



Nationwide results 1996 – 2020

NDR  **NATIONELLA
DIABETESREGISTRET**
SWEDISH NATIONAL DIABETES REGISTER

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https://www.ndr.nu/pdfs/NationWideResults_1996-2020.pdf

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Contents

The National diabetes register (NDR) – history and importance	1
Nationwide results for 1996 – 2020	2
Number of patients and classification of diabetes	2
Participation in the NDR	2
Coverage of the NDR	3
Clinical characteristics	3
Lifestyle factors	7
Body Mass Index (BMI)	7
Physical leisure time activity	8
Smoking	9
Glycaemic control and the use of technical devices	10
HbA1c	10
Technical devices in type 1 diabetes	13
Blood pressure and blood lipid levels	15
Blood pressure levels and antihypertensive treatment	15
Blood lipid levels and lipid-lowering treatment	18
Process measures of diabetes complications	20
Albuminuria	20
Retinopathy	21
Control of eye status	22
Control of foot status	23
Cover rate	24
Patient-reported outcome and experience measures (PROM and PREM)	29
Scientific publications 2020	29

The National diabetes register (NDR) – history and importance

The Saint Vincent Declaration* was the outcome of a meeting in 1989 that included diabetologists and experts, as well as representatives of patient organizations and the various European governments. The key objective of the conference was to identify ways of easing the burden of complications of diabetes. One of the key recommendations was to “establish monitoring and control systems using state-of-the-art information technology for quality assurance of diabetes health care provision and for laboratory and technical procedures in diabetes diagnosis, treatment and self-management.”

The National Diabetes Register (NDR) was launched in 1996 after an initiative by Swedish Society for Diabetology, for the purpose of promoting development of evidence-based diabetes care by offering up-to-date information about changes in the treatment of glycaemia and other risk factors, as well as complications of diabetes. 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 maximize the cost effectiveness of diabetes care. The NDR is maintained by the Region of Västra Götaland, Sweden, with the financial support of the Swedish Association of Local Authorities and Regions. The Swedish Diabetes Association, a patient organization, also supports the NDR.

The NDR has been an integrated part of Swedish diabetes care for more than 20 years and has engaged the participation of both hospitals and primary care clinics. The NDR is a tool to facilitate monitoring and to disseminate findings in an accessible, transparent, comparable and timely manner. Patient’s data are either reported continuously

via medical electronic records, through local extraction software, or registered directly online to the NDR. More than 70% of the entries are currently automated. All individuals have provided consent before reported to the registry.

The register is both a repository of clinical variables 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. Monitoring the performance of clinics from year to year for benchmarking with national and regional averages is one of the most important functions of the register. Following up on guideline recommendations, treatment and complications are equally important, at the national level.

The NDR also promotes and facilitates the influence and participation of patients in their care and treatment. For example, patients can easily access and monitor their own clinical information.

The nationwide coverage and prospective nature of the register allows for assessment of clinical and health care related investigations, with representative and real-world data. Scientific studies based on data from the NDR and other national registers supply vital insights into the consequences of diabetes and offer possibilities for evaluating procedures and treatment strategies at multiple levels.

* *Diabetes Care and Research in Europe: The Saint Vincent Declaration. Diabet Med 1990 May;7(4):360.*

Nationwide results for 1996 – 2020

This section presents nationwide results over time. We have selected a number of indicators for this report. Additional results are available on our website www.ndr.nu. The present report describes diabetes care in relation to the guidelines of the National Board of Health and Welfare, while also shedding light on patient populations, treatments, results of laboratory findings and process measures, including retinal scans and foot examinations.

The diabetes treatment should be individualized based on each patient's characteristics, but this report focuses on means, proportions and different targets levels, and three specific patient populations are highlighted. Please note that the results presented in the graphs of this report are all unadjusted for any covariates.

The three patient populations are:

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

Number of patients and classification of diabetes

The results for specialist clinics in this report are broken down by clinical diagnosis of type 1 diabetes and type 2

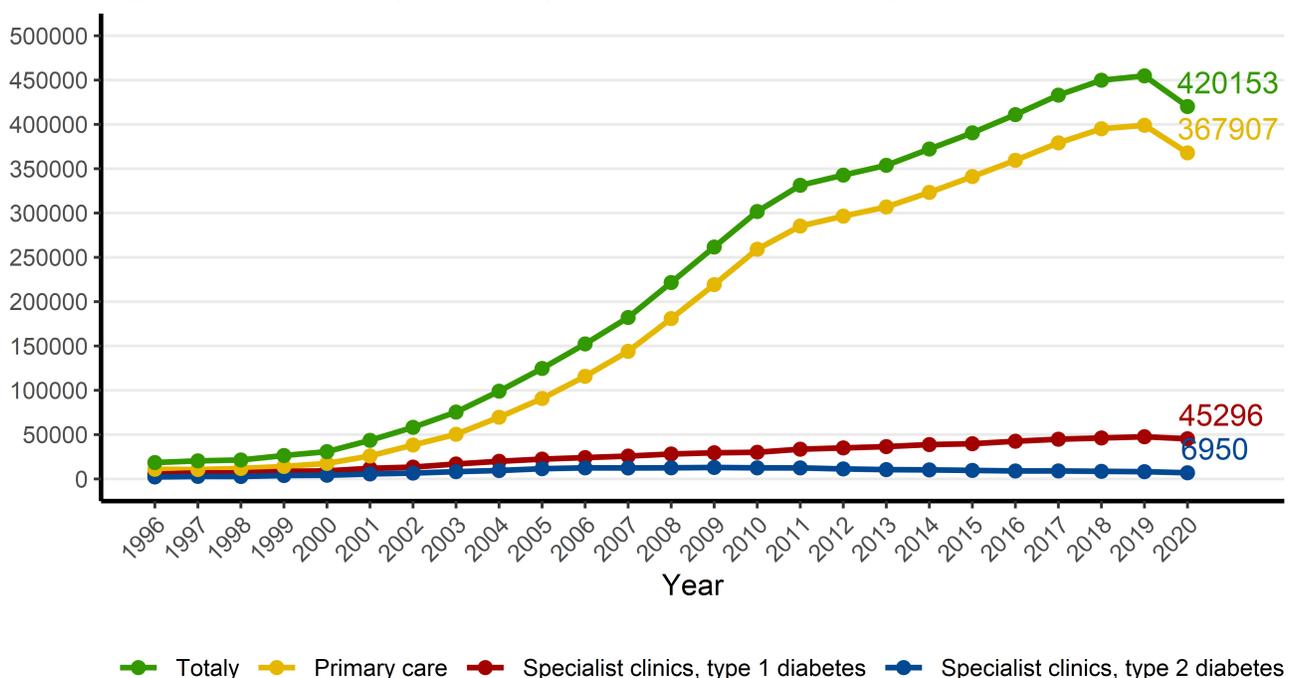
diabetes (ICD 10 codes). The results in the primary care include all persons with diabetes reported as one group, and 98% of these patients have been classified as type 2 diabetes (ICD 10 codes). In Sweden specialist clinics are responsible for the treatment of almost all patients with type 1 diabetes. These clinics also care for a minority of patients with type 2 diabetes and patients with secondary diabetes. Primary care is responsible for treatment of most patients with type 2 diabetes.

Participation in the NDR

Since 2015 the register receives reports from all 21 counties and all 91 specialist clinics, as well as the majority of primary care clinics (1225 units in 2020). Hence, 100% of specialist clinics and 90% of primary health care centres participate. Approximately 5,5% of Swedes have diabetes, but the prevalence presumably varies from one county to another, due to differences in age distribution and socio-economic factors. In Sweden type 2 represents approximately 90% of all diabetes.

Figure 1 shows the number of patients reported to the NDR each year from 1996 to 2020, broken down by primary care (almost all with type 2 diabetes), and specialist clinics by type 1 diabetes and type 2 diabetes. There is a marked decrease in the number of patients reported in 2020 compared to 2019. This is probably a direct effect of the corona pandemic since patients have not been able to visit their clinic to the same extent in 2020.

Figure 1. Number of patients reported to the NDR each year from 1996 to 2020.



Coverage of the NDR

The Swedish board of health and welfare makes yearly assessments of the coverages of all national quality registries in Sweden. Patients in the NDR were matched by the unique personal identification number to the Swedish prescribed drug register (SPDR). Patients aged ≥ 18 years

in the NDR 2018-2020 were compared to patients with at least one filled prescription of any glucose lowering drug (ACT code A10) in the SPDR during 2018-2019. The coverage for the NDR was 87% in 2019.

Clinical characteristics

Tables 1, 2 and 3 describes the clinical characteristics of the three populations. Patients with type 2 diabetes have a higher average age and shorter disease duration in primary care than at specialist clinics. Specialist clinics are reporting decreasing numbers of patients with type 2 diabetes. This has been seen since 2012 and is a result of primary care centres care for an increasing proportion

of this population. As is evident from the tables, mean age, diabetes duration and gender distribution have been relatively unchanged over the years. In 2020, type of diabetes and the year of onset of diabetes was reported in all patients. The figures 2-4 show the distributions of age in the different populations in 2020.

Table1. Patients with diabetes in primary care.

Year	Number	Mean age years (SD)	Mean duration years (SD)	Men (%)
1996	10907	68.3 (12.1)	9.3 (8.1)	5655 (51.8)
1997	10615	67.3 (13.1)	9.9 (8.8)	5471 (51.5)
1998	11833	68.2 (12.2)	9.4 (8.1)	6092 (51.5)
1999	14081	68.5 (12.0)	9.2 (7.9)	7482 (53.1)
2000	17508	68.3 (12.3)	9.1 (8.3)	9100 (52.0)
2001	25925	67.9 (12.3)	8.9 (8.3)	13512 (52.1)
2002	38258	68.1 (12.1)	9.1 (8.5)	20363 (53.2)
2003	50349	67.6 (12.0)	8.8 (8.2)	27150 (53.9)
2004	69606	67.6 (11.8)	8.5 (7.8)	37539 (53.9)
2005	90748	67.5 (11.8)	8.7 (7.9)	49058 (54.1)
2006	115761	67.6 (11.7)	8.7 (7.8)	63242 (54.6)
2007	143973	67.4 (11.8)	8.7 (7.8)	79149 (55.0)
2008	180915	67.4 (11.8)	8.8 (7.9)	99792 (55.2)
2009	219190	67.4 (11.9)	8.8 (8.0)	121419 (55.4)
2010	259146	67.5 (12.1)	8.9 (8.1)	143725 (55.5)
2011	285295	67.7 (12.1)	9.0 (8.2)	159191 (55.8)
2012	296480	67.8 (12.0)	9.2 (8.2)	166656 (56.2)
2013	306865	67.9 (12.0)	9.4 (8.3)	173987 (56.7)
2014	323266	68.1 (11.9)	9.5 (8.2)	184237 (57.0)
2015	341116	68.2 (11.9)	9.6 (8.2)	195505 (57.3)
2016	359495	68.3 (12.0)	9.7 (8.3)	206892 (57.6)
2017	379160	68.4 (12.0)	9.8 (8.3)	218696 (57.7)
2018	395053	68.5 (12.1)	9.9 (8.3)	228545 (57.9)
2019	398991	68.6 (12.1)	10.0 (8.3)	231567 (58.0)
2020	367907	68.3 (12.2)	10.3 (8.4)	215059 (58.5)

Figure 2. Histogram by age. Primary care, year 2020.

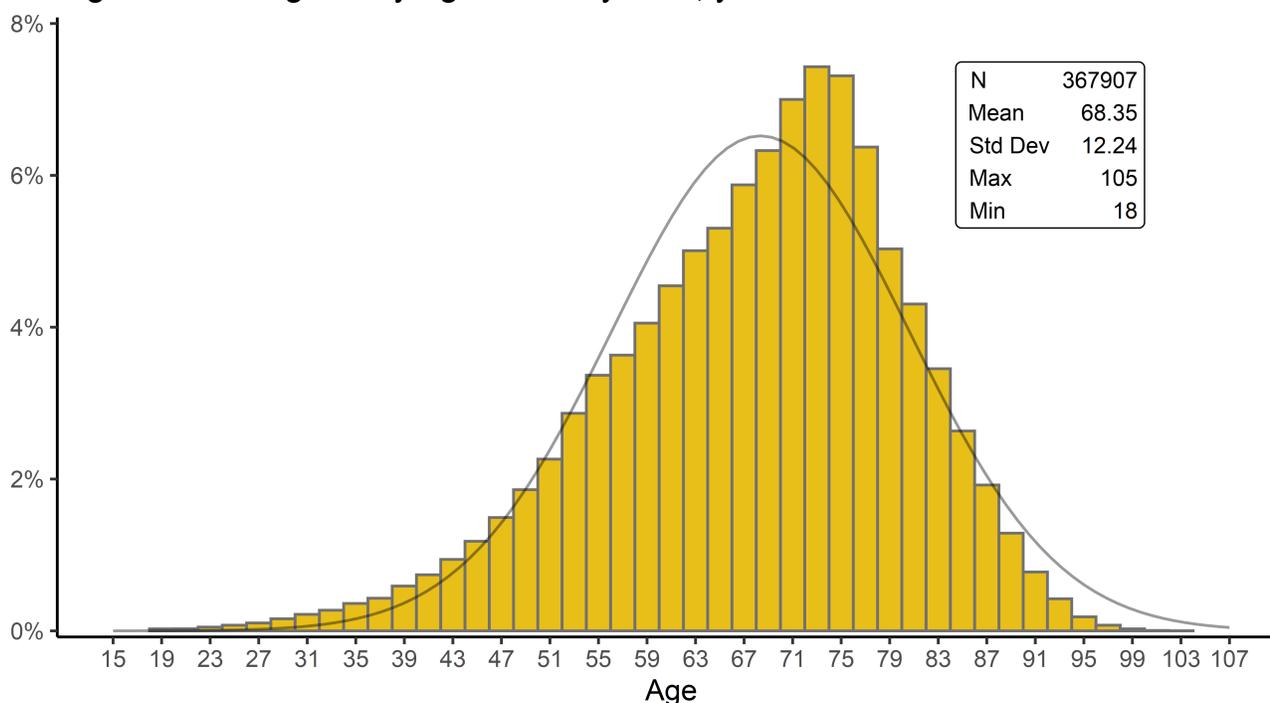


Table 2. Patients with typ 1 diabetes at specialist clinics.

