5.8)
Number of smokers (%)	2,635 (20.4)	3,410 (19.7)	4,054 (20.1)	4,391 (18.8)	4,142 (18.3)
Number of physically inactive patients (%)	4,563 (41.3)	5,949 (41.8)	6,887 (41.3)	7,893 (40.6)	8,564 (41.8)

Source: NDR – Swedish National Diabetes Register.

**Table 3b. Patients with HbA1c > 73 (mmol/mol). Type 1 diabetes at specialist clinics.**

	2009	2010	2011	2012	2013
Number	6,095	6,614	7,620	8,193	7,861
Mean age (SD)	44.2 (15.5)	44 (15.9)	43.6 (16.1)	43.8 (16.4)	44.1 (16.6)
Number (HbA1c)	6,095	6,614	7,620	8,193	7,861
Mean HbA1c, mmol/mol (SD)	83.7 (10.3)	83.5 (10.0)	83.8 (10.0)	84.1 (10.5)	84.3 (10.6)
Number (systolic blood pressure mm Hg) (SD)	5,818	6,341	7,252	7,780	7,546
Mean systolic blood pressure	127.6 (15.9)	127.2 (15.8)	126.7 (15.4)	126.6 (15.4)	126.9 (15.0)
Number (LDL)	4,716	5,095	5,875	6,399	6,048
Mean LDL, mmol/l (SD)	2.8 (0.9)	2.8 (0.9)	2.7 (0.9)	2.7 (0.9)	2.7 (0.9)
Number (BMI)	5531	6061	6827	7365	7071
Mean BMI, kg/sq m (SD)	26.2 (4.6)	26.2 (4.7)	26.2 (4.7)	26.2 (4.6)	26.4 (4.8)
Number of smokers (%)	1,078 (19.2)	1,210 (19.6)	1,341 (19.2)	1,447 (18.9)	1,399 (19.5)
Number of physically inactive patients (%)	1,259 (27.1)	1,531 (29.1)	1,907 (30.4)	2,039 (29.7)	2,004 (29.8)

Source: NDR – Swedish National Diabetes Register.

**Table 3c. Patients with HbA1c > 73 (mmol/mol). Type 2 diabetes at specialist clinics.**

	2009	2010	2011	2012	2013
Number	2,251	2,186	2,324	2,359	2,151
Mean age (SD)	59.5 (12.5)	60.4 (12.5)	60.3 (12.9)	60.7 (12.5)	60 (13.0)
Number (HbA1c)	2,251	2,186	2,324	2,359	2,151
Mean HbA1c, mmol/mol (SD)	85.7 (11.5)	85.6 (11.0)	86.1 (11.5)	86.1 (11.4)	86.6 (11.6)
Number (systolic blood pressure mm Hg) (SD)	2,122	2,070	2,163	2,236	2,050
Mean systolic blood pressure	135.1 (17.6)	134 (16.6)	133.7 (16.6)	133.7 (17.0)	133.2 (16.1)
Number (LDL)	1,724	1,696	1,774	1,848	1,633
Mean LDL, mmol/l (SD)	2.5 (0.9)	2.5 (1.0)	2.5 (1.0)	2.4 (1.0)	2.4 (1.0)
Number (BMI)	1,997	1,970	2,048	2,098	1,921
Mean BMI, kg/sq m (SD)	32 (5.8)	31.8 (6.0)	31.6 (5.9)	31.5 (5.7)	31.4 (5.7)
Number of smokers (%)	329 (15.9)	314 (15.7)	361 (17.3)	361 (16.7)	310 (16.1)
Number of physically inactive patients (%)	764 (44.1)	794 (46.3)	837 (44.6)	930 (47.9)	843 (46.9)

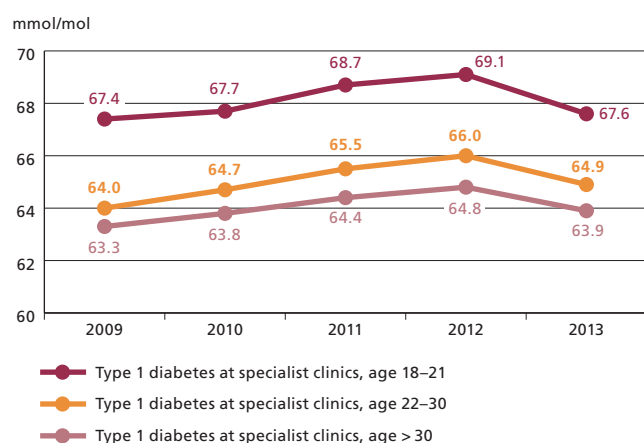
Source: NDR – Swedish National Diabetes Register.

## Young adults with type 1 diabetes

### They often have high HbA1c levels and are treated with insulin pumps.

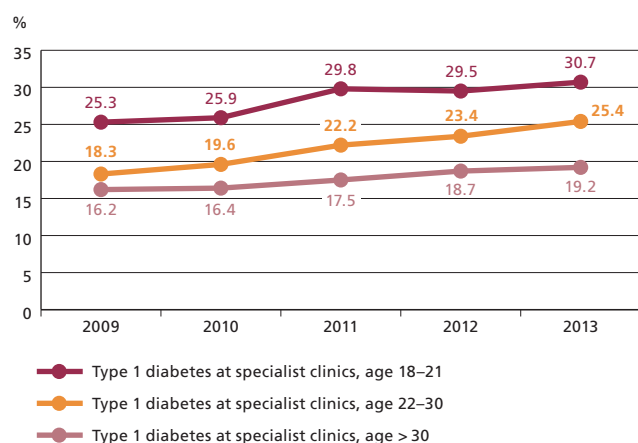
While the youngest type 1 diabetics in the NDR have the highest HbA1c levels, their trend was positive in 2013 as well. The HbA1c levels of young adults declined steadily during their first ten years in the register but then increased. (Figure 21). They are also the patients who are treated with insulin pumps most often (30% of 18–21 year-old women, Figure 22). One reason is that the use of insulin pumps is a growing phenomenon among children. Figure 23 show that adults are trending in the right direction. The percentage with HbA1c levels below 52 is rising and fewer have levels above 70. Nevertheless, 12% of them still have blood pressure above 130/80, while 15% smoke. Adapting the healthcare system to this population and setting the stage for improved results represent a major challenge.

**Figure 21.** Mean for HbA1c (mmol/mol) among patients in various age groups with type 1 diabetes at specialist clinics.



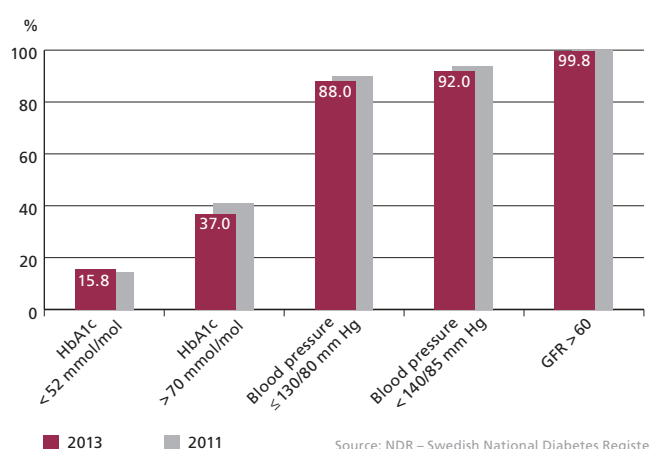
Source: NDR – Swedish National Diabetes Register.

**Figure 22.** Insulin pump among patients in various age groups.



Source: NDR – Swedish National Diabetes Register.

**Figure 23.** Percentage of patients at primary care clinics age 18–21 who reached their target levels.



Source: NDR – Swedish National Diabetes Register.

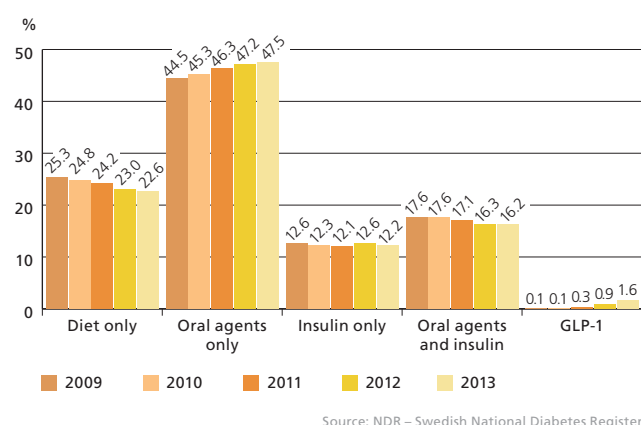
## Diabetes treatment

### Many patients with diabetes in primary care receive dietary treatment only

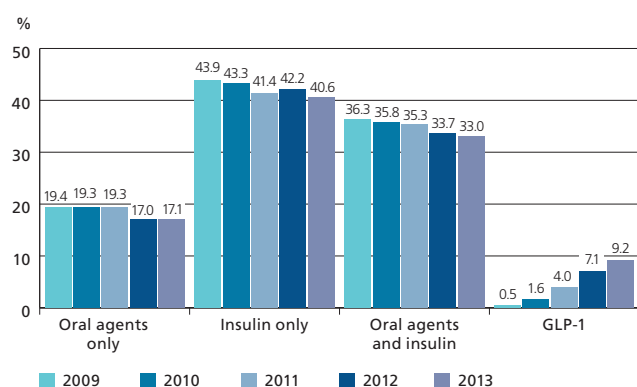
The proportion of patients with diabetes in primary care who receive dietary treatment only is declining but is still at approximately 20%. The proportion is also relatively high (almost 30%) among type 2 younger than 70 who have had the disease for less than 3 years, suggesting that treatment is not intense enough from the very beginning. Specialist clinics report that more than 9% of patients with type 2 they treat are receiving GLP-1 receptor agonists. In other words, the percentage of patients taking tablets alone or in combination with insulin has declined.

Primary care still treats only a negligible proportion of diabetics with GLP-1 receptor agonists, while the percentages have substantially increased for patients who take tablets and slowly decreased for those who receive dietary treatment.

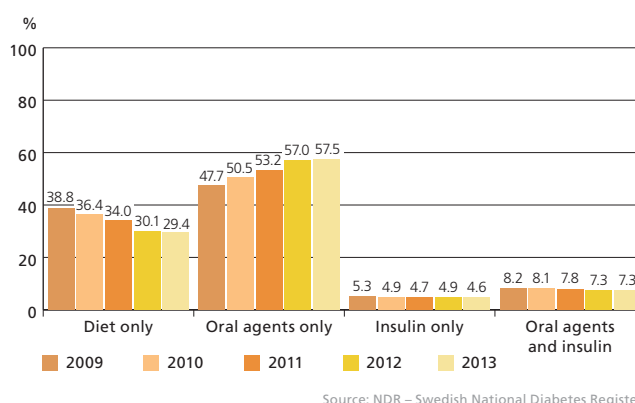
**Figure 24.** Various types of hypoglycaemic treatment. Primary care.



**Figure 25.** Hypoglycaemic treatment among patients with type 2 diabetes at specialist clinics.



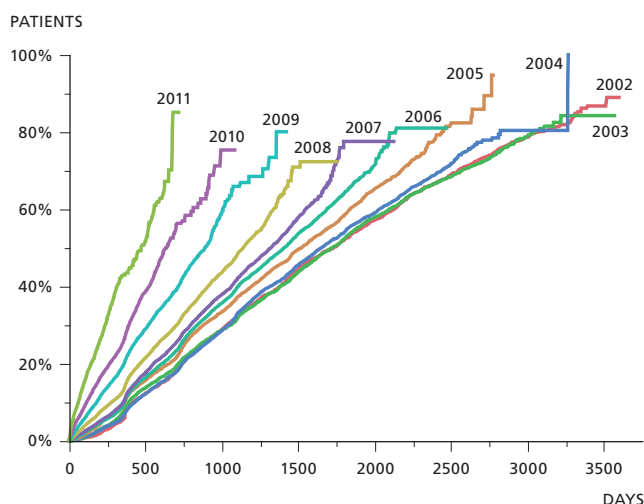
**Figure 26.** Hypoglycaemic treatment among patients < age 70 and diabetes duration ≤ 3 years. Primary care.



### Period from onset of type 2 diabetes to start pharmacological treatment has become shorter

Diet and exercise are the cornerstones of treating type 2 diabetes. Meeting targets as soon as possible is very important, and the current recommendation is to prescribe tablets (Metformin as the first-line therapy) at an early stage of the disease. Consistent with the recommendations of the guidelines, the period from onset of diabetes until commencement of pharmacological treatment is starting to shorten.