Year	Number	Mean age years (SD)	Mean duration years (SD)	Men (%)
1996	5322	41.7 (13.2)	20.2 (12.3)	2933 (55.1)
1997	6898	41.1 (13.2)	20.1 (12.5)	3758 (54.5)
1998	6802	41.6 (13.3)	20.1 (12.6)	3708 (54.5)
1999	8483	42.4 (13.4)	21.0 (12.8)	4643 (54.7)
2000	9096	42.9 (13.5)	21.1 (12.9)	5064 (55.7)
2001	11957	43.4 (13.9)	21.4 (13.3)	6644 (55.6)
2002	13352	44.0 (14.1)	21.7 (13.4)	7461 (55.9)
2003	16867	44.3 (14.4)	22.0 (13.7)	9319 (55.2)
2004	19891	44.7 (14.6)	22.2 (13.9)	11090 (55.8)
2005	22352	45.2 (14.8)	22.7 (14.2)	12362 (55.3)
2006	24071	45.4 (15.1)	22.9 (14.3)	13296 (55.2)
2007	25765	45.5 (15.3)	23.0 (14.5)	14291 (55.5)
2008	28113	45.5 (15.4)	23.0 (14.5)	15609 (55.5)
2009	29505	45.6 (15.7)	23.1 (14.7)	16386 (55.5)
2010	30056	45.5 (16.0)	23.1 (14.8)	16733 (55.7)
2011	33538	45.4 (16.2)	23.1 (14.9)	18884 (56.3)
2012	34986	45.4 (16.5)	23.2 (15.0)	19636 (56.1)
2013	36476	45.6 (16.7)	23.3 (15.1)	20414 (56.0)
2014	38749	45.9 (16.8)	23.6 (15.2)	21658 (55.9)
2015	39725	46.2 (16.9)	23.8 (15.3)	22129 (55.7)
2016	42516	46.4 (17.1)	23.9 (15.4)	23536 (55.4)
2017	44804	46.7 (17.2)	24.1 (15.5)	24945 (55.7)
2018	46208	47.0 (17.4)	24.2 (15.6)	25750 (55.7)
2019	47569	47.4 (17.6)	24.4 (15.7)	26560 (55.8)
2020	45296	47.5 (17.7)	24.7 (15.7)	25361 (56.0)

Figur 3. Histogram by age. Patients with typ 1 diabetes at specialist clinics, year 2020.

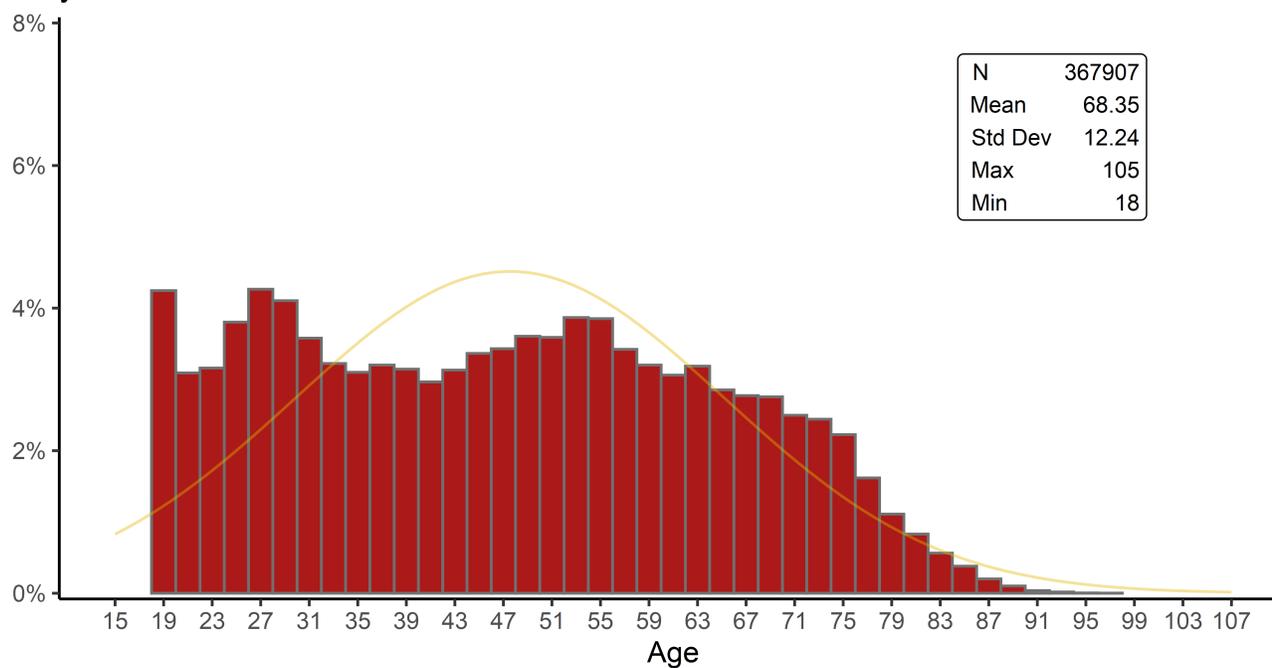
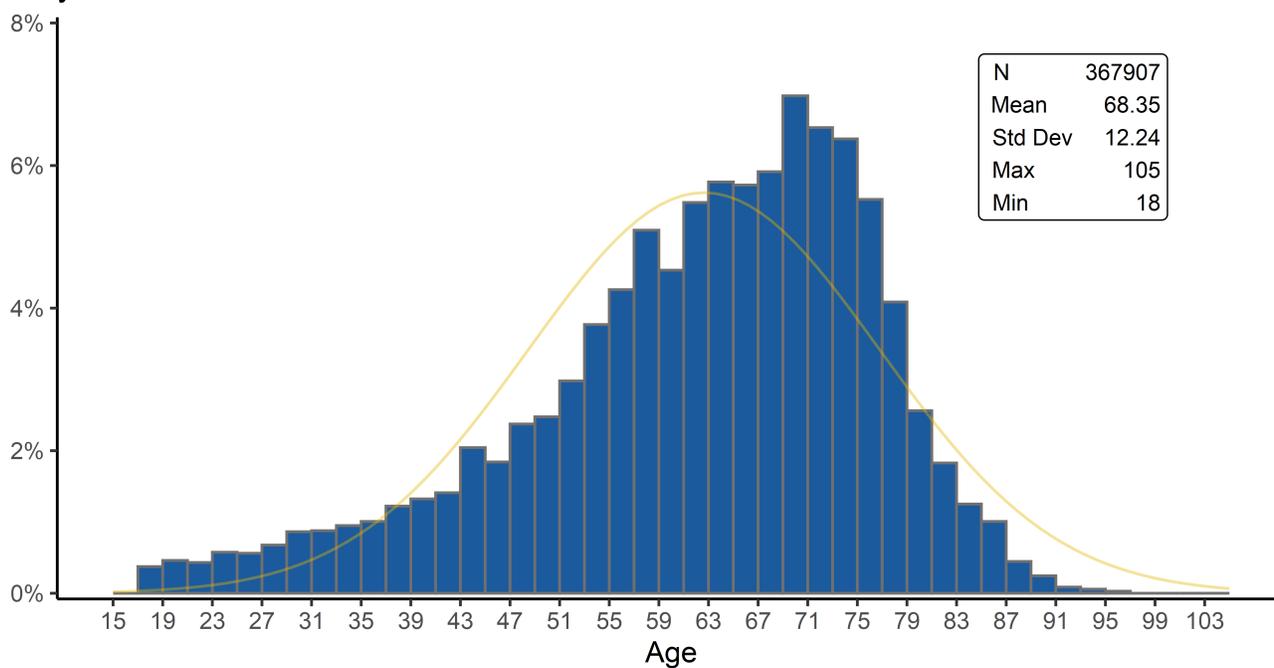


Table 3. Patients with typ 2 diabetes at specialist clinics.

Year	Number	Mean age years (SD)	Mean duration years (SD)	Men (%)
1996	2239	56.8 (11.3)	11.2 (8.4)	1357 (60.6)
1997	2871	57.2 (11.2)	11.5 (8.3)	1766 (61.5)
1998	2759	57.0 (11.2)	11.8 (8.7)	1642 (59.5)
1999	3859	57.7 (11.4)	11.9 (8.9)	2383 (61.8)
2000	4184	58.2 (11.4)	12.1 (8.9)	2605 (62.3)
2001	5653	58.7 (11.8)	12.1 (9.1)	3567 (63.1)
2002	6607	59.2 (11.8)	12.3 (9.2)	4188 (63.4)
2003	8221	59.9 (12.0)	12.6 (9.3)	5259 (64.0)
2004	9505	60.4 (12.0)	12.9 (9.3)	6125 (64.4)
2005	11542	61.2 (12.3)	13.1 (9.5)	7389 (64.0)
2006	12498	61.7 (12.2)	13.3 (9.5)	8065 (64.5)
2007	12381	62.1 (12.3)	13.6 (9.7)	7955 (64.3)
2008	12544	62.0 (12.5)	13.8 (9.8)	8037 (64.1)
2009	12941	62.2 (12.5)	13.9 (9.9)	8341 (64.5)
2010	12494	62.4 (12.4)	14.1 (9.9)	8119 (65.0)
2011	12441	62.3 (12.6)	14.4 (10.0)	8003 (64.3)
2012	11290	62.4 (12.7)	15.0 (10.2)	7324 (64.9)
2013	10495	62.3 (13.0)	15.2 (10.3)	6751 (64.3)
2014	10211	62.6 (13.0)	15.6 (10.3)	6546 (64.1)
2015	9626	63.0 (13.2)	16.1 (10.4)	6218 (64.6)
2016	8987	62.6 (13.5)	16.5 (10.7)	5822 (64.8)
2017	9029	62.8 (13.7)	16.8 (10.7)	5773 (63.9)
2018	8567	62.8 (13.9)	17.1 (10.8)	5497 (64.2)
2019	8186	62.9 (13.9)	17.5 (10.8)	5228 (63.9)
2020	6950	62.6 (14.2)	18.1 (10.9)	4400 (63.3)

Figur 4. Histogram by age. Patients with typ 2 diabetes at specialist clinics, year 2020.



Lifestyle factors

Body Mass Index (BMI)

BMI is a measure of body composition, and is calculated as $weight/height^2$ (kg/m^2).

Figure 5. Proportions of patients by BMI intervals over time. Primary care.

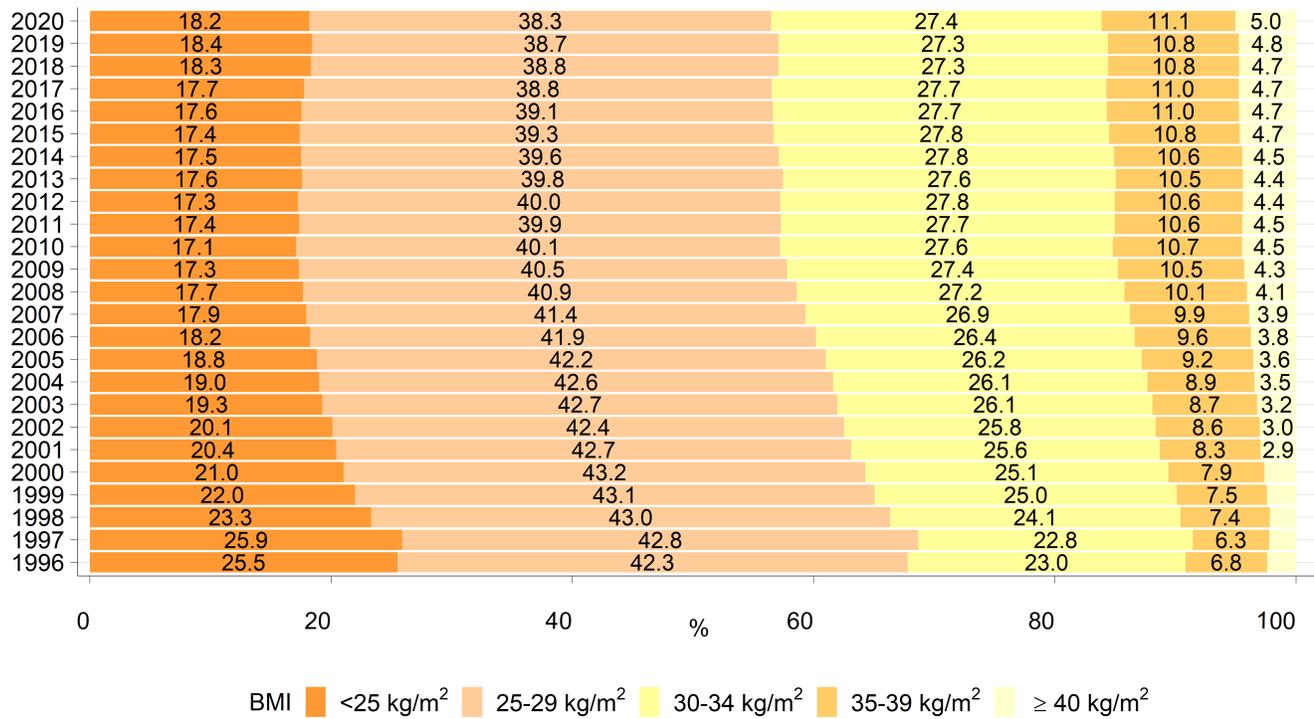
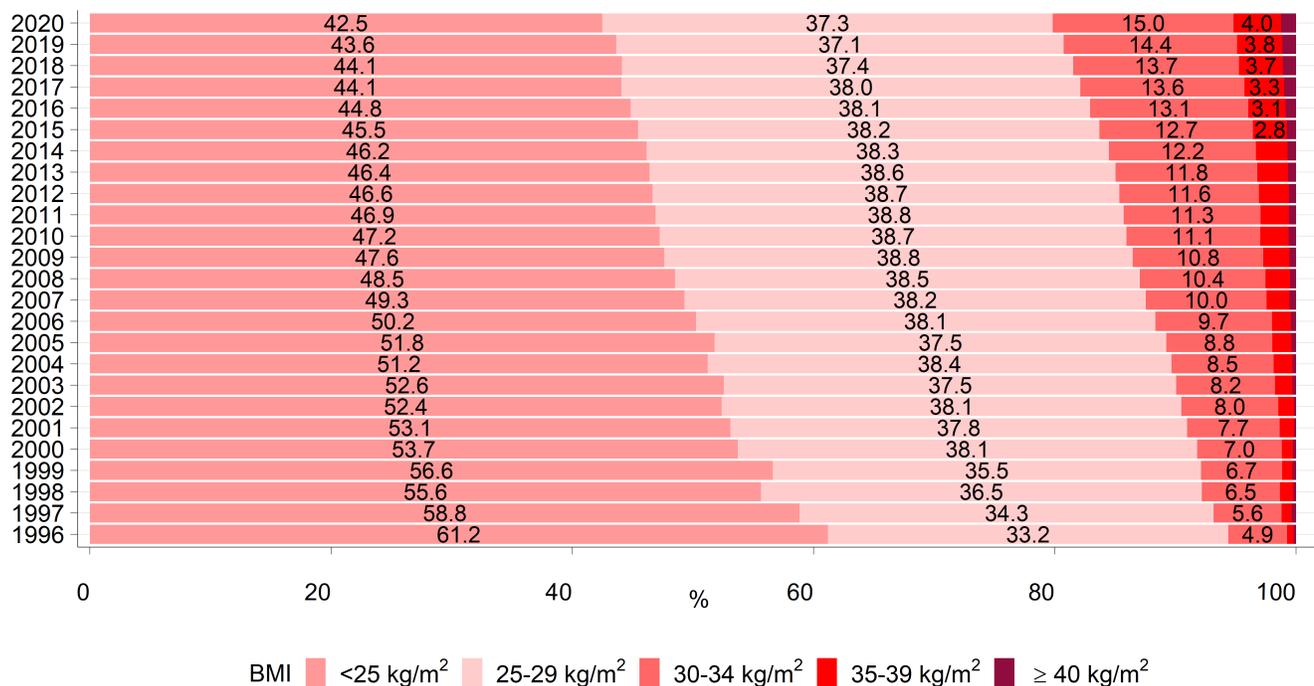


Figure 6. Proportions of patients by BMI intervals over time. Patients with type 1 diabetes at specialist clinics.



Physical leisure time activity

Physical leisure time activity is reported to the NDR using a five-graded scale from daily to never. In the NDR physical leisure time activity is defined as at least 30 minutes of walking or similar activity.

Figure 7. Proportions of patients at different levels of physical leisure time activity. Primary care.

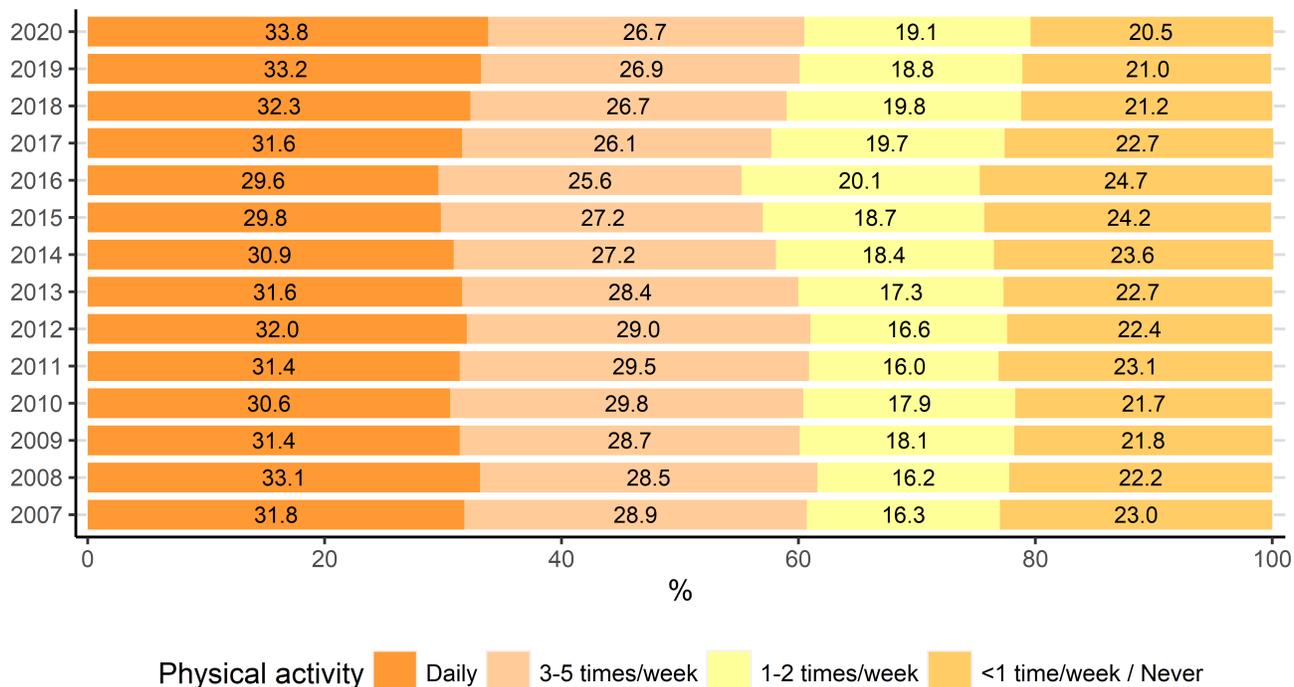
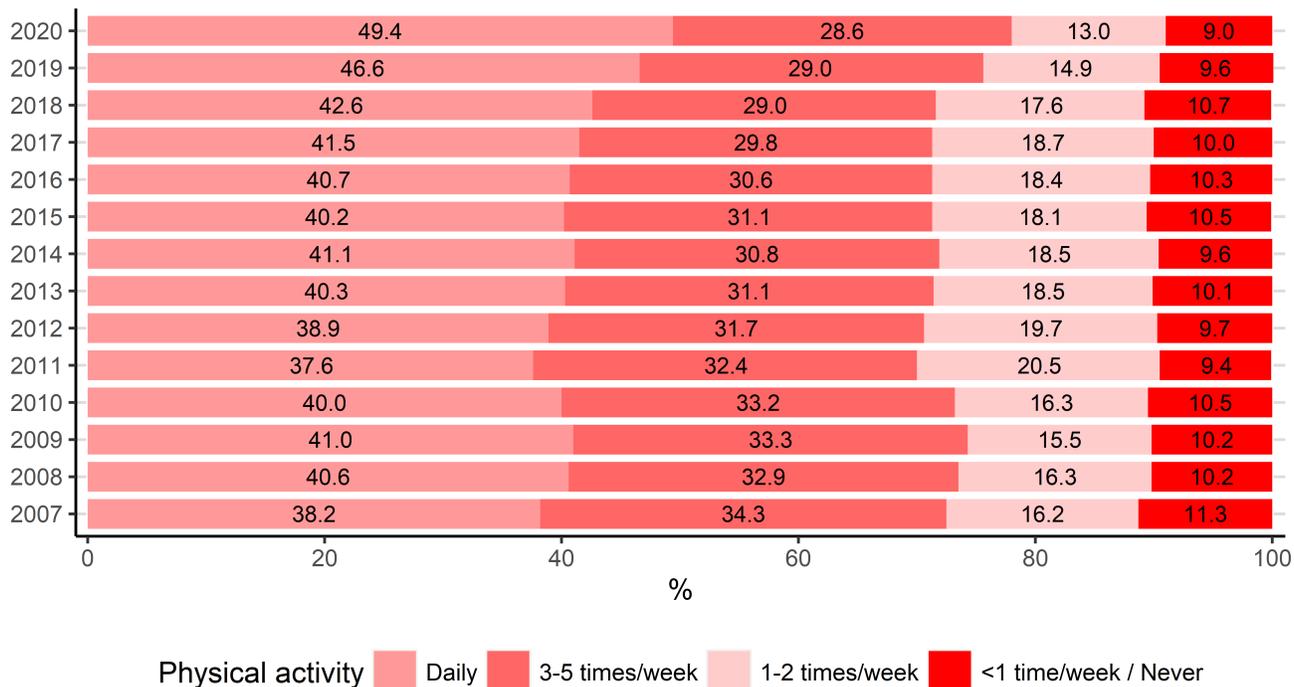


Figure 8. Proportions of patients at different levels of physical leisure time activity. Patients with type 1 diabetes at specialist clinics.



Smoking

In NDR, the definition of a smoker is person who is a current smoker or has stopped smoking during the last 3 months.

Figure 9. Proportions of women and men who smoke, by age group.
Primary care.

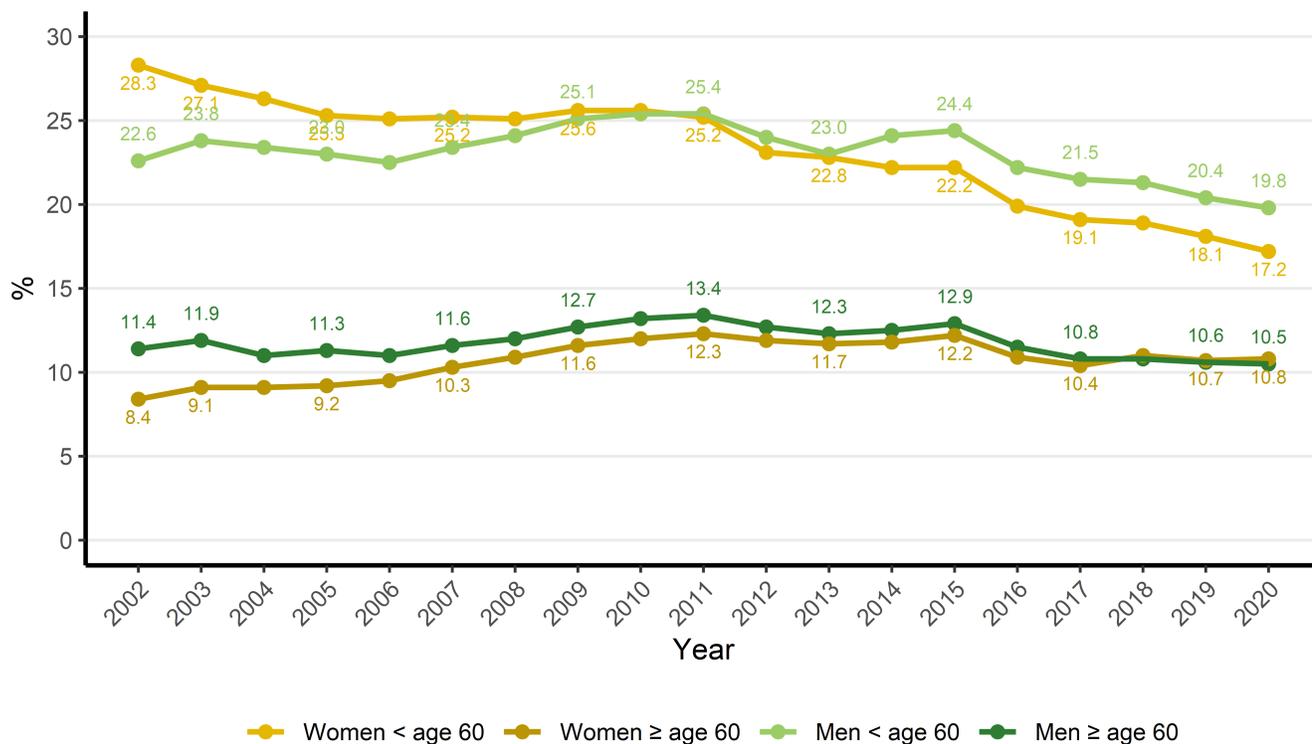
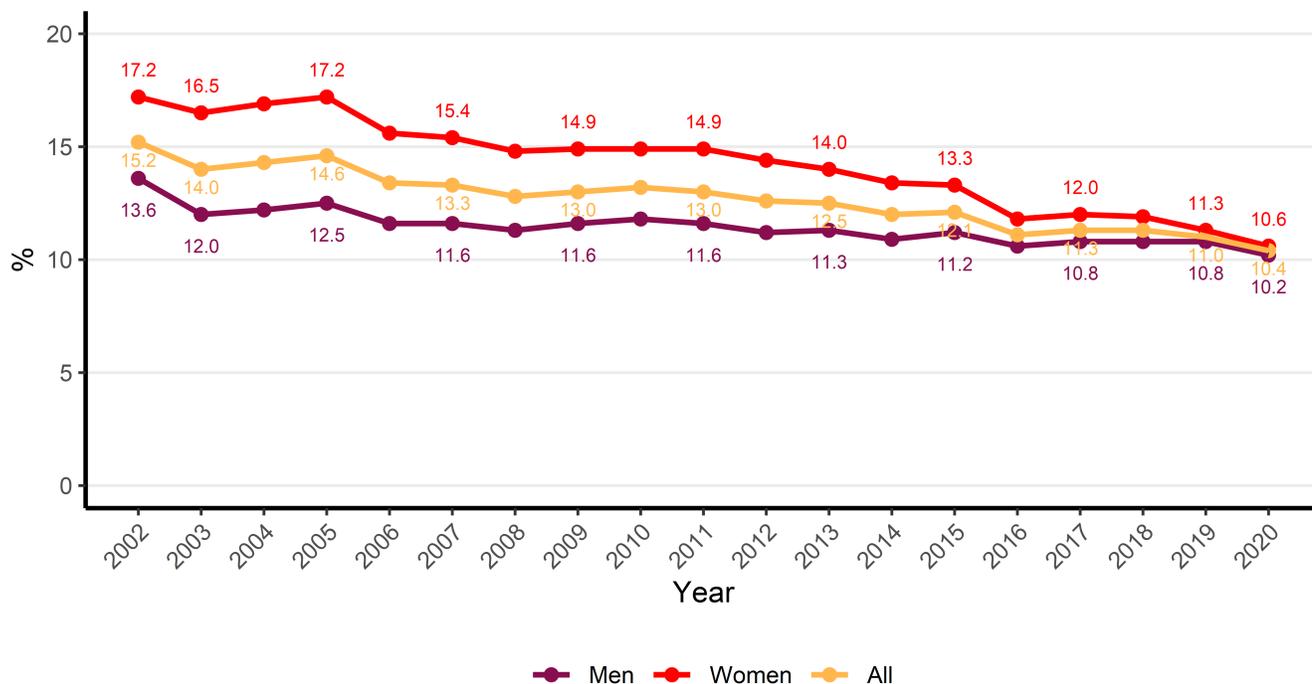


Figure 10. Proportions of women, men and in all, who smoke.
Patients with type 1 diabetes at specialist clinics.



Glycaemic control and the use of technical devices

HbA1c

The glycated haemoglobin A1c (HbA1c) levels reflect long-term glycaemic control and is strongly correlated with the risk of developing diabetes complications. In the NDR, HbA1c is reported in IFCC HbA1c units (mmol/mol). The IFCC HbA1c value can be converted to NGSP HbA1c (%) using a formula available at <http://www.ngsp.org/convert1.asp>. The following figures describe mean HbA1c values over time, as well as proportions of patients with HbA1c lower than 52 mmol/mol (52 mmol/mol IFCC=6.9% NGSP HbA1c) which is a target level according to Swedish national guidelines. A HbA1c value higher than 70 mmol/mol (70 mmol/mol IFCC=8.6% NGSP) denotes a high risk for complications of diabetes.