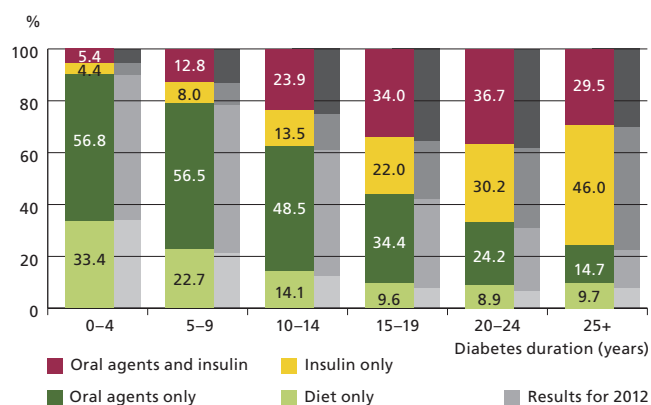
Time to pharmacological treatment has been reduced from year 2002 to 2011.



### The majority of patients with type 2 are receiving insulin treatment 15 years after onset.

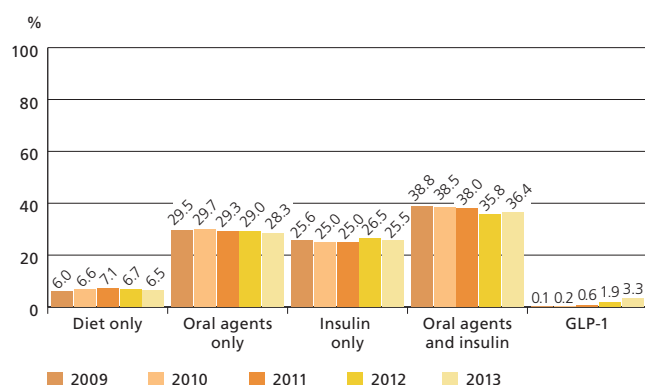
As was the case early, the percentage of patients receiving combination treatment (tablets and insulin) or insulin alone is rising with duration of the disease (Figure 27). A total of 56% of patients in primary care are receiving one of these treatments 15 years after onset. Most type 2 diabetics with inadequate HbA1c control (>73 mmol/mol) are receiving combination treatment or insulin alone (Figure 29).

**Figure 27.** Various types of hypoglycaemic treatment by intervals of diabetes duration. Primary care, 2013.



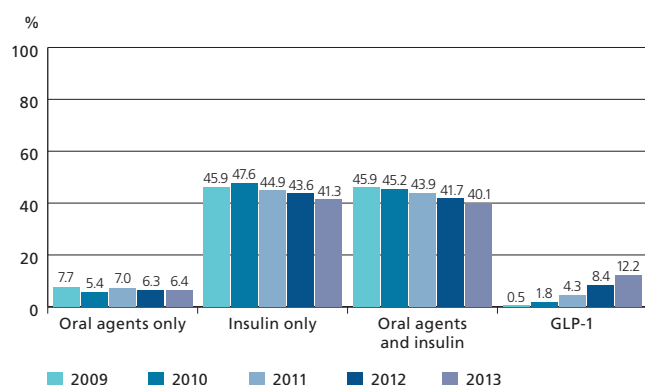
Source: NDR – Swedish National Diabetes Register.

**Figure 28.** Hypoglycaemic treatment among patients with HbA1c >73 (mmol/mol). Primary care.



Source: NDR – Swedish National Diabetes Register.

**Figure 29.** Hypoglycaemic treatment among patients with HbA1c >73 (mmol/mol). Type 2 diabetes at specialist clinics.

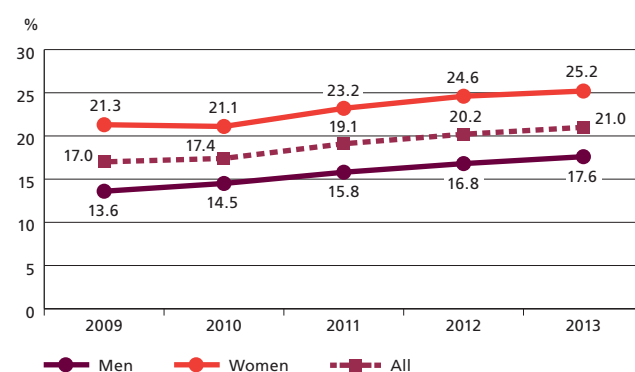


Source: NDR – Swedish National Diabetes Register.

## More women than men use insulin pumps

Among patients with type 1, approximately 25% of women and only 17% of men use insulin pumps. Thus, one out of five patients with type 1 use insulin pumps, which represents a steady increase over the past few years.

**Figure 30.** Insulin pump among patients with type 1 diabetes at specialist clinics.



Source: NDR – Swedish National Diabetes Register.

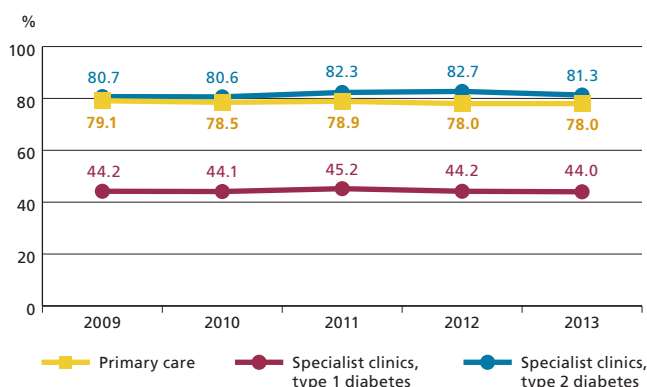
## Blood pressure

**In the wake of positive trends over time, more than half of patients with diabetes in primary care have blood pressure below 140/85.**

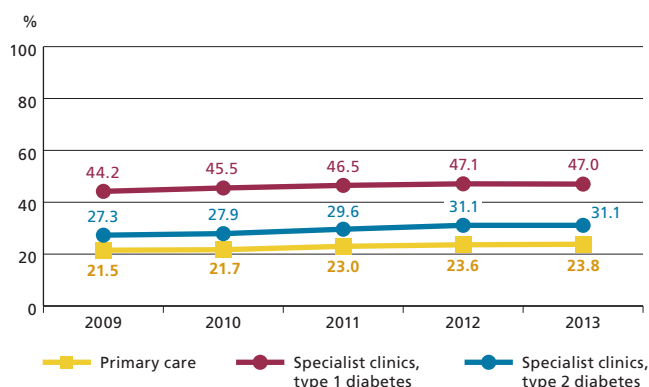
The trend of better control and increased antihypertensive treatment is continuing (Figures 31–39).

Approximately 80% of patients with type 2 and 44% of type 1 diabetics are taking antihypertensives. Two different targets have been set: < 130/80 (current guidelines) and < 140/85. Almost 55% of patients in primary care and 76.6% of patients with type 1 have blood pressure below 140/85.

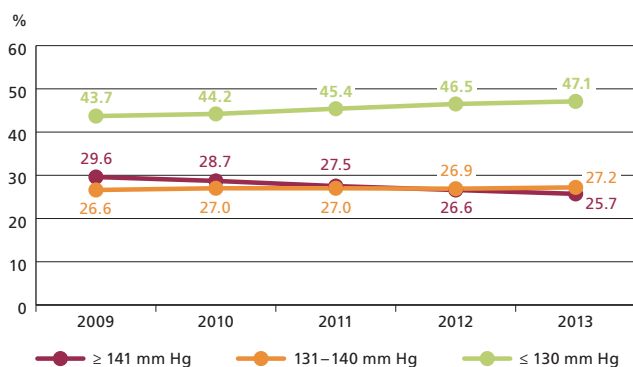
The fact that a disproportionate percentage of patients have exactly 130/80 or 140/80 indicates that the results are generally rounded off, usually to the nearest ten. It is very important to measure blood pressure as accurately as possible. Blood pressure should be taken when the patient is in a sitting position after having rested for 5 minutes and rounded down to the nearest even number. If the measurement is automated, the exact numbers should be specified. There is also a great need for validated automated blood pressure monitors and a standardised measurement method. 24-hour blood pressure is not entered in the NDR.

**Figure 31. Antihypertensive drugs.**

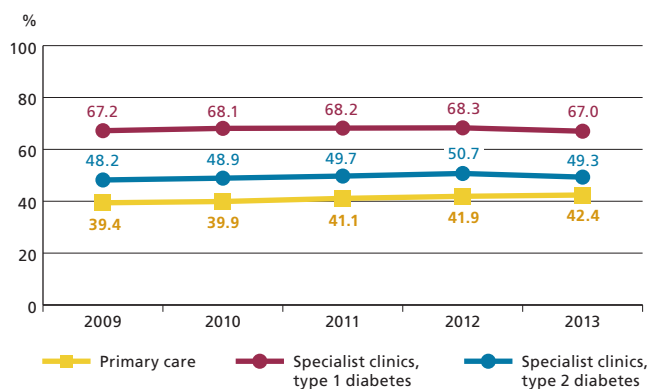
Source: NDR – Swedish National Diabetes Register.

**Figure 34. Blood pressure < 130/80 mm Hg.**

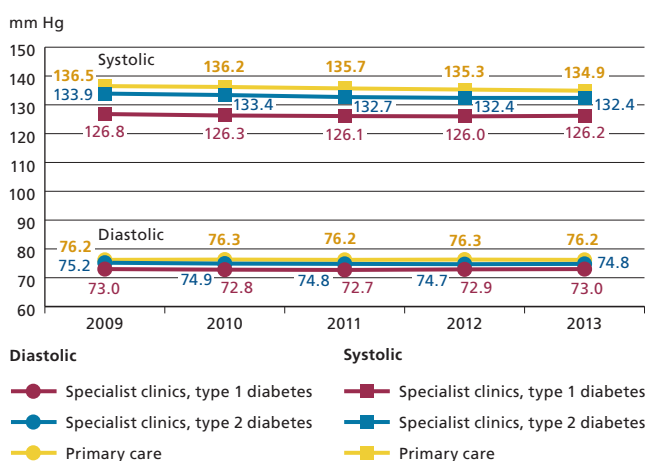
Source: NDR – Swedish National Diabetes Register.

**Figure 32. Systolic blood pressure in various intervals. All patients with type 2 diabetes.**

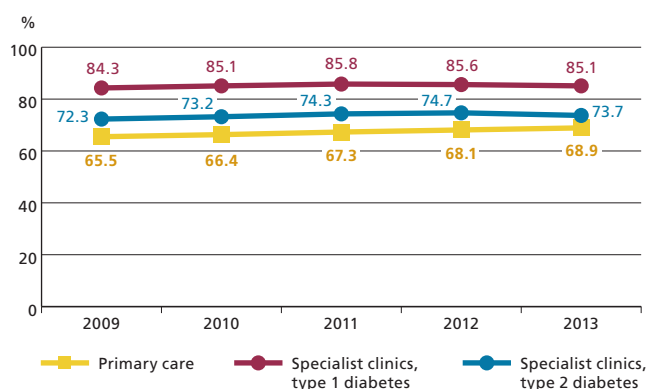
Source: NDR – Swedish National Diabetes Register.

**Figure 35. Blood pressure ≤ 130/80 mm Hg.**

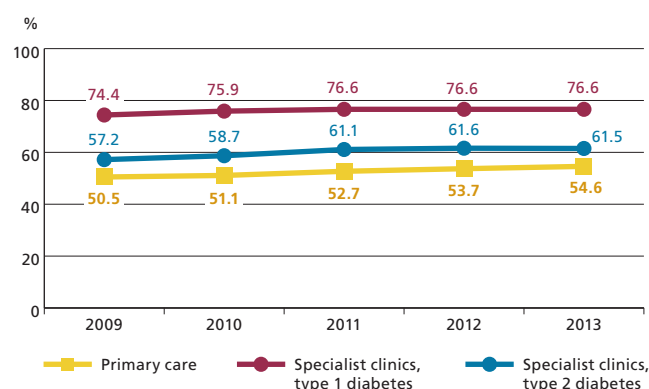
Source: NDR – Swedish National Diabetes Register.