Figure 11. Mean HbA1c levels (IFCC, mmol/mol) over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

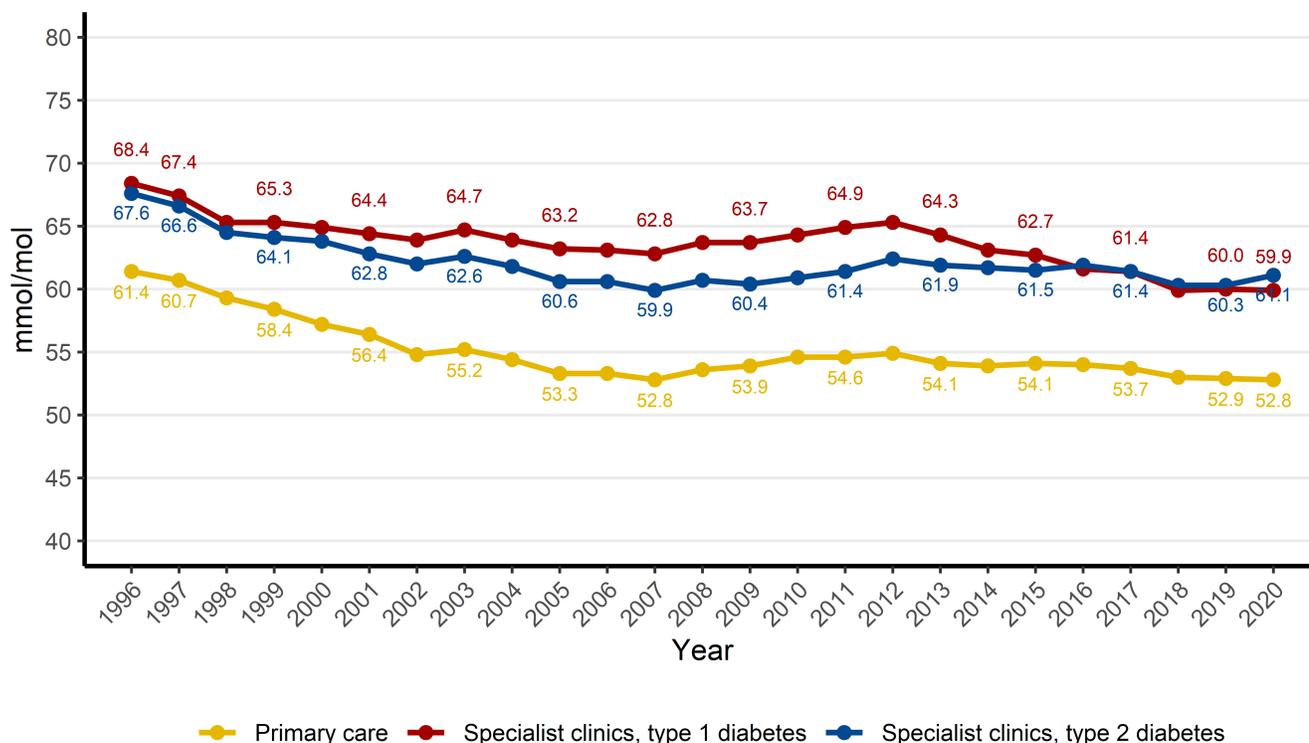


Figure 12. Mean HbA1c levels (NSPG, %) over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

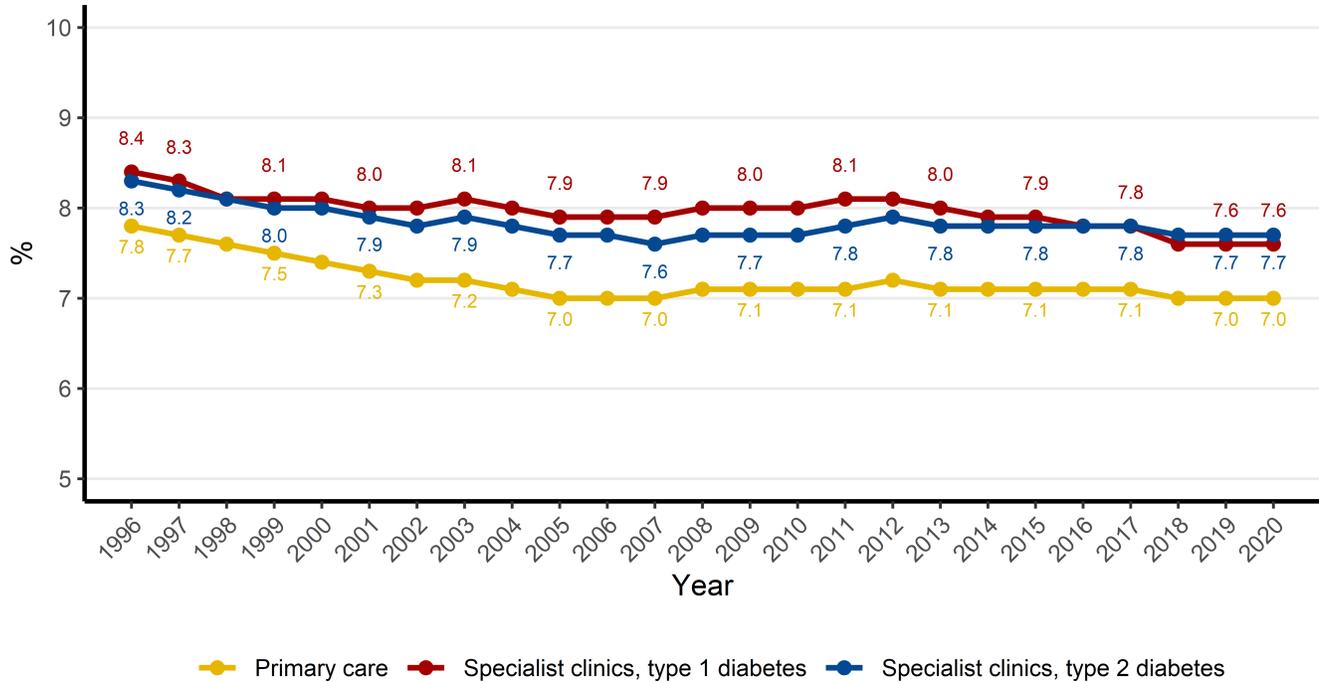


Figure 13. Proportions of patients with Hba1c < 52 mmol/mol (6.9% NGSP) over time in primary care, in type 1 diabetes and type 2 diabetes in specialist clinics.

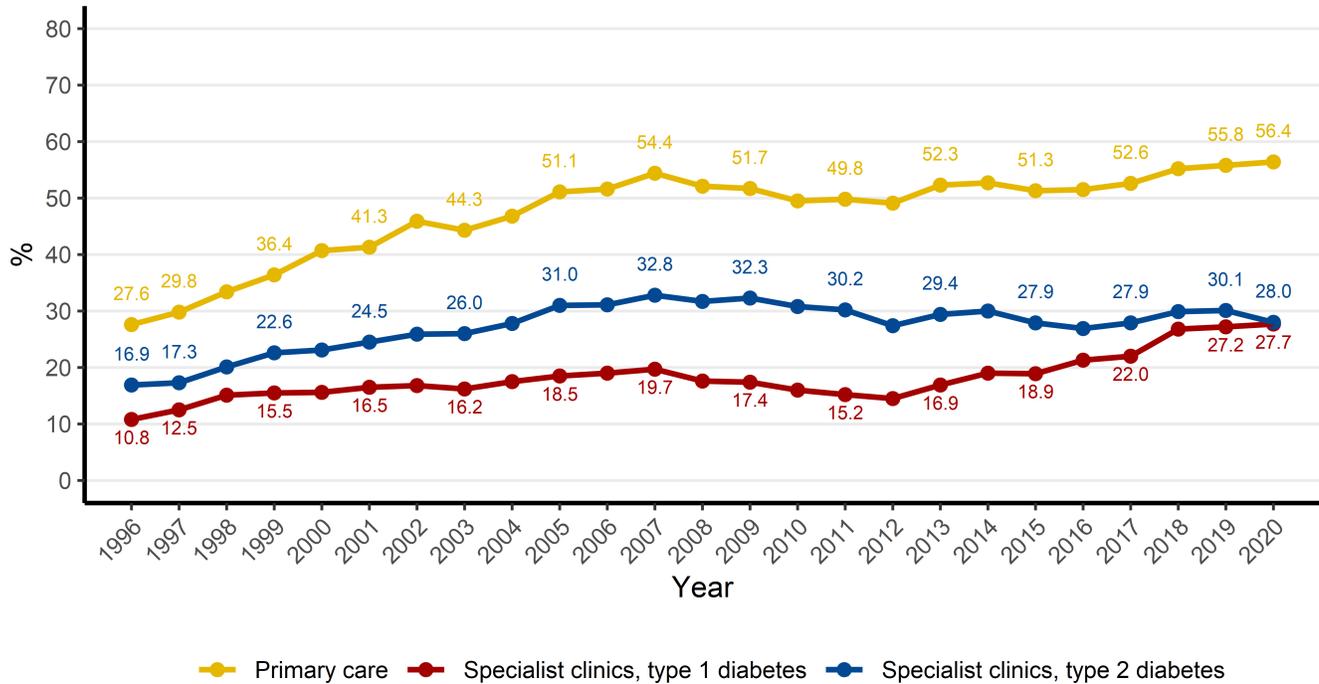
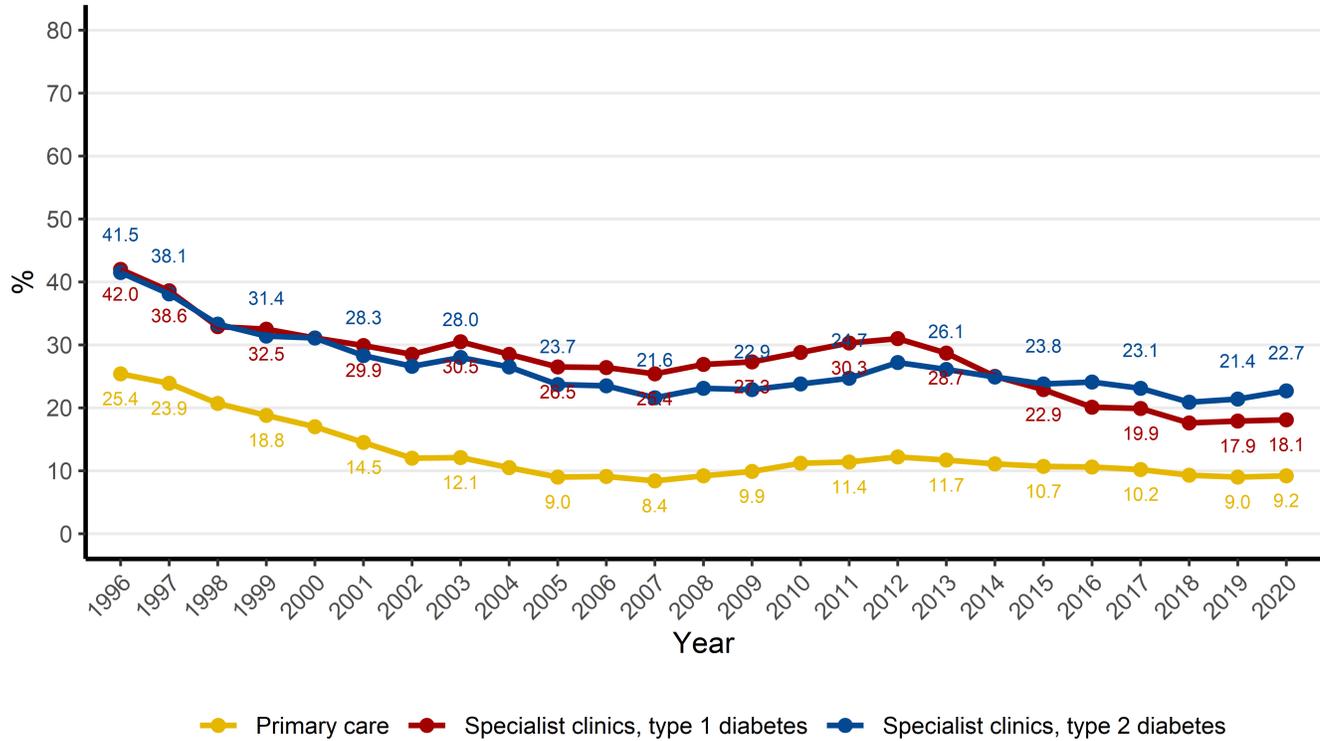


Figure 14. Proportions of patients with Hba1c > 70 mmol/mol (8.6% NGSP) over time in primary care, in type 1 diabetes and type 2 diabetes in specialist clinics.



Technical devices in type 1 diabetes

The way insulin is administered, by multiple daily injections or by insulin pumps, have been registered in the NDR since 2002. The use of sensor-based glucose monitoring, including both real-time and intermittent scanning devices have been reported since June 2016 with a cover rate of 94% in 2020.

Figure 15. Proportions of patients using insulin pumps among patients with type 1 diabetes over time in men, in women and in all.

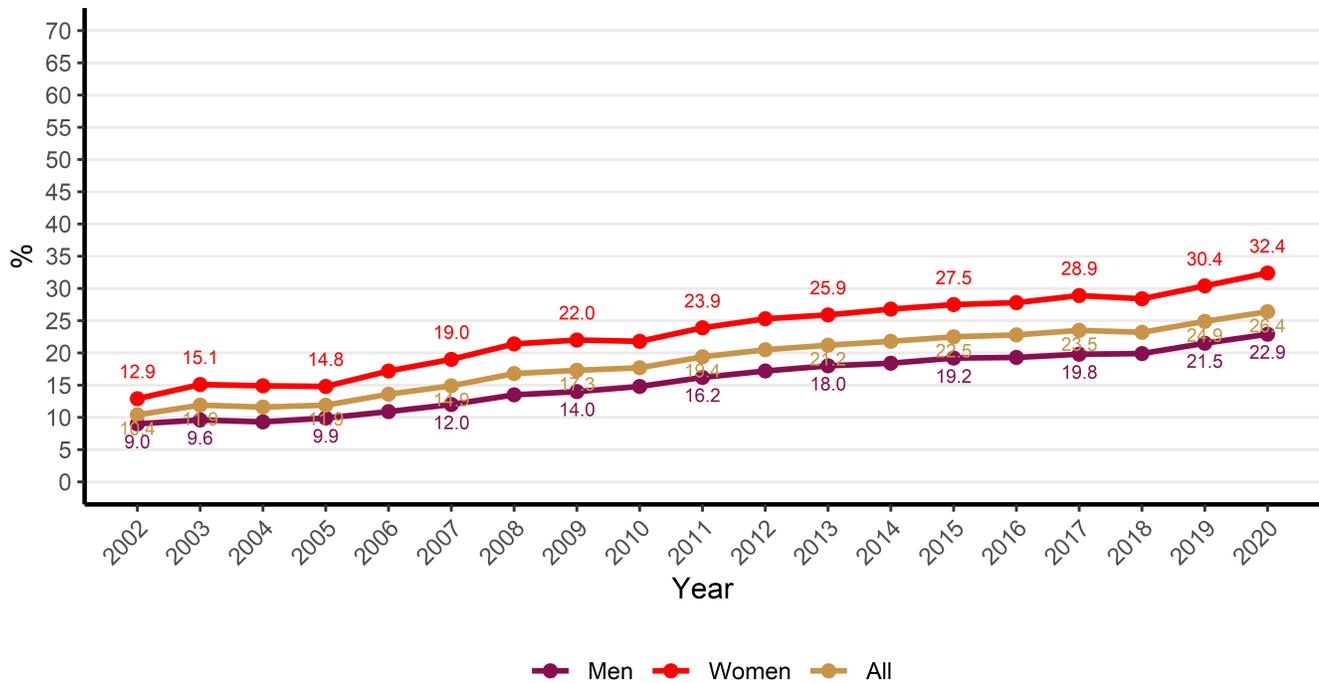


Figure 16. Proportions of patients using insulin pumps among patients with type 1 diabetes over time in different age groups.

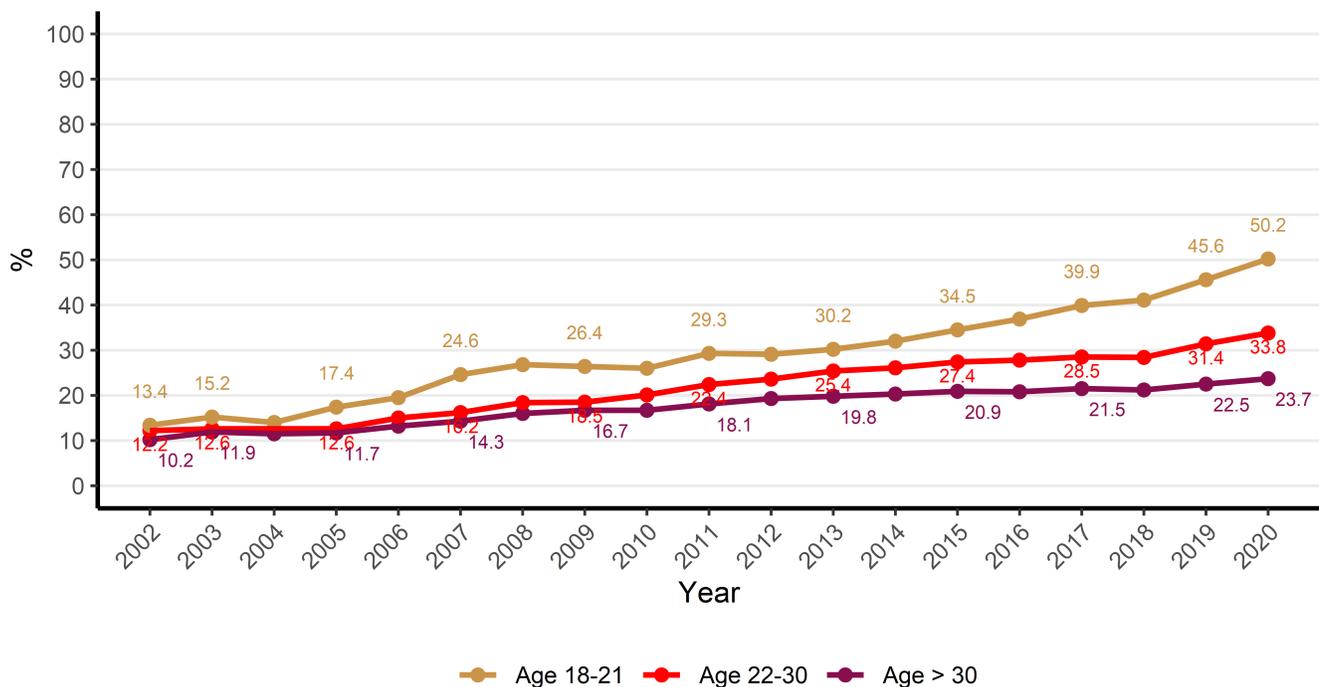
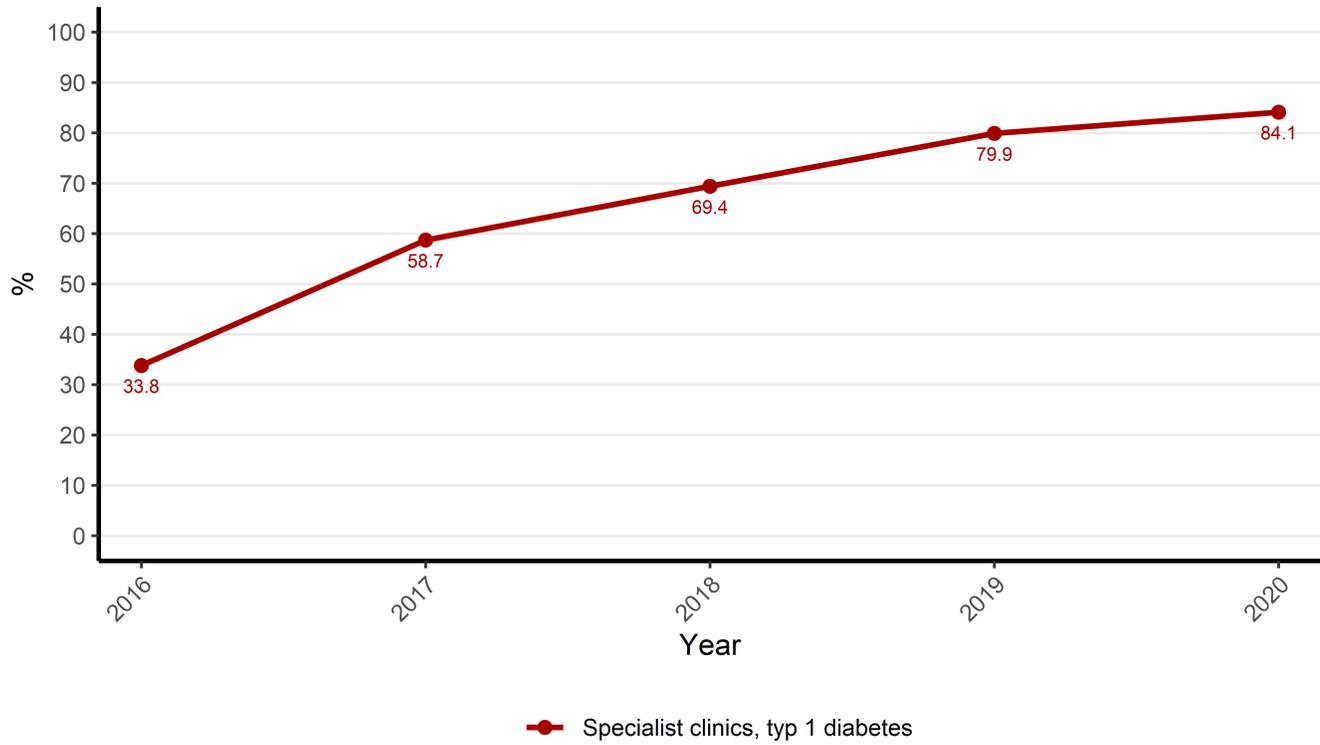


Figure 17. Proportion of patients with type 1 diabetes using sensor-based glucose monitoring, including both real-time and intermittent scanning devices.



Blood pressure and blood lipid levels

Blood pressure levels and antihypertensive treatment

Blood pressure is recommended to be measured when the patient is in a sitting position after having rested for 5 minutes and rounded off to the nearest even number. If the measurement is automated, the exact numbers should be reported. 24-hour blood pressure measurements are currently not entered in the NDR. The use of antihypertensive treatment (ATC codes) is a yes/no question. The following figures show mean systolic and diastolic blood pressure levels over time, and proportions of patients using antihypertensive drugs, as well as proportions of patients with blood pressure lower than 140/85 mmHg with or without treatment.

Figure 18. Mean systolic blood pressure (mmHg) over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

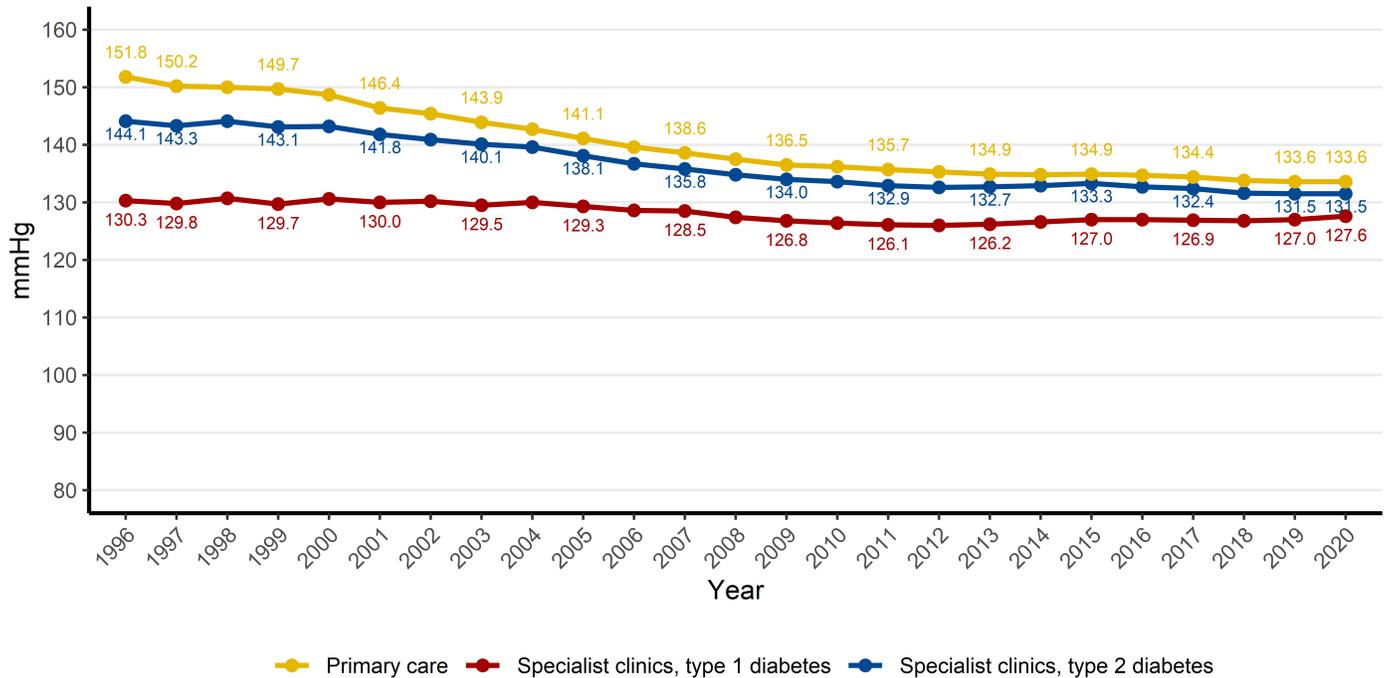


Figure 19. Mean diastolic blood pressure (mmHg) over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

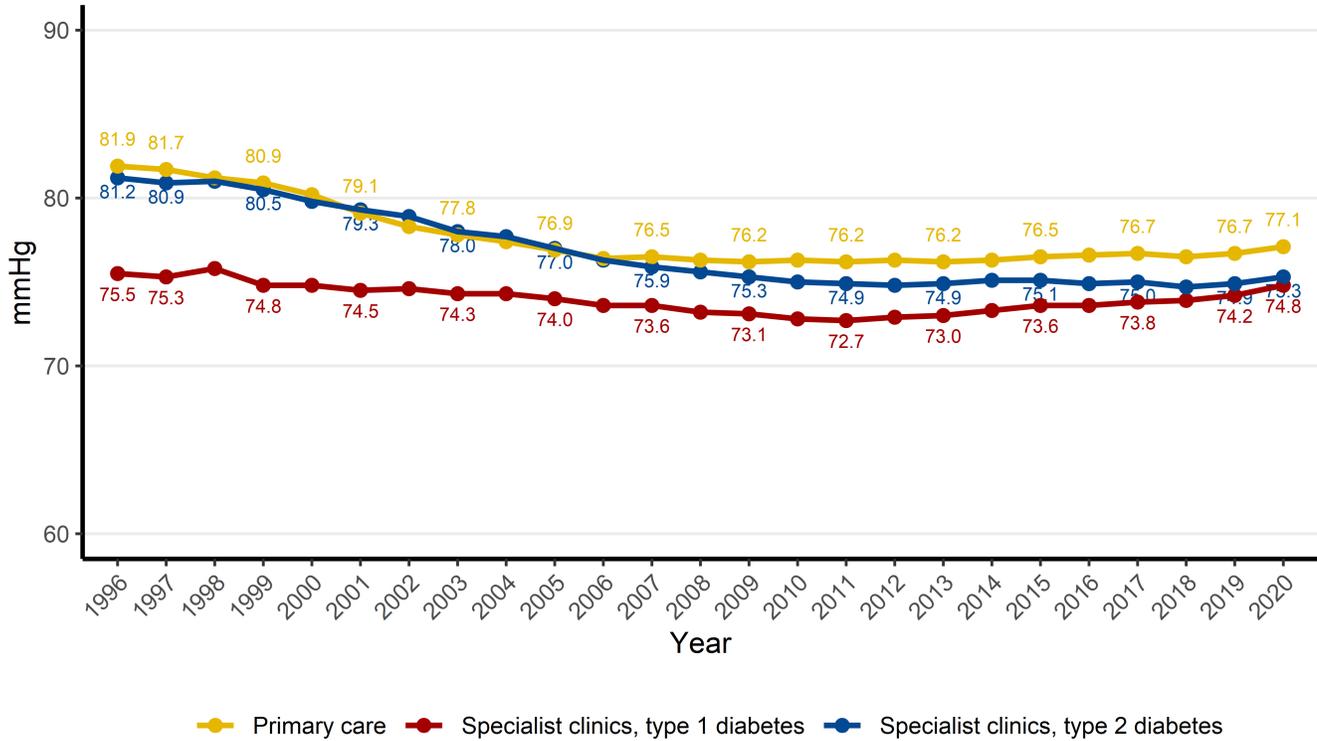


Figure 20. Proportions of patients using antihypertensive treatment over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