**Figure 33. Mean blood pressure (mm Hg).**

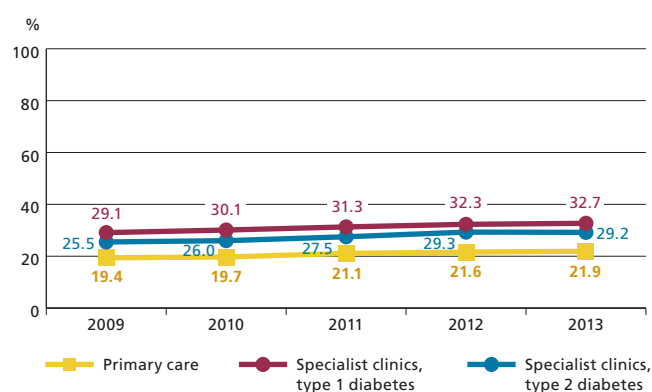
Source: NDR – Swedish National Diabetes Register.

**Figure 36. Blood pressure ≤ 140/85 mm Hg.**

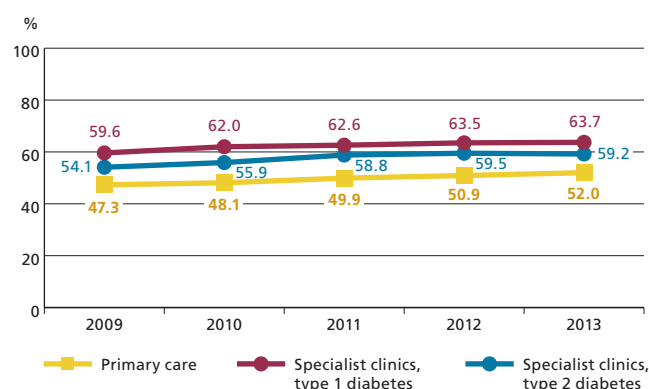
Source: NDR – Swedish National Diabetes Register.

**Figure 37. Blood pressure < 140/85 mm Hg.**

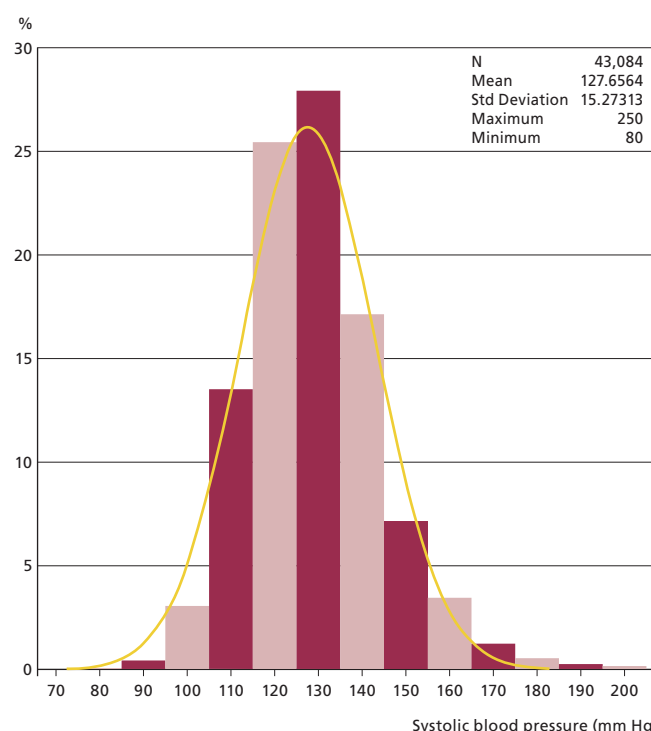
Source: NDR – Swedish National Diabetes Register.

**Figure 38. Blood pressure < 130/80 mm Hg among patients treated with antihypertensive drugs.**

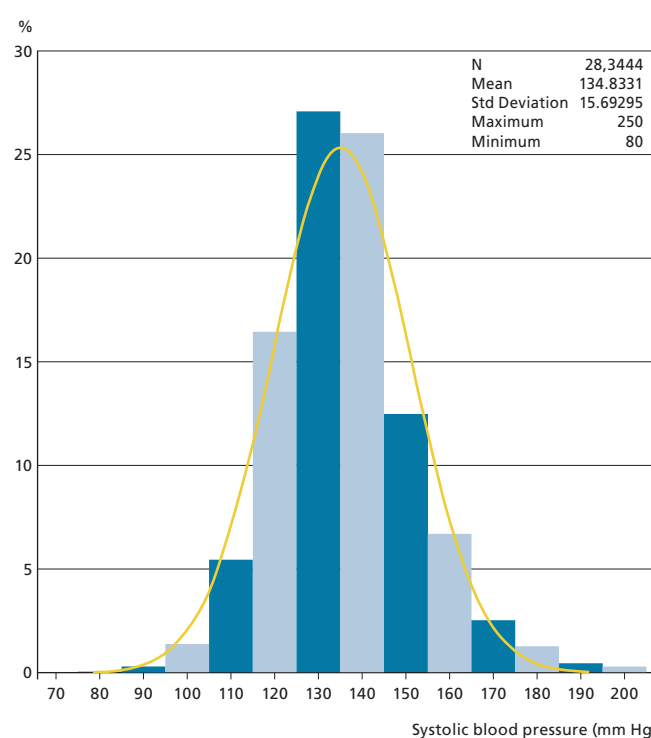
Source: NDR – Swedish National Diabetes Register.

**Figure 39. Blood pressure < 140/85 mm Hg among patients treated with antihypertensive drugs.**

Source: NDR – Swedish National Diabetes Register.

**Distribution of blood pressure values****Figure 40. Histogram for systolic blood pressure (mm Hg). All patients with type 1 diabetes, 2013.**

Source: NDR – Swedish National Diabetes Register.

**Figure 41. Histogram for systolic blood pressure (mm Hg). All patients with type 2 diabetes, 2013.**

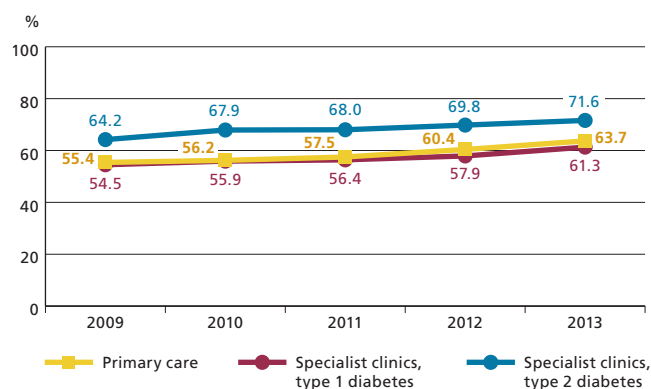
Source: NDR – Swedish National Diabetes Register.

## Blood lipids

**A total of 60% of patients, in primary care are treated with blood lipid lowering drugs, less than half of those with type 1 diabetes.**

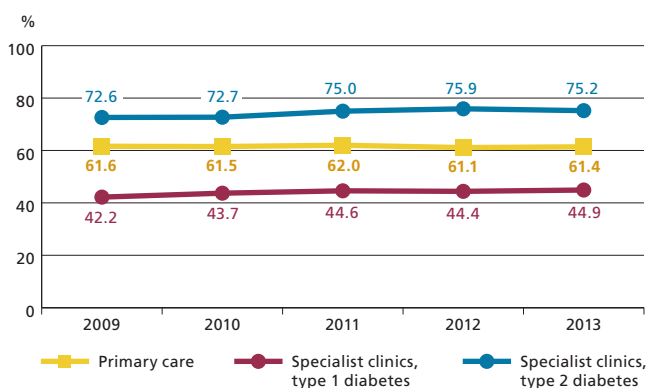
Cholesterol levels are continuing to improve as well (Figures 42–44). Though most pronounced for LDL cholesterol, the changes are also evident for HDL and total cholesterol. Triglyceride levels, which are not significantly affected by statin treatment, are unchanged among all patient populations. With the exception of patients with type 2 at specialist clinics, however, the initial increase in lipid lowering treatment has levelled off in recent years. Altogether almost half of all patients – both patients with type 1 and those in primary care – have LDL cholesterol levels above 2.5mmol/l.

**Figure 44.** LDL cholesterol < 2,5 mmol/l among patients treated with lipid lowering drugs.



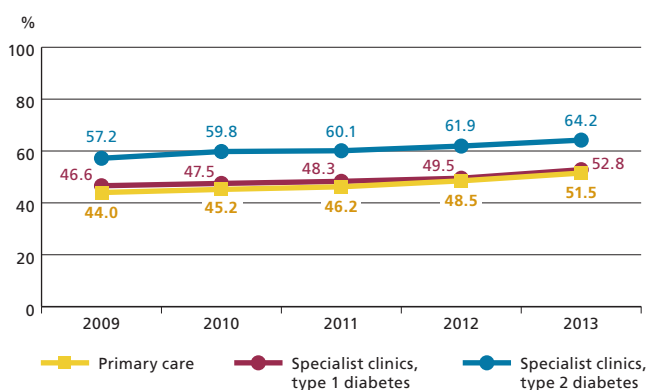
Source: NDR – Swedish National Diabetes Register.

**Figure 42.** Lipid lowering drugs.



Source: NDR – Swedish National Diabetes Register.

**Figure 43.** LDL cholesterol < 2,5 mmol/l.



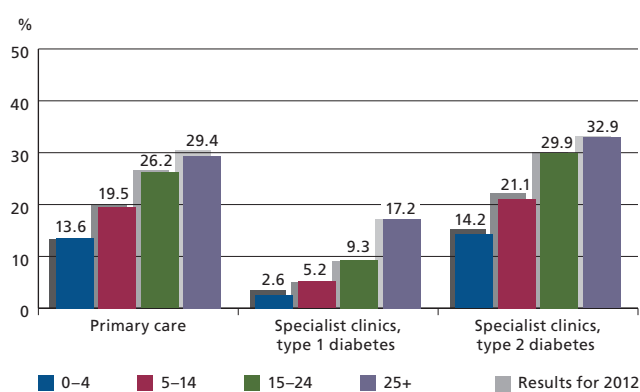
Source: NDR – Swedish National Diabetes Register.

## Impact on the Kidneys

### Many cases of proteinuria still not entered in the register

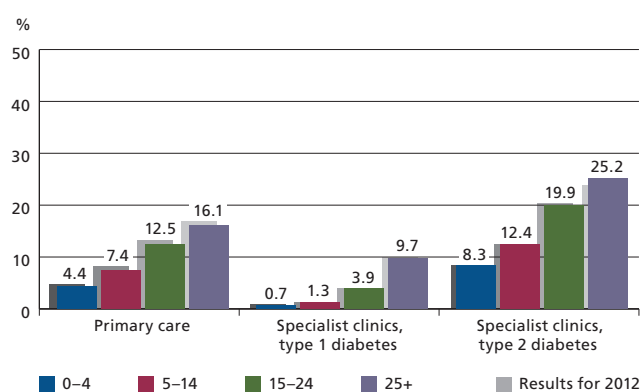
Almost one out of every five patients in primary care and more than one out of every ten patient with type 1 have microscopic proteinuria. The percentage of microscopic and macroscopic proteinuria cases rises the longer patients have diabetes (Figures 45–46).

**Figure 45.** Microalbuminuria (urine albumin excretion 20–200 microgram/min) by diabetes duration, 2013.



Source: NDR – Swedish National Diabetes Register.

**Figure 46.** Macroalbuminuria (urine albumin excretion > 200 µg/min) by diabetes duration, 2013.



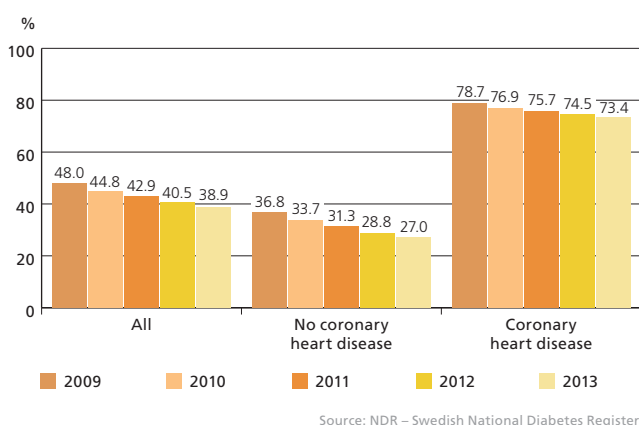
Source: NDR – Swedish National Diabetes Register.

## Acetylsalicylic Acid

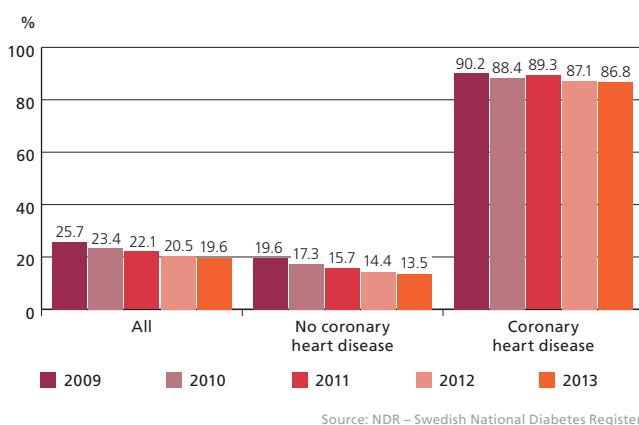
### Less treatment with aspirin for patients without ischaemic heart disease

Figures 47–49 present the use of acetylsalicylic acid (aspirin). Treatment with aspirin has gradually declined for both patients with type 1 and type 2 without ischaemic heart disease. Use of aspirin remains high for patients with ischaemic heart disease.

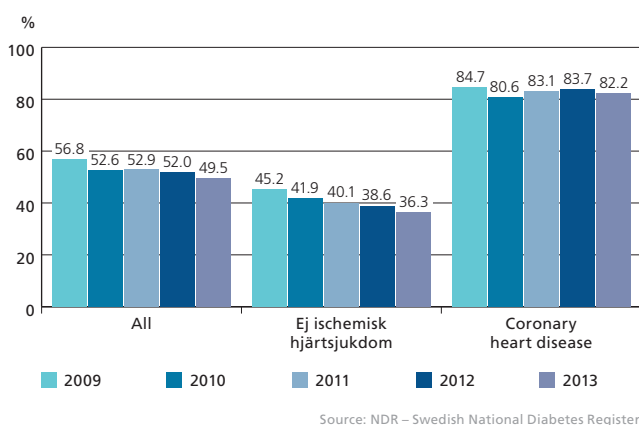
**Figure 47.** Acetylsalicylic acid for all patients and for patients with coronary heart disease in primary care.



**Figure 48.** Acetylsalicylic acid for all type 1 diabetes patients and for all type 1 diabetes patients with coronary heart disease at specialist clinics.



**Figure 49.** Acetylsalicylic acid for all type 2 diabetes patients and for all type 2 diabetes patients with coronary heart disease at specialist clinics.

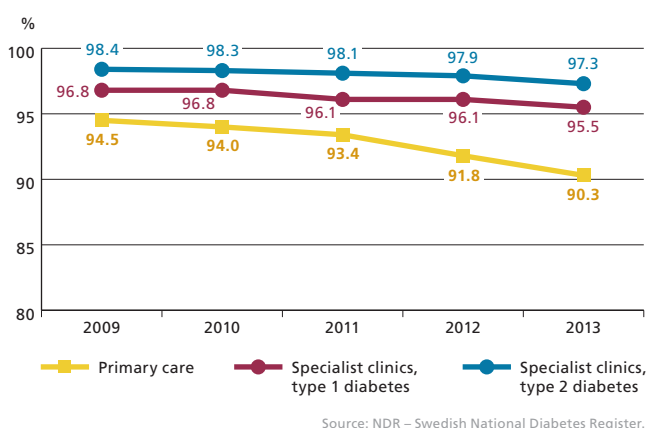


## Process Measure: Eye and Foot Examinations

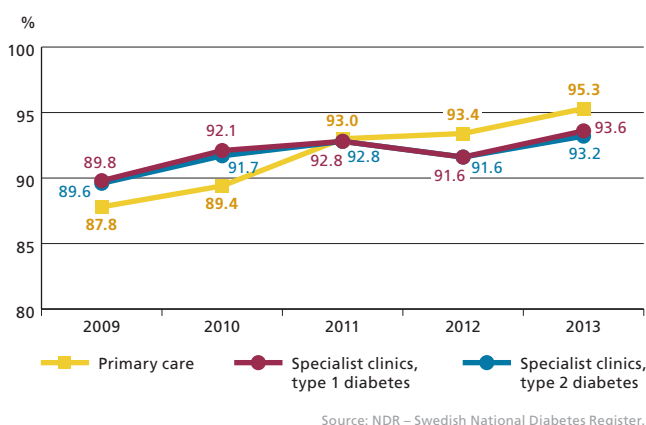
### Well-functioning processes

The national guidelines for diabetes care recommend a fundus examination every other year for type 1 diabetics and every three years for patients with type 2, or every year for patients with diabetes retinopathy. Figure 50 shows that specialist clinics are examining almost the same percentage of patients as before (95.5% of type 1 diabetics and 97.3% of type 2 diabetics) while primary care clinics are tending to examine somewhat fewer (90.3%). Approximately 93–95% of patients have had their foot examination done (Figure 51).

**Figure 50.** Monitoring of eye status during the last 2 years among patients with type 1 diabetes at specialist clinics and the last 3 years among patients with type 2 diabetes at specialist clinics and in primary care.



**Figure 51.** Monitoring of foot status during the last year.



## Estimated 5-year Risk for Cardiovascular Disease

### Potential for improvements in multifactorial treatment

Based on the NDR risk model for type 2 diabetes (see website), Figure 52 shows the absolute risk of developing cardiovascular disease (myocardial infarct/stroke) in 5 years among primary care patients age 30–79 in 2013. The model proceeds from 12 cardiovascular risk factors: duration of diabetes, HbA1c levels, systolic blood pressure, total cholesterol levels, HDL cholesterol levels, smoking, BMI, microalbuminuri, macroalbuminuri, previous cardiovascular disease, age and gender. The model was satisfactorily validated by testing a large number of patients with type 2 throughout Sweden. The nationwide average for absolute 5-year risk was 13.3%.

Figure 52 shows a county-by-county breakdown for 2013 of the percentage of patients with absolute risk greater than 10%, defined as medium risk – or 15%, defined as high risk – for cardiovascular disease in accordance with the NDR model. The county-to-county variations are moderate. The proportion of patients with greater than 10% risk ranges from 46% to 70%, for a nationwide average of 57%, while the proportion with greater than 15% risk ranges from 25% to 46%, for a nationwide average of 33%.

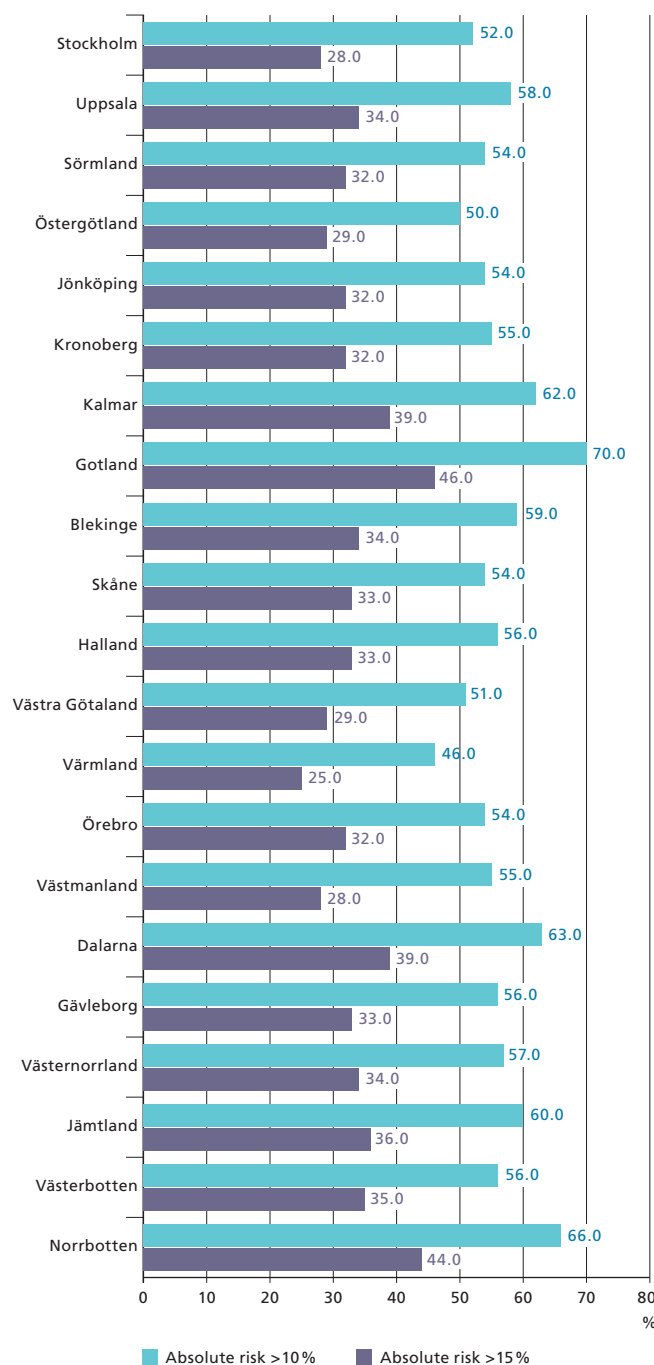
We have also calculated a normal risk – the absolute risk of someone of the patient's age, gender and disease duration who has achieved normal levels for the modifiable risk factors: HbA1c (52 mmol/mol), systolic blood pressure (135 mmHg), total cholesterol (4.4 mmol/l), HDL cholesterol (1.1 mmol/l), BMI 25 kg/sq m, no proteinuria and non-smoker. The nationwide five-year normal risk averaged 11.7%.

### How much of the risk is modifiable?

Figure 53 shows the modifiable risk – the percentage of absolute risk that can be affected by the modifiable risk factors, calculated by dividing the difference between the absolute risk and normal risk by the normal risk. The nationwide average for modifiable risk was 18%. Figure 53 also shows the proportion of patients with modifiable risk above 10%, the counties varying from 34% to 68%, for a nationwide average of 49%.

The analysis is based on 143,157 patients with type 2 age 30–79 in the NDR for 2013 for whom data is available for all 12 risk factors that make up the estimated 5-year risk for cardiovascular disease. HDL cholesterol and proteinuria are the risk factors for which data are most frequently missing.

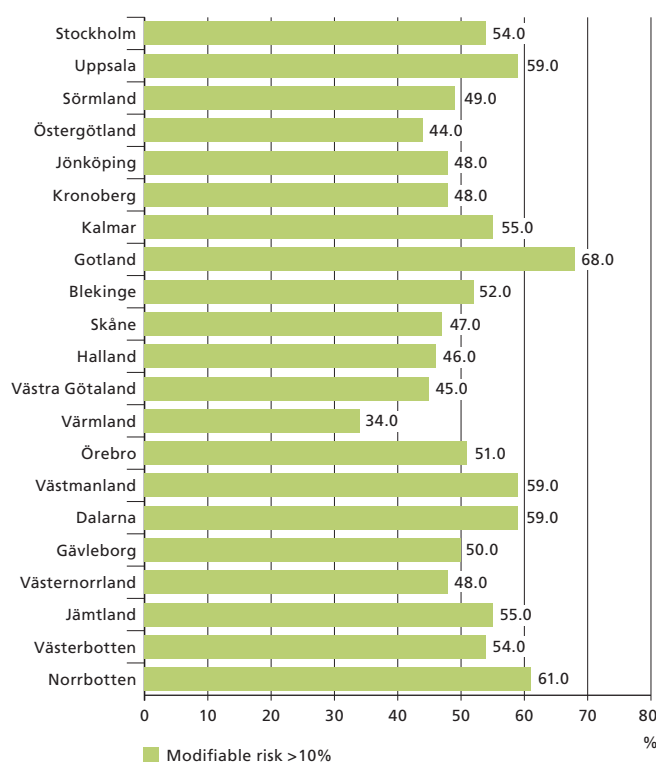
**Figure 52.** 5-year risk for cardiovascular disease, NDR risk model. Patients in primary care age 30–79 by county.



Source: NDR – Swedish National Diabetes Register.



**Figure 53.** 5-year risk for cardiovascular disease, NDR risk model. Patients in primary care age 30–79 by county.



Source: NDR – Swedish National Diabetes Register.

## Patients with Recent Onset of Type 2 Diabetes

### The better the levels, the lower the risk

Figure 54 shows the absolute 5-year risk for cardiovascular disease (cardiac infarct or stroke) among patients age 30–79 in primary care who have developed type 2 diabetes within the past three years. The risk is based on the NDR

risk model for type 2 diabetes (see website), which proceeds from 12 cardiovascular risk factors: duration of diabetes, HbA1c levels, systolic blood pressure, total cholesterol levels, HDL cholesterol levels, smoking, BMI, micro-albuminuri and macroalbuminuri, previous cardiovascular disease, age and gender. Cross-section analyses reveal that average absolute risk declined significantly from 10.4% in 2011 to 9.8% in 2013.