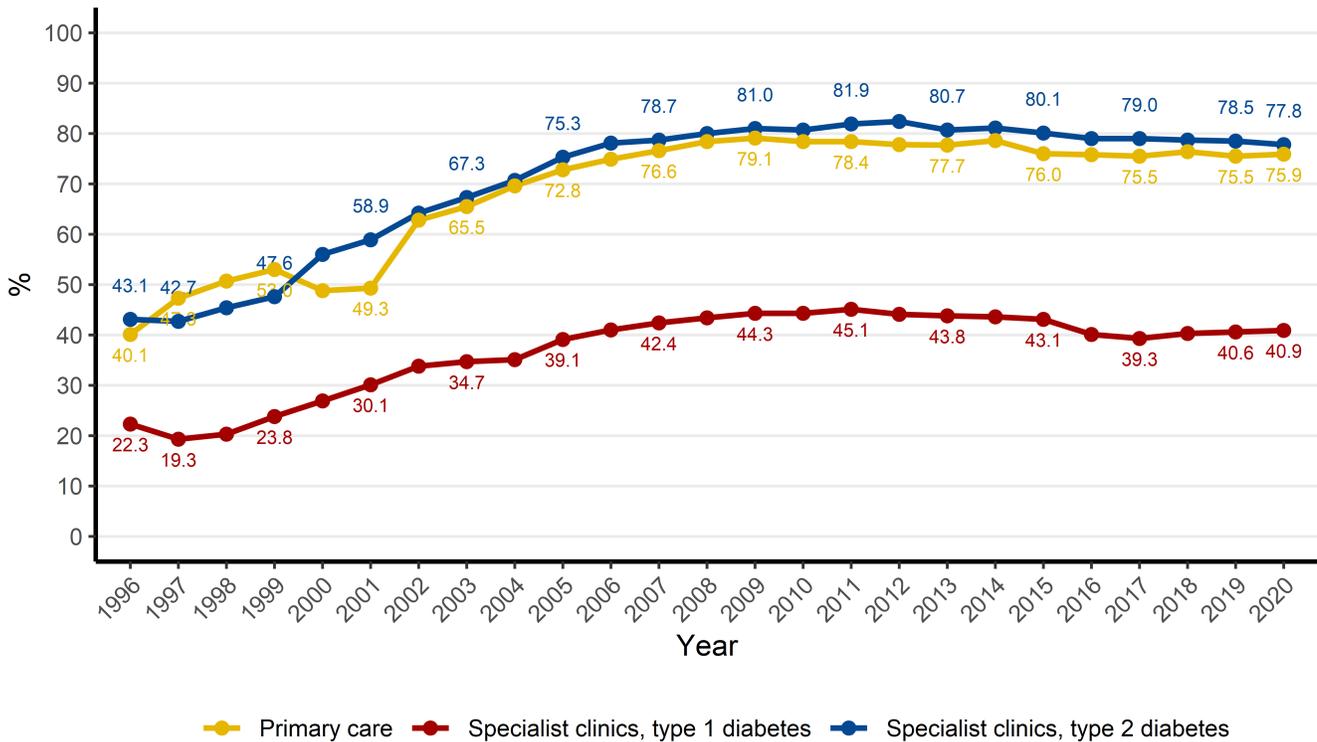


Figure 21. Proportions of patients with blood pressure <140/85 mmHg over time primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

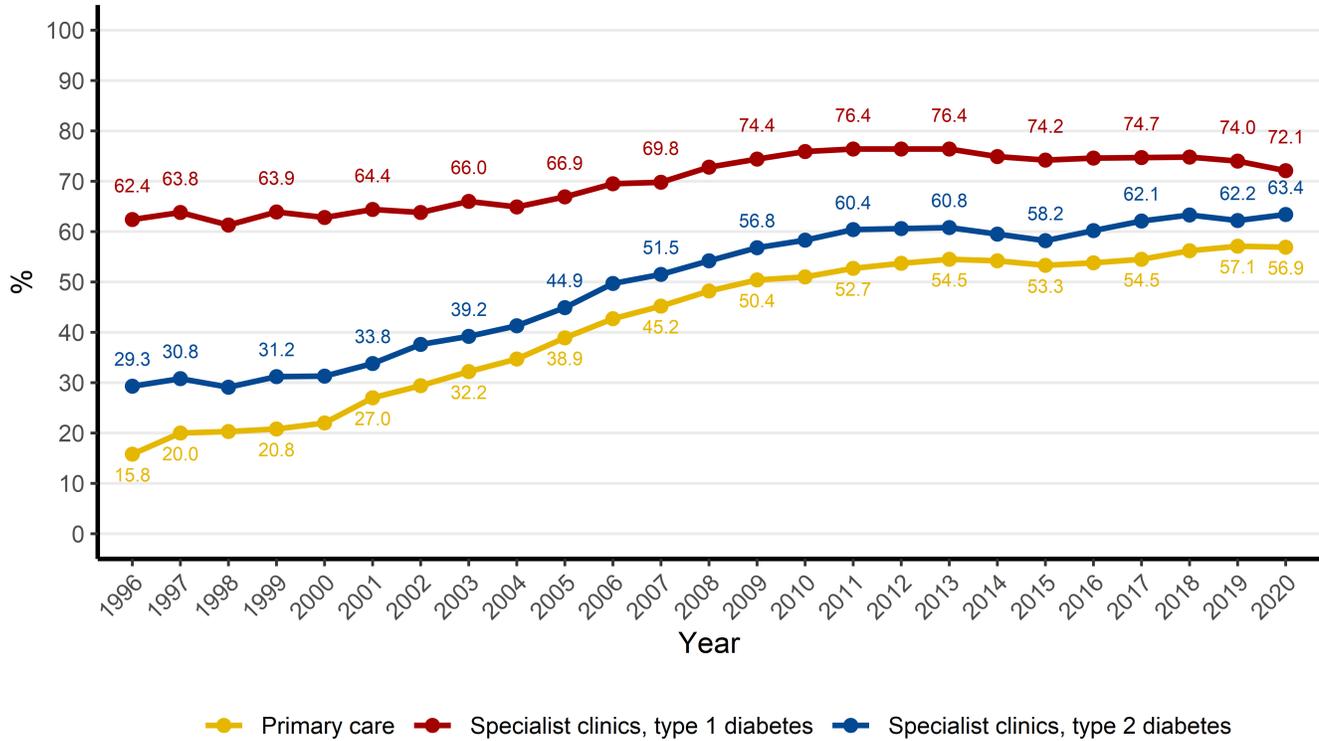
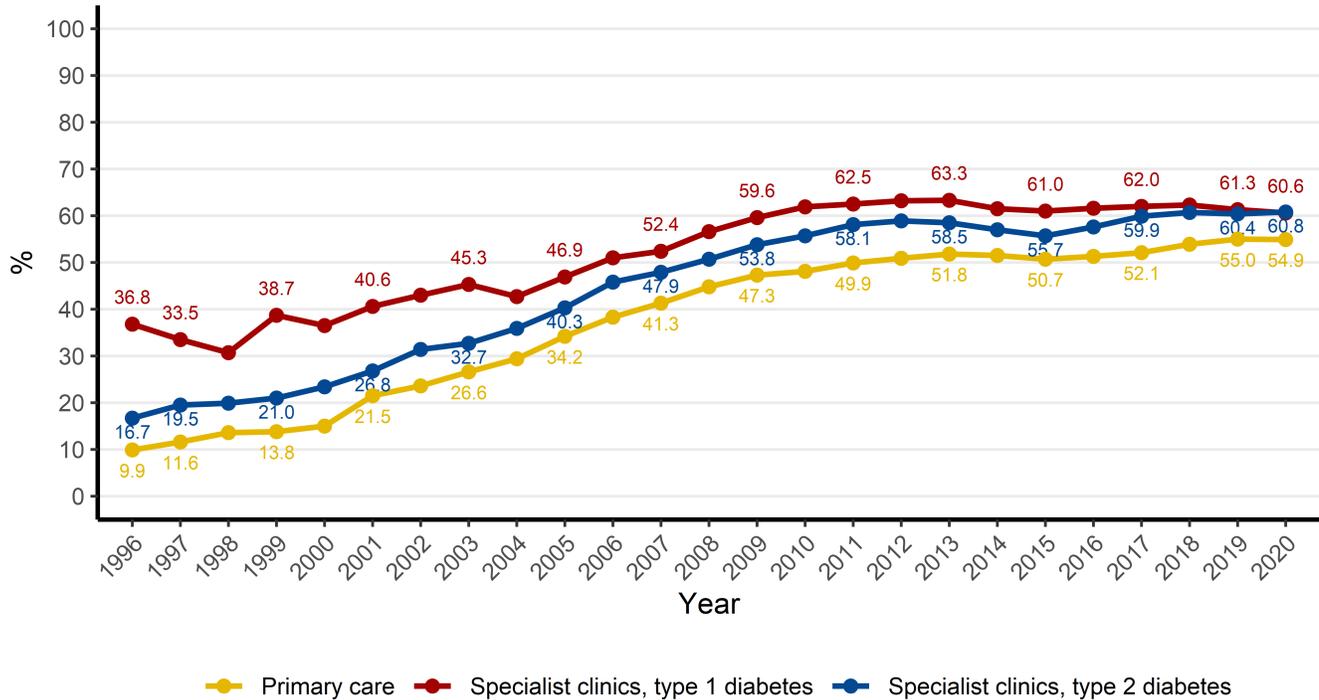


Figure 22. Proportions of patients with antihypertensive treatment and blood pressure < 140/85 mmHg over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.



Blood lipid levels and lipid-lowering treatment

The use of lipid-lowering medication (ATC codes) (yes/no) has been registered in the NDR since 1996, whereas the blood lipids levels have been registered since 2002.

Figure 23. Proportions of patients with LDL cholesterol < 2.5 mmol/L over time primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

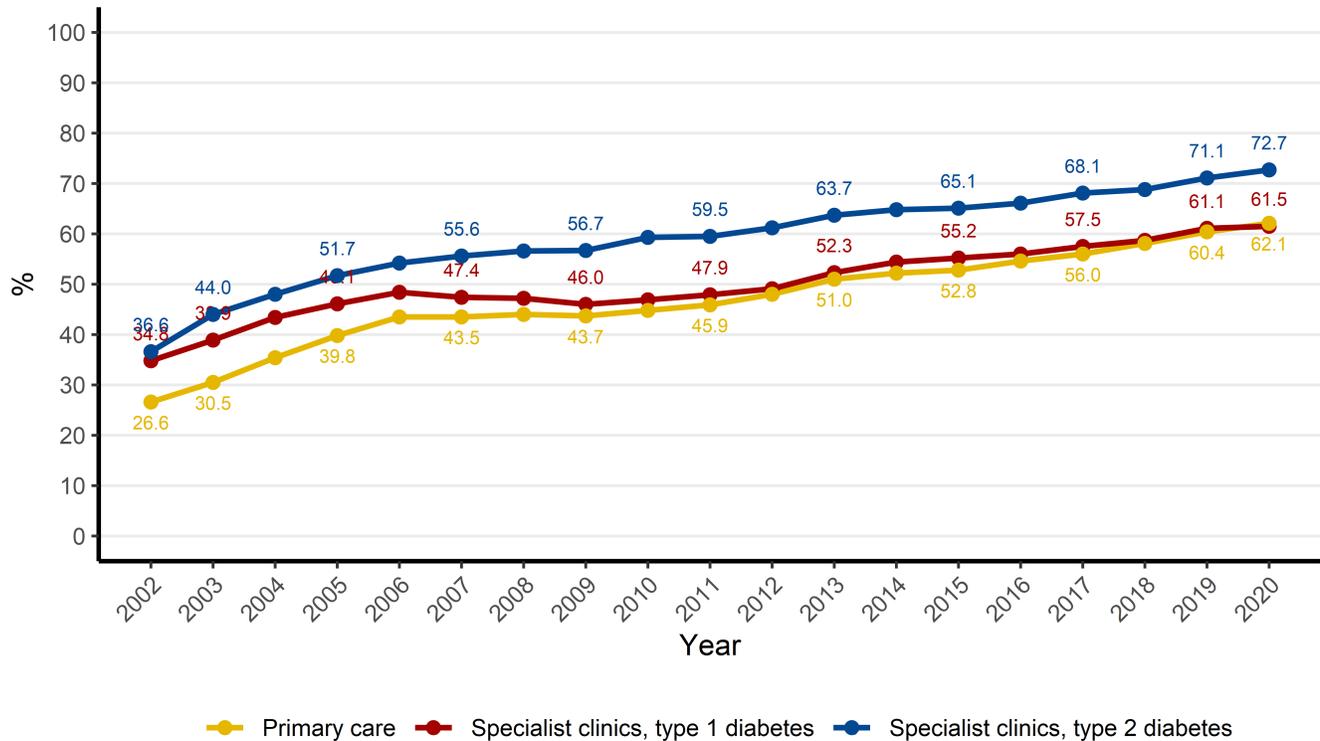


Figure 24. Proportions of patients with lipid-lowering medication over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

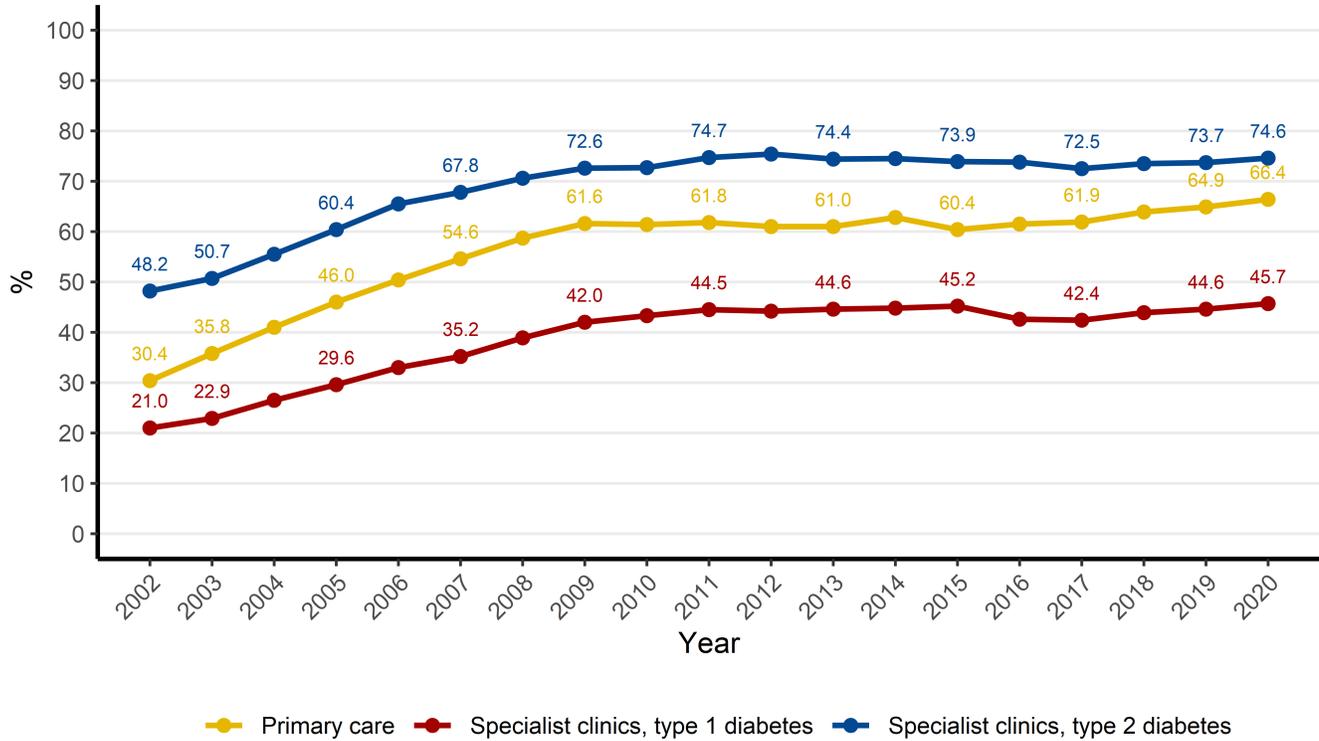
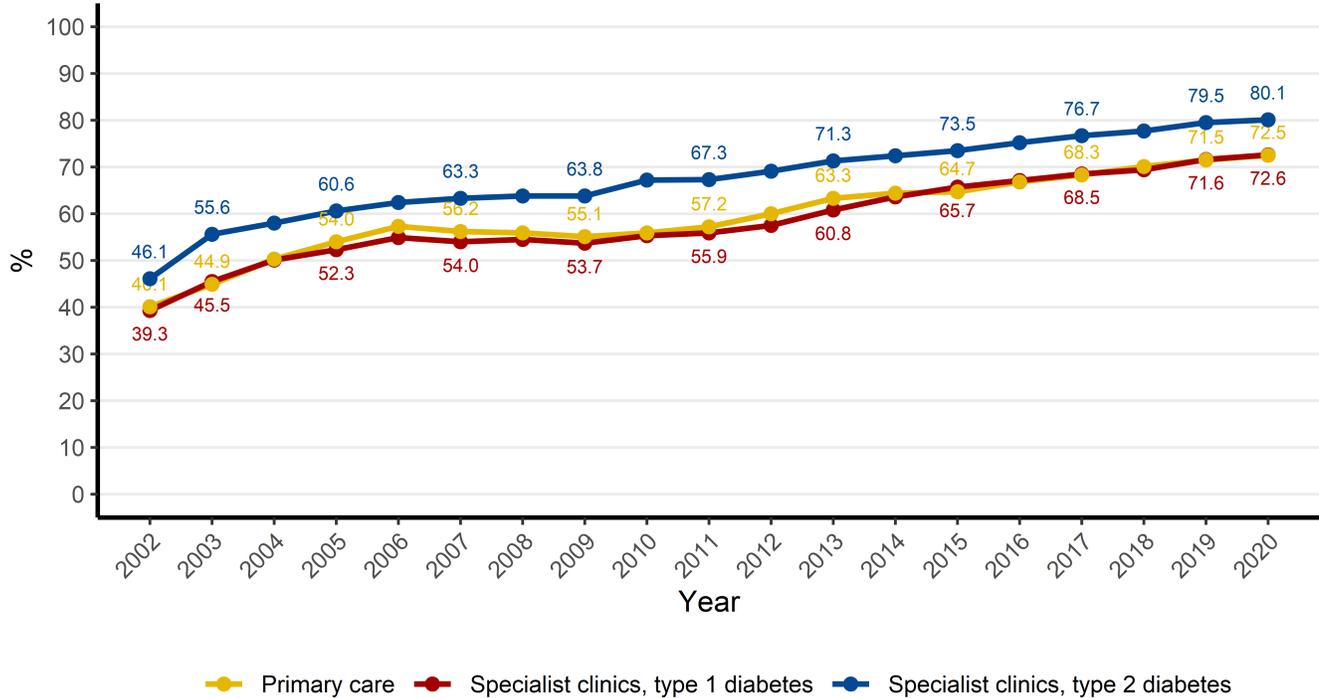