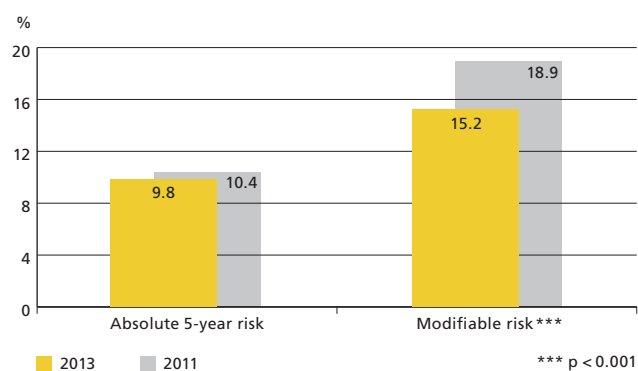
Figure 54 also shows the modifiable risk – the difference between the absolute risk and normal risk divided by the normal risk. The normal risk is based on a patient who has achieved the target levels for the modifiable risk factors. The fact that average modifiable risk declined significantly from 18.9% in 2011 to 15.2% in 2013 points to more intensive treatment following initial diagnosis.

Figure 55 shows average HbA1c, systolic blood pressure, BMI and LDL cholesterol levels shortly after onset of diabetes. HbA1c, systolic blood pressure and LDL cholesterol levels all declined significantly from 2011 to 2013, while BMI was unchanged.

Figure 56 shows the percentages of patients who have achieved the target levels for HbA1c levels, blood pressure, blood lipid levels, consumption of medication, smoking cessation and physical activity. The percentages increased significantly for HbA1c, blood pressure, LDL cholesterol and smoking cessation, while physical activity (no more than twice a week, or 30 minutes altogether) was unchanged.

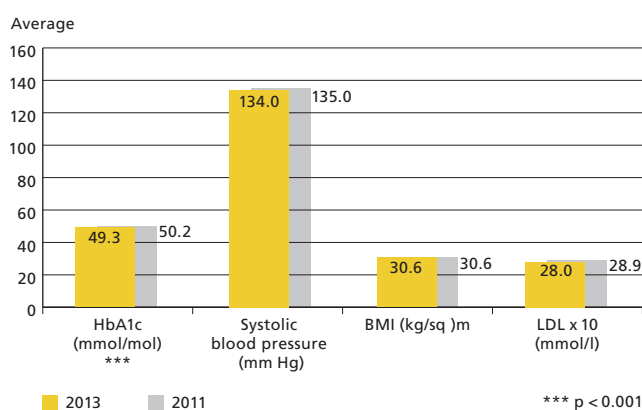
This risk analysis uses the threshold for hypertension (140/85 mmHg) that is the latest target level specified by the European Societies of Cardiology and Hypertension. The switch from the previous target of 130/80 mm Hg is supported by the ACCORD-BP randomised study of approximately 10,000 type 2 diabetics in the U.S., as well as the NDR BP-II observational study of 35,000 type 2 diabetics under treatment for hypertension as published in the Journal of Hypertension in 2012. In accordance with the GRADE system, well-designed observational studies like NDR BP-II can be upgraded to evidence level A on a par with randomised studies. The study found that blood pressure of 140/80 mm Hg or higher substantially increased the risk of cardiovascular disease, whereas there was no significant difference between the 115–129 mm Hg and 130–139 mm Hg ranges.

**Figure 54.** Cross section 2011 and 2013. 5-year risk for cardiovascular disease, NDR risk model. Patients in primary care age 30–79, duration no more than 3 years.



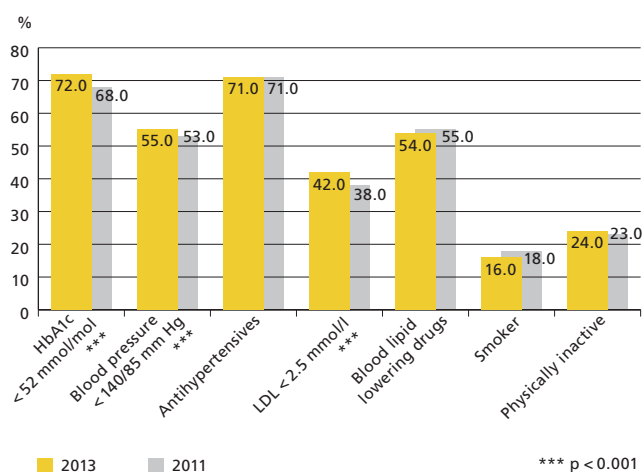
Source: NDR – Swedish National Diabetes Register.

**Figure 55.** Average HbA1c, systolic blood pressure and BMI. Patients in primary care age 30–79 with duration no more than 3 years.



Source: NDR – Swedish National Diabetes Register.

**Figure 56.** Patients in primary care age 30–79 with duration no more than 3 years.



Source: NDR – Swedish National Diabetes Register.

## Percentage of Primary Care Patients with Three or More High-risk Factors

### May be identified with the “Button”.

Previous reports have presented the percentage of patients with decidedly high blood pressure and HbA1c levels in order to highlight the fact that they run a higher risk of diabetes complications. Describing the total impact of the various risk factors, as opposed to each one separately, is also a useful exercise. This indicator, as well as the 5-year risk for diabetes complications, has been designed with that purpose in mind.

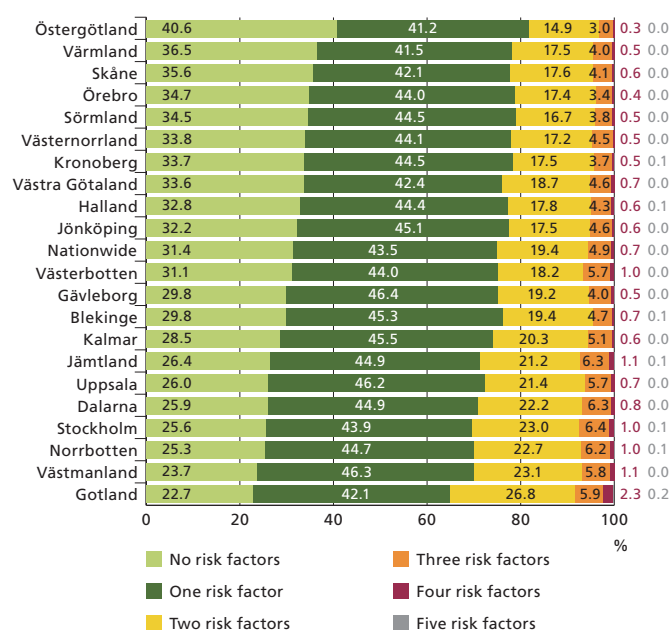
The indicator shows the percentage of primary care patients with three or more high-risk factors. The indicator could have been designed otherwise – no research has clearly established that three or more factors represent the most suitable criterion. Among other possible designs might be two or more factors, or three factors including smoking.

Thus, the indicator is accompanied by a county-by-county diagram broken down by the number of high-risk factors, as well as a diagram that shows the percentage of patients with three or more high-risk factors. The factors are LDL > 2,5 mmol/l, systolic blood pressure > 150 mm/Hg, HbA1c > 70 mmol/mol, smoking and microalbuminuri.

Fewer than 6% of patients nationwide have three or more high-risk factors, more than 31% have no factors and almost 44% have one factor.

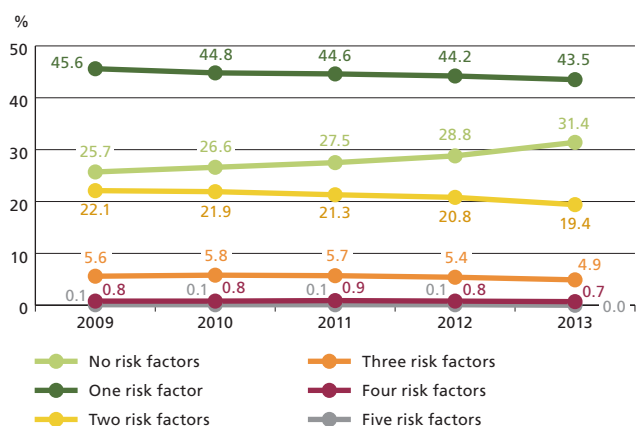
In addition to the fact that the indicator can be designed in a number of different ways, the rate of data loss must be taken into consideration. A patient must have data in the NDR for all of the risk factors during the period in order to be included in the comparison. Only 142,364 of the more than 305,000 patients in primary care met those criteria. Given the probable correlation between working methods, monitoring and entry in the NDR, that sample is likely to have fewer risk factors than the entire population. The differences in data loss among the various counties further exacerbate the data loss to the point of unreliability.

**Figure 57.** Breakdown of risk factors (microscopic proteinuria, HbA1c >70, LDL >2.5, BP >150, smoking), primary care, county.



Source: NDR – Swedish National Diabetes Register.

**Figure 58.** Percentage of patients in primary care nationwide with risk factors (microscopic proteinuria, HbA1c >70, LDL >2.5, BP >150, smoking).



Source: NDR – Swedish National Diabetes Register.

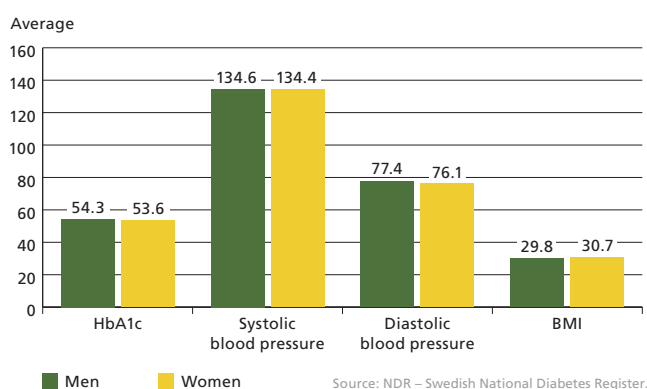
## Women and Men

### Higher blood lipid levels and less blood lipid lowering treatment among women with type 2 diabetes

Age-standardised results for patients with type 2 age 30–80 broken down by gender are available for several indicators. Women average lower HbA1c levels and more of them achieve the target of < 52. Similarly, women average lower diastolic blood pressure and more of them achieve the target of < 140/85 mmHg. However, there is no significant gender gap when it comes to systolic blood

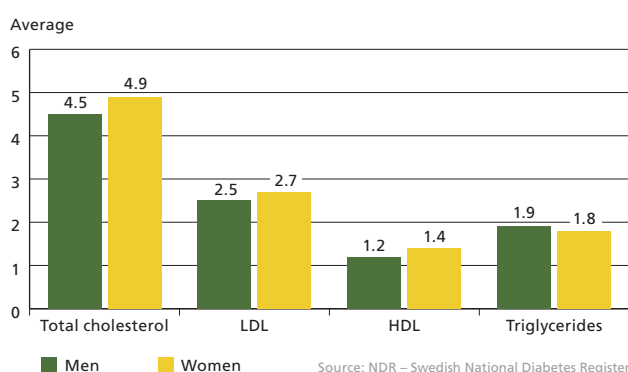
pressure and only minor differences with respect to consumption of antihypertensives. Women have in average higher total cholesterol, LDL cholesterol and triglyceride levels, and significantly fewer achieve the targets of < 4.5 mmol/l and < 2.5 mmol/l respectively for the first two levels. Women also are less often treated with blood lipid lowering drugs. No difference in the percentage of non-smokers. Women average higher BMI (fewer are below 30) and are considerably less likely to exercise at least three times a week. The gender gap is statistically significant and is particularly pronounced with respect to BMI, total cholesterol and LDL cholesterol levels, as well as the target levels for HbA1c, blood pressure, total cholesterol and LDL cholesterol, plus consumption of blood lipid lowering drugs. The gap is similar to the situation for 2011–2012. Longitudinal studies can shed light on the implications of these differences for possible future complications.

**Figure 59.** Average risk factors for women and men with type 2 diabetes age 30–80. Significant differences after age standardisation: \*\*\*p < 0.001.



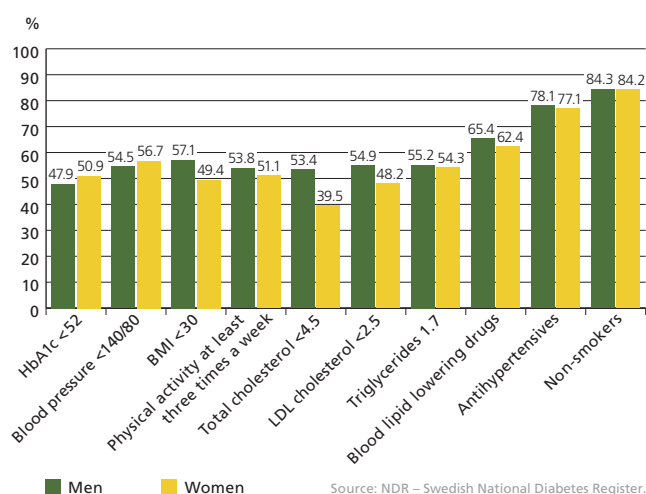
Source: NDR – Swedish National Diabetes Register.

**Figure 60.** Average blood lipid levels (mmol/l) for women and men with type 2 diabetes age 30–80. All differences are significant after age standardisation, p < 0.001.



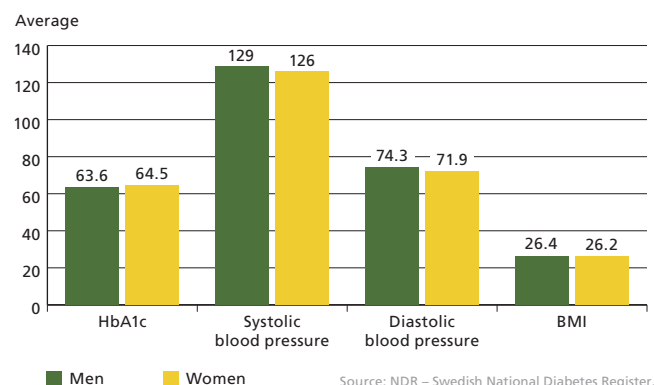
Source: NDR – Swedish National Diabetes Register.

**Figure 61.** Percentage of women and men with type 2 diabetes age 30–80 who reached the target levels. Except for smokers, all differences are significant after age standardisation,  $p < 0.001$ .

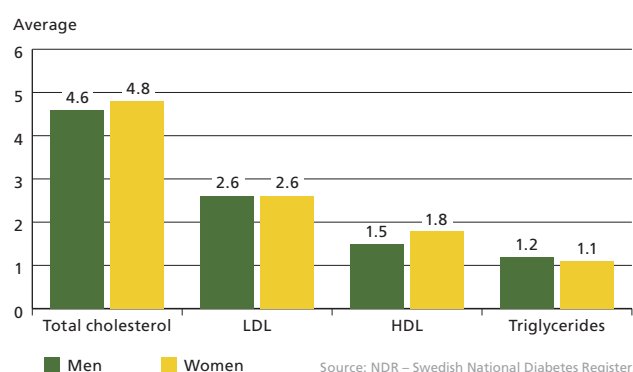


Age-standardised results for people with type 1 diabetes age 18 and older broken down by gender are available for several indicators. Women have in average higher HbA1c levels and are less likely to achieve the target of < 52 mmol/mol. A somewhat lower percentage of women are non-smokers. Average BMI is the same, though fewer women have BMI < 30. The same percentage of women and men exercise at least 3 times a week. Women have in average lower blood pressure and are more likely to achieve the target of < 140/85 mm Hg despite the fact that they consume fewer antihypertensives. Women have higher HDL cholesterol and lower triglyceride levels. Women have in average the same LDL cholesterol levels as men and are just as likely to achieve the target of < 2.5 mmol/l despite the fact that they consume fewer blood lipid lowering drugs. The gender gap is statistically significant and particularly evident with respect to blood pressure, blood lipid levels, HDL cholesterol levels, triglyceride levels, BMI < 30 and non-smoking. As was the case in 2011–2012, more women (22%) than men (15%) with type 1 diabetes are receiving insulin pump treatment. The overall situation is fairly consistent with 2011–2012. Longitudinal studies can shed light on the implications of these differences for possible future complications.

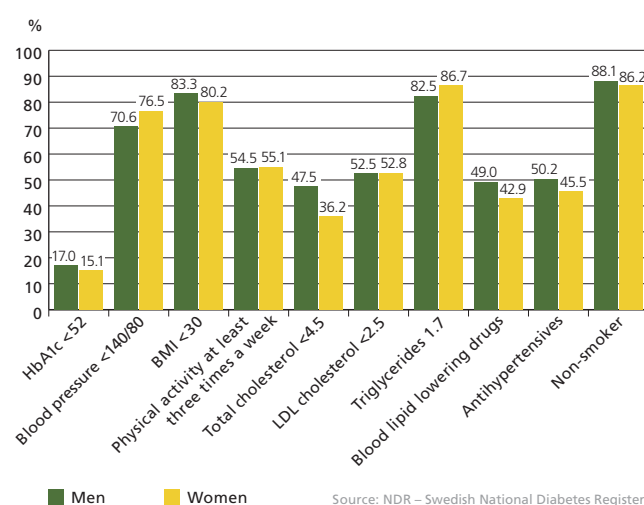
**Figure 62.** Average risk factors for women and men with type 1 diabetes age 18 and older. Significant differences after age standardisation: \*\*\*  $p < 0.001$



**Figure 63.** Average blood lipid levels (mmol/l) for women and men with type 1 diabetes, age 18 and older. All differences are significant after age standardisation,  $p < 0.001$ .



**Figure 64.** Percentage of women and men with type 1 diabetes age 18 and older who reached target levels. Except for LDL ( $p = 0.2$ ) and physical activity ( $p = 0.2$ ), all differences are significant.



# Facts about the NDR

## Integral to Swedish diabetes care

The Swedish Association for Diabetology (SFD) established the National Diabetes Register (NDR) in 1996 in response to the St. Vincent Declaration, whose purpose was to persuade European countries to reduce the prevalence of diabetes complications. The NDR was designed to enable comparisons between the results achieved at all clinics treating diabetics and the nationwide average for a number of clinical variables. The register now offers online tools for comparisons over time, as well as among counties and clinics. The tools are intended for use as part of local improvement efforts.

The NDR has become integral to Swedish diabetes care, particularly since the late 1990s as research has increasingly demonstrated the importance of various risk factors for diabetes complications and cardiovascular disease, not to mention the efficacy of new treatments for high blood pressure, blood sugar and blood lipid levels. Thus, the register meets the indispensable need for an instrument that monitors treatment outcomes.

## How the NDR is structured

The SFD runs the NDR on behalf of the Swedish Association of Local Authorities and Regions. The register is financed by appropriations from the Executive Committee for National Quality Registers and the the Västra Götaland Register Centre. Refer to [www.ndr.nu](http://www.ndr.nu) for the NDR regulations.

### NDR Steering Committee

- President, SFD (Convenor): Professor Mona Landin Olsson, Lund University Affiliated with the specialist clinic in Helsingborg
- President, Swedish Diabetes Association Fredrik Löndahl
- Director: Soffia Guðbjörnsdóttir, Associate Professor, Director, Västra Götaland Register Centre, Gothenburg
- Ulf Samuelsson, Associate Professor, Director, Child and Adolescent Clinic, Linköping University Hospital

### Representatives of:

- Swedish Society of Endocrinology Professor Mikael Rydén, Karolinska University Hospital, Huddinge
- Representative of primary care: Kristina Bengtsson-Boström, Associate Professor, Billingen Health Centre, Skövde
- Section for Endocrinology and Diabetes, Swedish Association of Paediatricians Ulf Samuelsson, Associate Professor, Director, Child and Adolescent Clinic, Linköping University Hospital
- Swedish Association of Diabetes Nurses: Lars Berg, Diabetes Nurse, Southern Älvsborg Hospital/Borås
- Ulla-Britt Löfgren, Diabetes Nurse, Project Manager, NDR
- Pär Samuelsson, Development Manager, NDR

### NDR Research group

The Research group is responsible for processing NDR data, as well as compiling annual and scientific reports for national and international conferences. The committee also promotes the use of the data in clinical research. The NDR has published a number of its scientific reports in national and international journals over the past few years.

- Soffia Guðbjörnsdóttir, Associate Professor
- Jan Cederholm, Associate Professor
- Björn Eliasson, Associate Professor
- Katarina Eeg-Olofsson, Md, Specialist
- Björn Zethelius, Associate Professor
- Ann-Marie Svensson, Associate Director
- Mervete Miftaraj, Biostatistician

## Maintenance and development

### Västra Götaland Register Centre

The national quality registers operate under the auspices of the various county councils and receive financial assistance from the Swedish Association of Local Authorities and Regions. The Västra Götaland Region is responsible for a number of registers, including the NDR.

Now that efforts to monitor the healthcare system are increasingly dependent on quality assessment data, there is a greater need to collaborate with the registers above and beyond basic reporting procedures.

#### *The tasks of the Register Centre are to:*

- supply the registers with various resources
- provide support and skills for launching and developing registers
- serve as a regional asset for improving quality register efforts

### Technical development

The IT Division of the Register Centre is responsible for technical development and maintenance of the NDR website, software and online reports for each clinic. The division sets standards for ongoing technical development and improvement and has established a shared platform for all registers.

### Data entry

Electronic data entry at [www.ndr.nu](http://www.ndr.nu) provides a clinic with immediate access to its results, as well as county-by-county and nationwide comparison statistics. A patient's data may be entered repeatedly throughout the course of a year. Approximately 86% of NDR users sign on with personnel cards.

### Direct transmission of medical records

Information is also transmitted directly from medical record systems and through local extraction software to the NDR database. More than half of the entries are automated.

### Input data

In addition to entry date, care provider code and Swedish personal identity number, the following data are requested: year of onset, type of diabetes, type of treatment, method of administering insulin, HbA1c levels, weight, height, waist circumference, blood pressure, blood lipid levels, serum creatinine levels, and 14 closed

questions: hypertension and lipid lowering treatment, aspirin or Waran treatment, microscopic and macroscopic proteinuria, history of stroke or myocardial infarct, fundus examination, retinopathy or visual impairment, foot examination, smoking status, physical activity and hypoglycaemia. The latest levels and care event are entered. Refer to reporting form.

Form for supplementing or revising entries in the most recent report.

Diabetes profile to be used in information for patients. The profile is generated automatically on the basis of all mandatory data that has been entered, as well as the optional answers that the clinic has provided. Brief comments may also be entered. The profile may be printed out during an appointment and increase patient participation in treatment programmes.

An overview shows the clinic's diabetes population (broken down by gender, current age, onset age, disease duration and treatment method), including national comparison figures for each level of care.

A search list is a tool that allows the user to combine the criteria to which a particular subpopulation is subject in order to process data, monitor quality and focus on patients – either individuals or groups – with special intervention needs.

A search can also be performed to identify patients for whom no data have been entered in relation to a particular variable. The purpose of the function is to obtain more complete information for use as part of the clinic's monitoring and improvement efforts.

The statistics show the clinic's outcomes, along with national comparison figures at each level of care. The results are based on input data for the period of time that the user selects.

Customised statistics show figures from a period of the user's choice. The user can generate comparison data from two different time periods. The statistics can be presented as a cumulative diagram, a bar and pie chart, or a table. The function is under development.

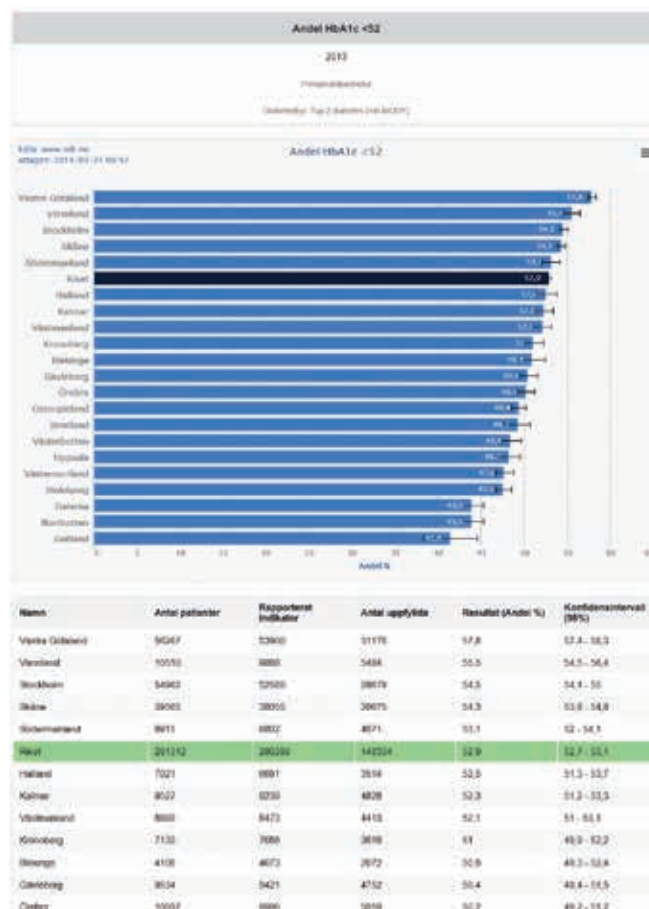
## Feedback

Each clinic has immediate access to its own outcomes, as well as nationwide comparison figures. The results are based on input data for the period of time that the user selects. A clinic can autonomously generate their annual report, including nationwide comparison figures. The NDR compiles and publishes a nationwide overview during the first half of the following year. The reports serve as a tool for monitoring and improvement efforts by individual clinics and the various county councils. The results are presented in an increasingly transparent manner as the register expands its coverage.