Figure 25. Proportions of patients treated with lipid-lowering medication and with LDL cholesterol < 2.5 mmol/L over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

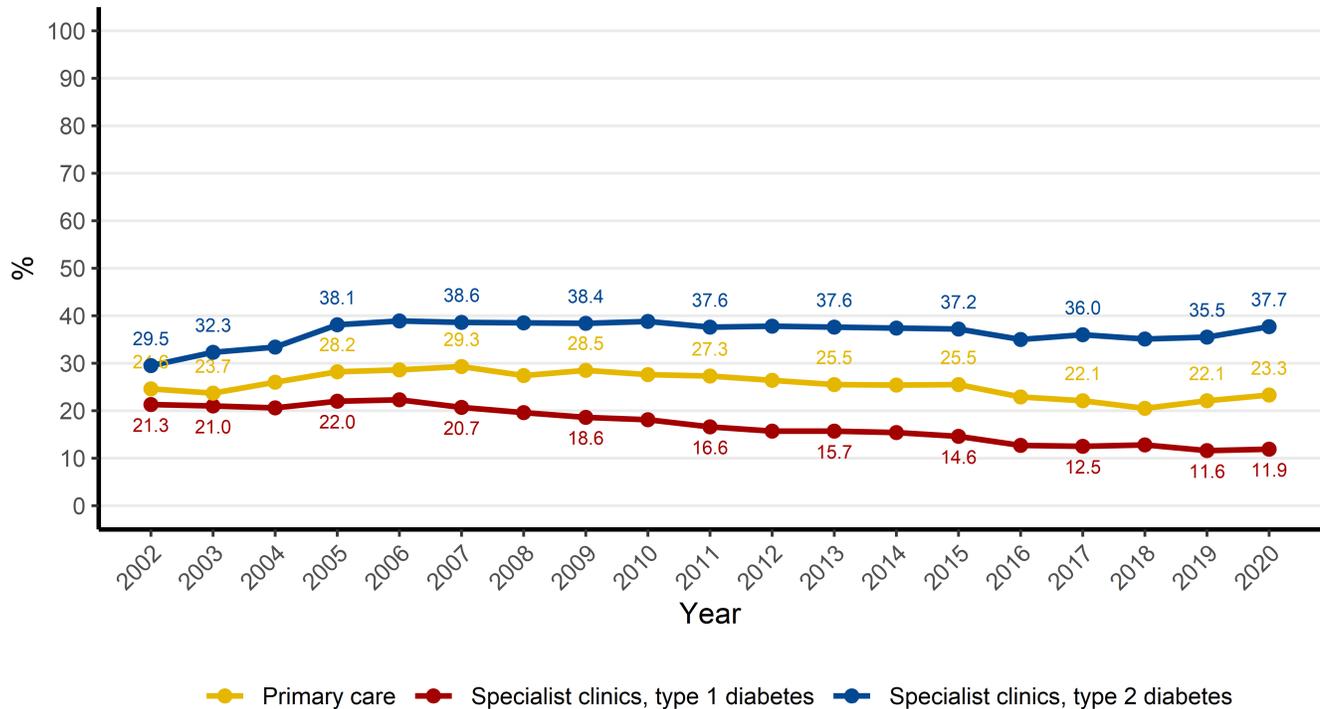


Process measures of diabetes complications

Albuminuria

The recommendation for detection of microalbuminuria is to screen annually. The clinical definition of microalbuminuria used in the NDR is two positive tests out of three samples taken within 1 year, with an albumin/creatinine ratio of 3-30 mg/mmol (30-300 mg/g) or urine albumin (U-albumin) measurement of 20-200 $\mu\text{g}/\text{min}$ (20-300 mg/L). Macroalbuminuria is defined as an albumin/creatinine ratio of more than 30 mg/mmol (>300 mg/g) or U-albumin >200 $\mu\text{g}/\text{min}$ (>300 mg/L).

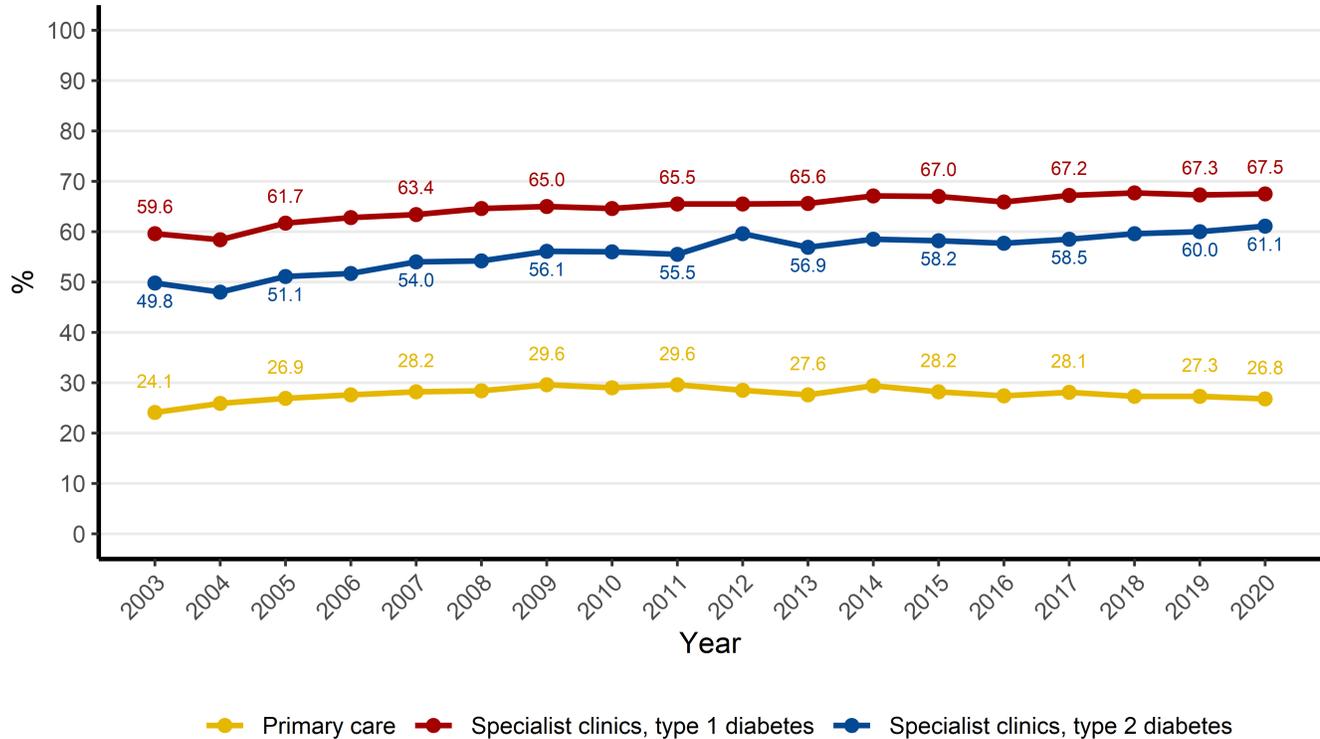
Figure 26. Proportions of patients with albuminuria (including both micro- and macroalbuminuria) in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.



Retinopathy

Retinopathy is defined as presence of either mild, moderate or severe non-proliferative retinopathy or proliferative retinopathy at the time. Presence of retinopathy has been reported to the NDR since 2003, initially according to ICD-10 codes, but since 2018 according to the international consensus on grading.

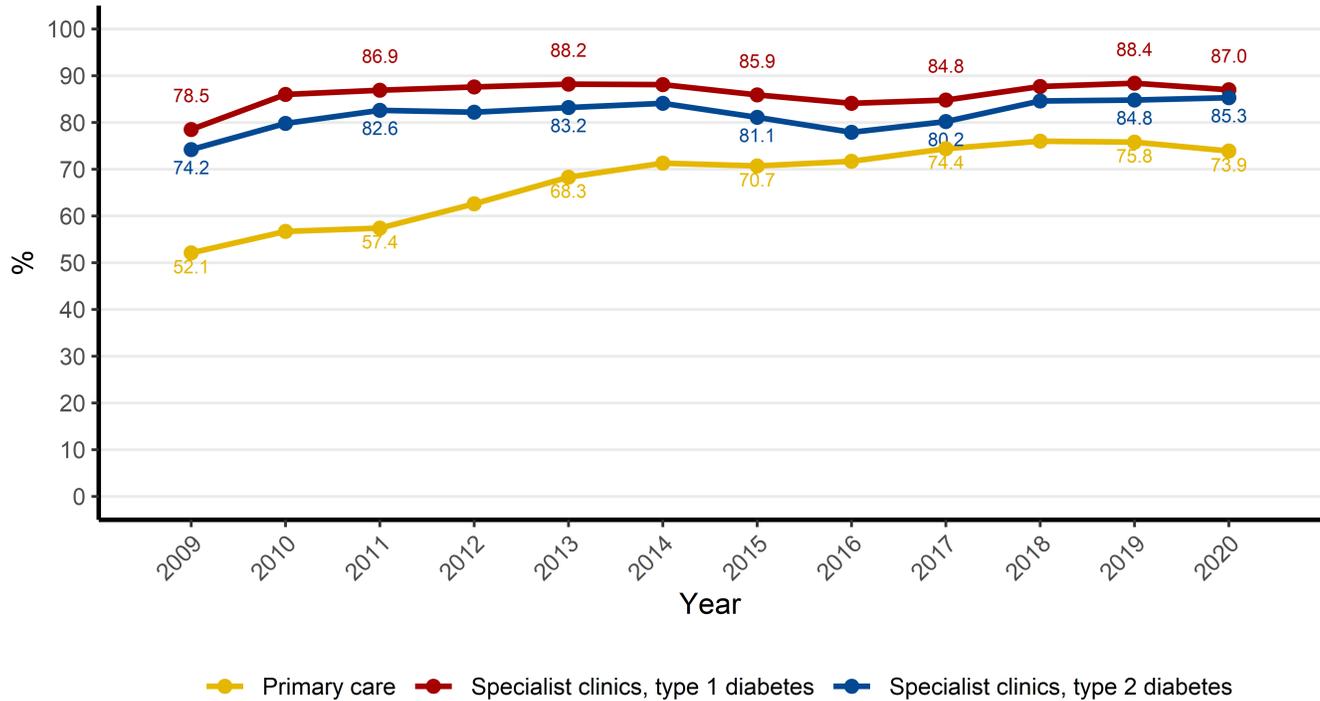
Figure 27. Proportions of patients with retinopathy over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.



Control of eye status

The Swedish national guidelines for diabetes care recommend an examination of eye status with a retinal scan (in patients without known retinopathy) every two years for patients with type 1 diabetes, and every three years for patients with type 2 diabetes. Patients with mild to moderate retinopathy are recommended examinations every year, and patients with more severe retinopathy more often based on individual conditions.