## The "Button"

County coordinators and officials have exhibited growing interest in county-by-county and clinic outcomes. In response to this demand, the NDR designed and launched a brand new tool (the "Button") during the year that permits a user to follow an indicator, as well as generate comparison figures, at the local, county and nationwide level.

The "Button" offers unprecedented options for monitoring outcomes and documenting improvement efforts at a clinic. The "Button" can be accessed on our website.

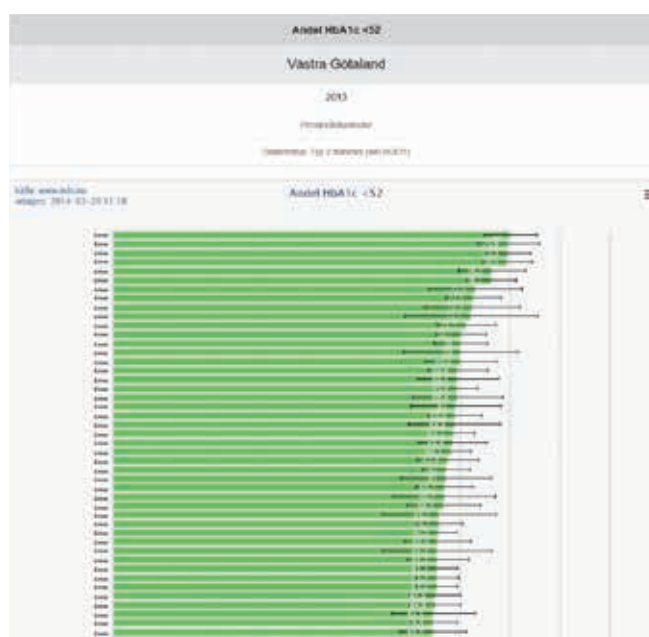


## The "Button"

# knappen



One click for improvement work





## Quality and validity

The online input software includes instructions and definitions, as well as a number of mandatory and built-in validation checks. Data entry is validated on a continual basis by means of required fields, fixed alternatives and automated plausibility checks built into the software. The database includes automated reporting of statistics for the percentage of completed variables so that the clinics can monitor the quality of their own data entry. Patients are assigned to the last clinic at which they had an appointment during the year, whether it be specialist or primary care.

Previous validation studies have found a high rate of agreement between medical records and NDR data for most variables. There were no systematic discrepancies between patients for whom data had or had not been entered. NDR data for primary care throughout the Västra Götaland Region have been validated against medical records, the Inpatient Register and the Prescribed Drug Register. Generally speaking, the data exhibit a very high rate of agreement.

Register data are always subject to methodological problems due to selection and measurement errors, as well as non-participation. Measurement errors, the difference between a measured and true value, occur in all databases. Such errors are caused by deficient instruments and methods, along with unreliable responses. Standardised measurement methods and secure data transmission reduce the risk of error. Given that the NDR is not comprehensive, it contains sampling errors. The selectivity of data loss, rather than the phenomenon itself, is the problem. The most effective antidote is to increase the participation rate at the country and regional levels. Nevertheless, variations in the participation rate at the clinic level affect assessments of the results. This report is representative of diabetes care at most specialist clinics, as well as primary care in many counties.

## New developments and other NDR projects

- Insulin pump project. On behalf of the European Association for the Study of Diabetes (EASD) and for the purpose of enhancing traceability and patient safety, the NDR will add questions about insulin pumps and incidents that may be associated with their use. The goal for 2014 is to enter the indications, complications and reasons for termination of insulin pump treatment. Data entry is to be as simple as possible and hopefully become routine when treatment commences.
- A total of 18 external research projects were granted in 2013. The NDR published 15 articles in scientific journals and had 16 abstracts accepted at medical conferences. The NDR generates many statistical reports every year. Demand has decreased, however, since we launched our "Button" tool, which permits users to generate their own customised reports.
- The NDR is participating in a number of national and international research partnerships.
- Ten PhD students are affiliated with NDR in several different areas, including patient reported outcome measures (PROMs), health economics, cardiology, nephrology, general medicine, paediatric diabetology and clinical improvement methodology.
- The NDR Risk Engine, an online service for calculating the 5-year risk of cardiovascular disease, is gaining in popularity. The annual report presents county-by-county results for the first time.
- The NDR website needs a comprehensive overhaul, and a new development project is under way. The goal is to make register data more graphically appealing and comprehensible, encouraging improvement efforts and reaching out to patients and other new target groups.
- The NDR participates regularly in various training activities initiated by the county councils.
- Representatives of the NDR deliver regular lectures about the register, improvement efforts and research in many different venues.

## The NDR is involved in a host of projects concerning register efforts, including:

- National PROM Network.
- Västra Götaland Regional Quality Register for Primary Care.
- Diabetes and pregnancy: a working committee has launched a project to address register logistics and indicators.
- Quality register data at [www.1177.se](http://www.1177.se). The objective is to empower patients and their families, creating new opportunities for them to take action and assume control. Making administration and management of the healthcare system more transparent.
- SVEUS Project on outcomes, resource utilisation and compensation in diabetic care as part of the National Partnership for Development of Diagnostic Descriptive Systems and Value-based Compensation Systems – Diabetes.
- Descriptive and compensation systems will be designed in close collaboration with participating county councils, the Swedish Association for Diabetology, Swedish Association of General Practice, Swedish Association of Diabetes Nurses and representatives of care providers. The overall purpose of the research project is to develop a new compensation system for diabetes care in participating counties on behalf of the Ministry of Health and Social Affairs. The goal of the partnership is to ensure that county councils have greater control over the care they provide while creating compensation systems that encourage cost-effectiveness efforts (better outcomes for less money).
- Dialogue Project: development of a new feedback tool, introduction of self-reported data in interaction with diabetics and caregivers. The tool is to use state-of-the-art visualisation technology and interactive design concepts to improve the ability of patients to participate in their care and learn about diabetes.
- National Platform for Improvement Research.
- A National Board of Health and Welfare project to address goal fulfilment in diabetes care.

## Data Entry for 2014

### Current Status

Date  Care provider (code)  Swedish per. ID no.

1. Year of onset (diagnosed according to WHO criteria, excluding gestational diabetes)

2. Type of diabetes (clinical assessment)  
 Type 1, ind. LADA ☐ Type 2, incl. MODY ☐  
 Secondary, such as pancreatitis ☐ Unclear ☐  
 Diet only ☐ Insulin ☐ Tabl. ☐ Tabl. & insulin ☐ Inj. GLP-I ☐

3a. Diabetes treatment

3b. Method of administering insulin  
 Injection ☐ Insulin pump ☐

4. HbA1c (mmol/mol)

5. Weight (kg, without coat, jacket or shoes)

6. Height (cm, without shoes)

7. Waist (cm)<sup>1)</sup>

8. Blood pressure (mm Hg, sitting after resting for 5 minutes)  /

9. Antihypertensives  
 Yes ☐ No ☐ Unknown ☐

10. Blood lipids (mmol/l)  
 Cholesterol  Triglycerides  HDL  LDL<sup>7)</sup>

11. Blood lipid lowering drugs  
 Yes ☐ No ☐ Unknown ☐

12a. Macroalbuminuri <sup>2)</sup>  
 Yes ☐ No ☐ Unknown ☐

12b. Serum creatinine

13. Microalbuminuri <sup>3)</sup>  
 Yes ☐ No ☐ Unknown ☐ Normalised level ☐

14. Ischaemic heart disease <sup>4)</sup>  
 Yes ☐ No ☐ Unknown ☐

15. Cerebrovascular disease (ever, TIA, stroke)  
 Yes ☐ No ☐ Unknown ☐

16. Aspirin (or other platelet aggregation inhibitor)  
 Yes ☐ No ☐ Unknown ☐ Waran ☐

17a. Fundus examination (ophthalmoscopy or inspection by specialist) Year  Month (MM)

17b. Diabetic retinopathy  
 Yes ☐ No ☐ Unknown ☐ Diagnosis, worse-seeing eye <sup>8)</sup>   
 Laser treatment Yes ☐ No ☐ Unknown ☐

18. Vision loss (due to diabetes <0.3 in better-seeing eye, corr.)  
 Yes ☐ No ☐ Unknown ☐

19a. Foot examination (past year)  
 Yes ☐ No ☐ Unknown ☐ Date

19b. Foot category <sup>5)</sup>  
 1 Healthy foot ☐ 2 Neuropathy and/or angiopathy ☐  
 3 Previous diabetic ulcer ☐ 4 Serious ongoing foot disease ☐

20. Smoking habits  
 Never smoked ☐ Smokes every day ☐ Smokes but not every day ☐  
 Quit smoking ☐ Quit smoking, year  Month (MM)

21. Physical activity (30-minute walk or equivalent. Individually adapted and all forms of activity included)  
 Never ☐ < once a week ☐ Once or twice a week ☐  
 3-5 times a week ☐ Every day ☐

22. Severe hypoglycaemia <sup>6)</sup> (no. of events the past year)  
 0 ☐ 1-2 ☐ 3-5 ☐ >5 ☐

<sup>1)</sup> With patient standing after normal exhalation, horizontal between lower ribcage and top of the hip bone

<sup>2)</sup> Diagnosis requires albumin/creatinine ratio > 30 mg/mmol (or U-albumin > 200 µg/min, or > 300 mg/l)

<sup>3)</sup> Diagnosis requires two out of three samples within a year to be positive, i.e., albumin/creatinine ratio 3-30 mg/mmol (or U-albumin 20-200 µg/min, or 20-300 mg/l). Normalised level after pharmacological treatment

<sup>4)</sup> Ever. Angina pectoris, myocardial infarct, PTCA, bypass surgery

<sup>5)</sup> Level 1: Healthy foot - diabetes without complications; Level 2: neuropathy and/or angiopathy - peripheral vascular disease; Level 3: previous diabetic ulcers, foot deformities, severe callus, amputation; Level 4: serious foot disease - ulcer, critical ischaemia, infection, severe osteoarthropathy, Charcot foot

<sup>6)</sup> Help by an outsider

<sup>7)</sup> Does not need to be reported as it is computed automatically in accordance with Friedewald's formula if cholesterol, triglyceride and HDL cholesterol levels are reported concurrently. LDL levels may be reported manually in accordance with another formula

<sup>8)</sup> Simplex retinopathy, PPDR = preproliferative diabetic retinopathy, CSM = Clinically significant macular oedema, PDR = proliferative diabetic retinopathy

# Example from specialist clinic

## Hospital views

Each hospital has a table, along with a “Target” snapshot of its results (mean and percentage) compared with the nationwide mean. The Target shows patients with type 1 diabetes at hospital.

The Target is not a comprehensive measure of the quality of diabetes care at the hospital, but rather an incentive for analysis, learning and improvement.

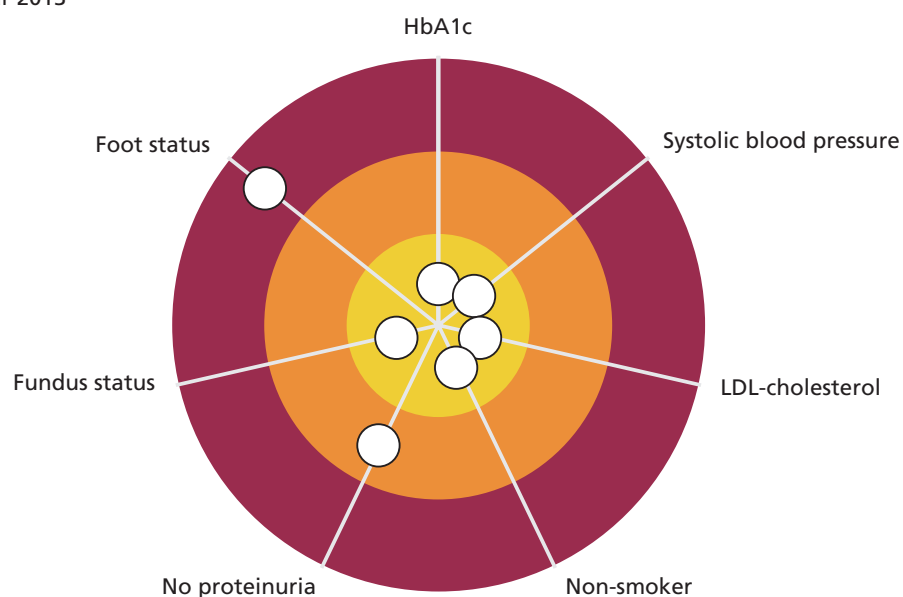
The three shades indicate:

- The hospital’s results are poorer than the nationwide mean by a statistically significant margin.
- The hospital’s results are on a par with the nationwide mean.
- The hospital’s results are better than the nationwide mean by a statistically significant margin.

## Sahlgrenska University Hospital/Sahlgrenska

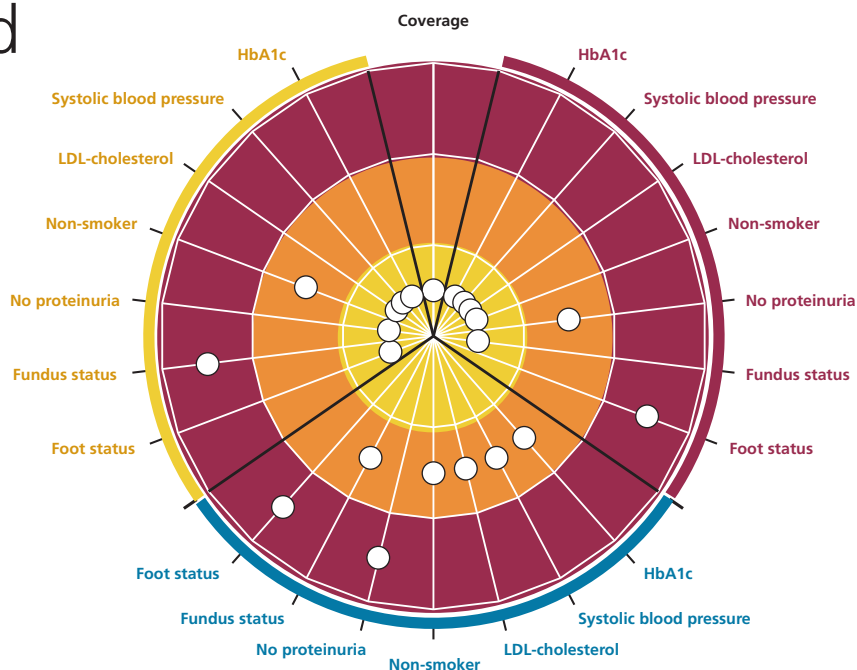
Mean age 46, n=1,170

○ Year 2013



# Västra Götaland

- Primary care**  
N = 58,165  
Mean age = 68.3  
Mean duration = 9.3  
Men = 56.4%
- Specialist clinics, type 1 diabetes**  
N = 6,541  
Mean age = 45.6  
Mean duration = 22.9  
Män = 56.9%
- Specialist clinics, type 2 diabetes**  
N = 2,148  
Mean age = 63.6  
Mean duration = 16.0  
Män = 67.4%

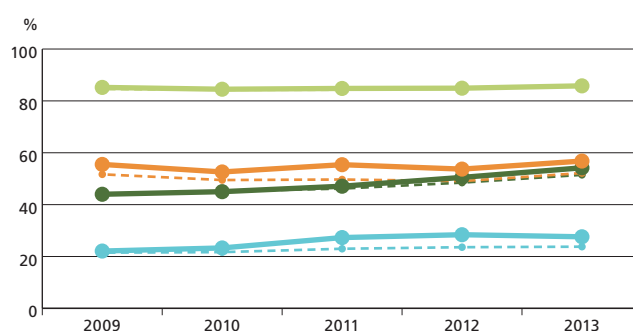


Indications	Primary care		Specialist clinics, type 1 diabetes		Specialist clinics, type 2 diabetes	
	Nation-wide	County council	Nation-wide	County council	Nation-wide	County council
<b>Mean value</b>						
HbA1c, mmol/mol	54.1	52.9	64.3	63.1	62	61.6
Systolic blood pressure, mm Hg	134.9	133.9	126.2	125.2	132.4	131.5
LDL-cholesterol, mmol/l	2.6	2.5	2.6	2.5	2.3	2.3
<b>Proportion (%)</b>						
Non-smoker	85.7	85.8	88.2	90.0	86.8	88.0
No proteinuria	92.3	93.7	94.5	94.1	83.3	78.3
Fundus status*	90.3	89.5	95.5	96.9	97.3	98.0
Foot status**	95.3	96.9	93.6	90.2	93.2	90.2

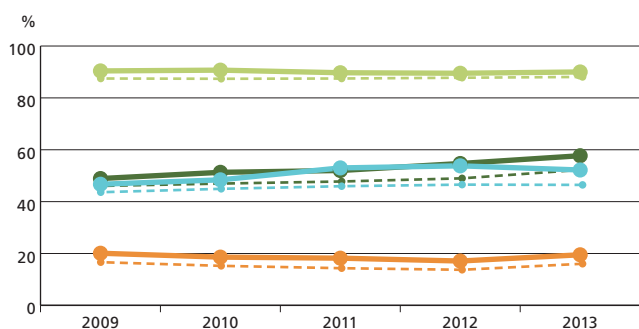
\* the last 2 years among patients with type 1 diabetes at hospital, as well as the last 3 years among patients with type 2 diabetes at hospital and primary care

\*\* last year

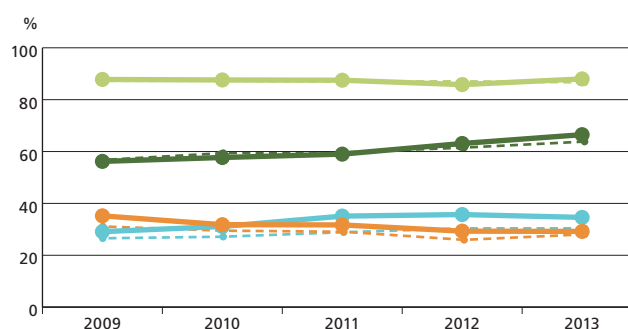
Västra Götaland: primary care and nationwide.



Västra Götaland: specialist clinics type 1 diabetes and nationwide.



Västra Götaland: specialist clinics type 2 diabetes and nationwide.



— HbA1c <52 mmol/mol

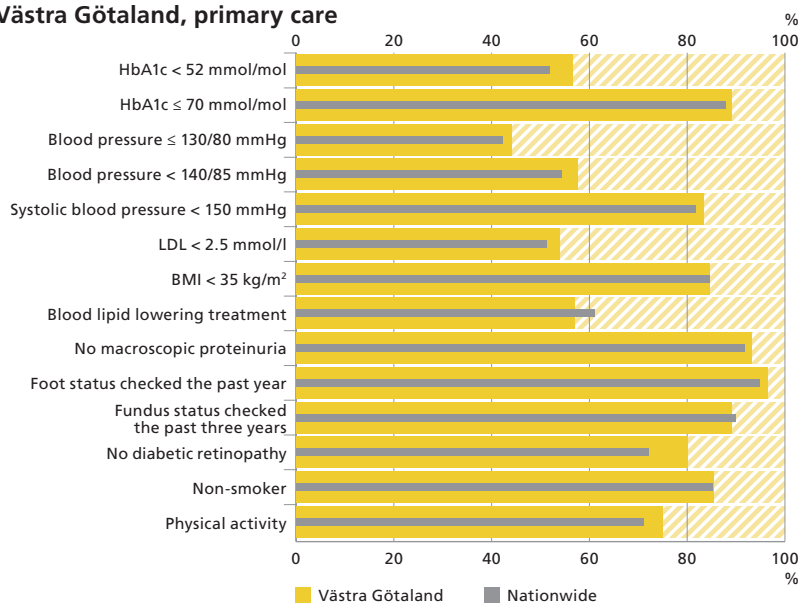
— LDL cholesterol <2.5 mmol/l

— Blood pressure <130/80 mm Hg

— Non-smoker

--- Dashed lines = Nationwide

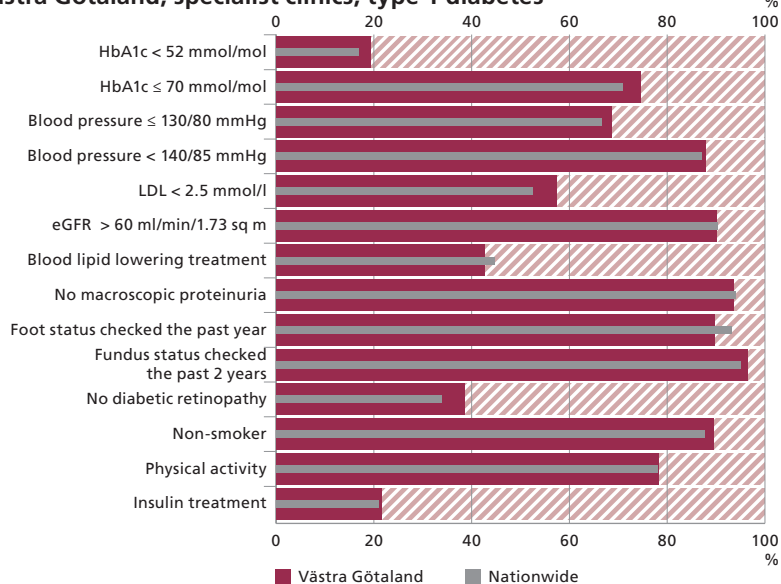
## Västra Götaland, primary care



Indications	Västra Götaland (%)	Nation-wide (%)
HbA1c < 52 mmol/mol	56.8	52.2
HbA1c ≤ 70 mmol/mol	89.6	88.3
Blood pressure ≤ 130/80 mmHg	44.3	42.4
Blood pressure < 140/85 mmHg	57.8	54.6
Systolic blood pressure < 150 mmHg	83.8	82.1
LDL < 2.5 mmol/l	54.2	51.5
BMI < 35 kg/sq m	85.1	85
Blood lipid lowering treatment	57.3	61.4
No macroscopic proteinuria	93.7	92.3
Foot status checked the past year	96.9	95.3
Fundus status checked the past three years	89.5	90.3
No diabetic retinopathy	80.5	72.4
Non-smoker	85.8	85.7
Physical activity *	75.4	71.5

\*Physical activity, regularly 3–5 times/week or daily

## Västra Götaland, specialist clinics, type 1 diabetes



Indikatorer	Västra Götaland (%)	Nation-wide (%)
HbA1c < 52 mmol/mol	19.5	16.9
HbA1c ≤ 70 mmol/mol	75.0	71.3
Blood pressure ≤ 130/80 mmHg	69.1	67.0
Blood pressure < 140/85 mmHg	88.4	87.6
Systolic blood pressure < 150 mmHg	57.7	52.8
LDL < 2.5 mmol/l	90.6	90.9
BMI < 35 kg/sq m	42.8	44.9
Blood lipid lowering treatment	94.1	94.5
No macroscopic proteinuria	90.2	93.6
Foot status checked the past year	96.9	95.5
Fundus status checked the past three years	38.8	34.0
No diabetic retinopathy	90.0	88.2
Non-smoker	78.6	78.4
Physical activity *	21.7	21.0

\*Physical activity, regularly 3–5 times/week or daily

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**Centre of Registers Region Västra Götaland**  
**Centre for National Quality Registers**

The Centre of Registers Region Västra Götaland is a repository of information for registers of healthcare quality. The Swedish Association of Local Authorities and Regions has charged the Centre with supporting the development, operation and use of national quality registers, as well as taking advantage of the registers to promote research and quality improvements.

[www.registercentrum.se](http://www.registercentrum.se)