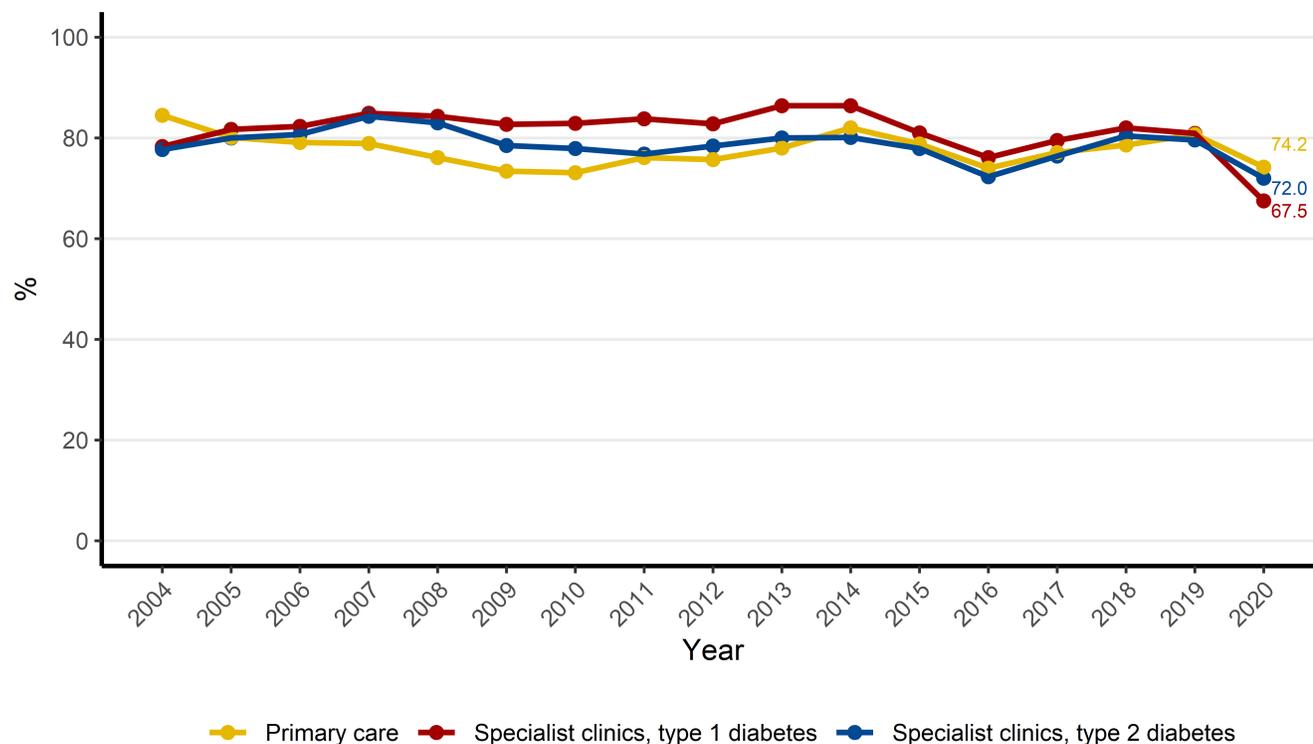
Figure 28. Proportions of patients with eye examination during the last 2 years among patients with type 1 diabetes at specialist clinics and the latest 3 years among patients with type 2 diabetes at specialist clinics and primary care



Control of foot status

Clinical examination of foot status regarding diabetes foot disease is recommended yearly and more often in patients with high risk of complications. Control of foot status during the last year is a (yes/no) question in the NDR. Below the figure is a table with the corresponding numbers of the proportions.

Figure 29. Proportions of patients with examination of foot status during the last year over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.



Proportions of patients with examination of foot status during the last year over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

Year	Primary care (%)	Specialist clinics, type 1 diabetes (%)	Specialist clinics, type 2 diabetes (%)
2004	84.5	78.3	77.7
2005	80.1	81.7	80.0
2006	79.1	82.3	80.7
2007	78.9	84.9	84.3
2008	76.1	84.3	83.0
2009	73.4	82.7	78.5
2010	73.1	82.9	77.9
2011	76.1	83.8	76.8
2012	75.7	82.8	78.4
2013	78.0	86.4	80.0
2014	82.0	86.4	80.1
2015	78.8	81.0	77.9
2016	74.0	76.1	72.3
2017	77.1	79.5	76.4
2018	78.6	82.0	80.4
2019	80.7	80.9	79.6
2020	74.2	67.5	72.0

Cover rate

Figure 30. HbA1c registered since 1996.



Figure 31. Systolic blood pressure registered since 1996.

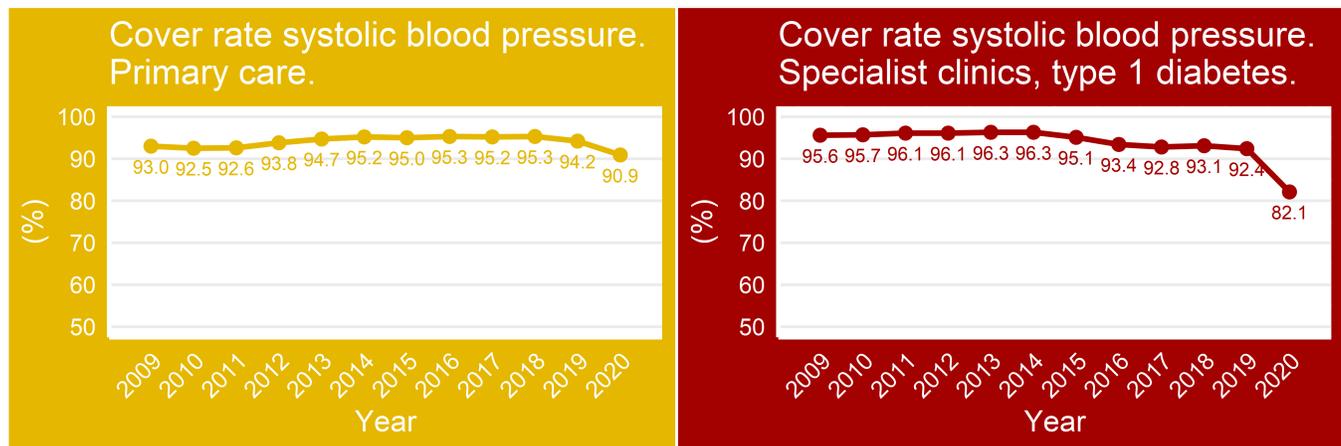


Figure 32. Antihypertensive drugs registered since 1996.

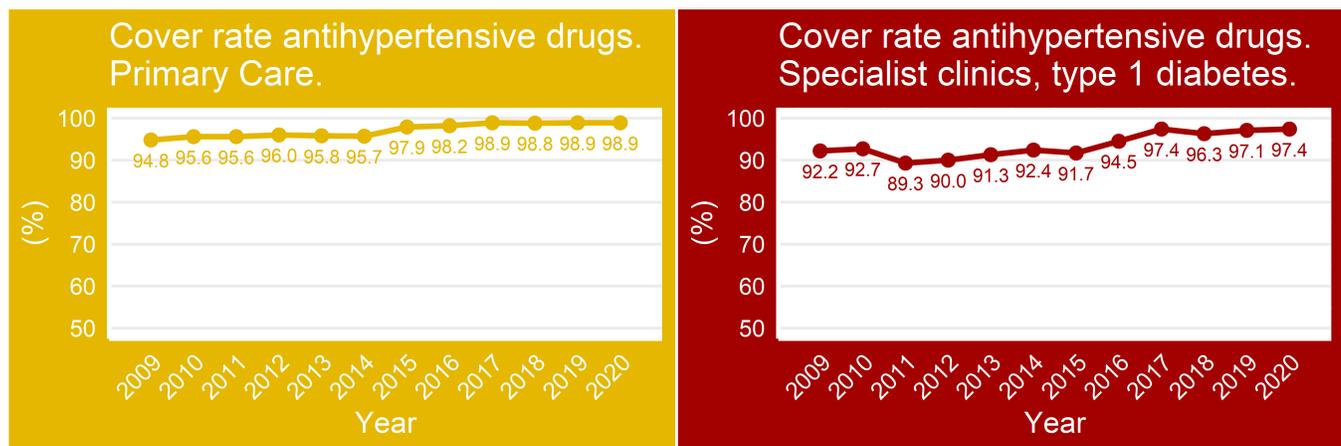


Figure 33. Cholesterol registered since 2002.



Figure 34. LDL-cholesterol registered since 2002.

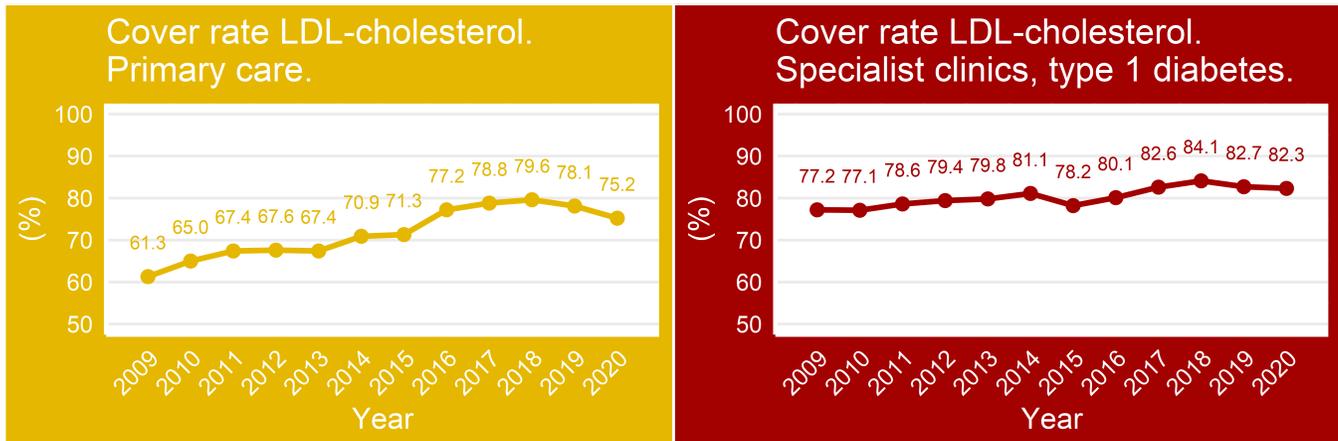


Figure 35. Lipid lowering drugs registered since 1996.

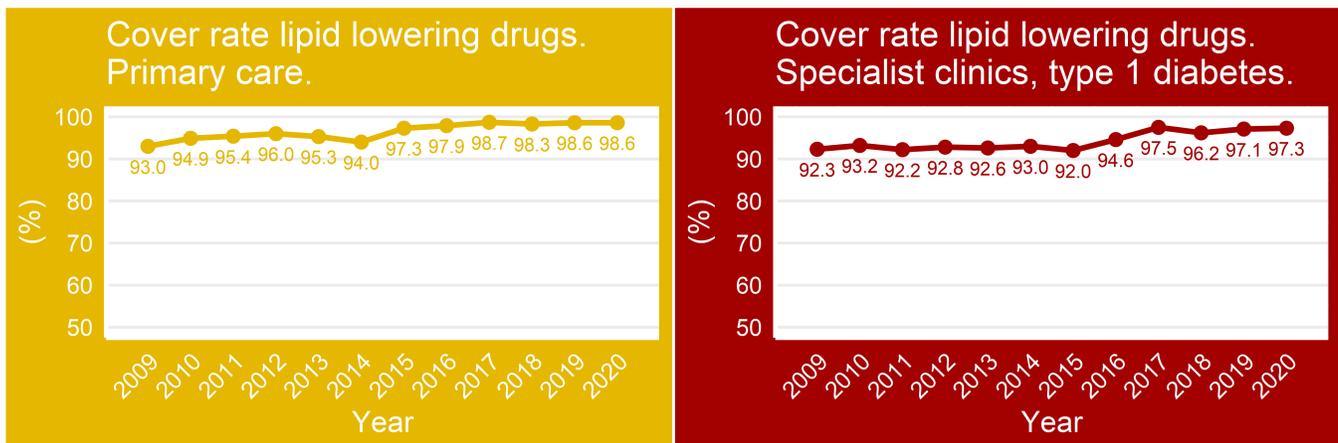


Figure 36. Albuminuria registered since 1996.

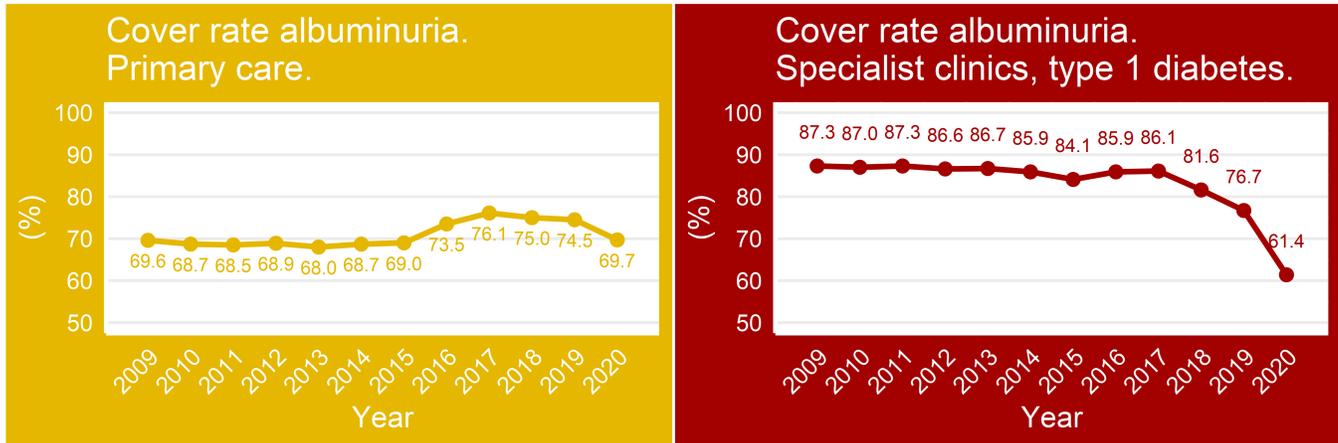


Figure 37. Diabetes treatment registered since 1996.

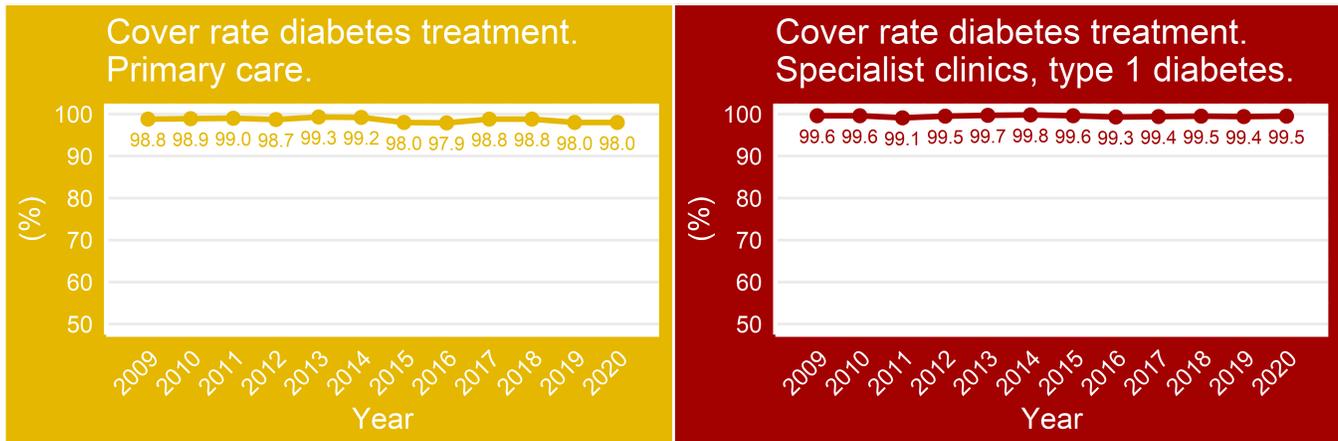


Figure 38. Physical leisure activity registered since 2007.

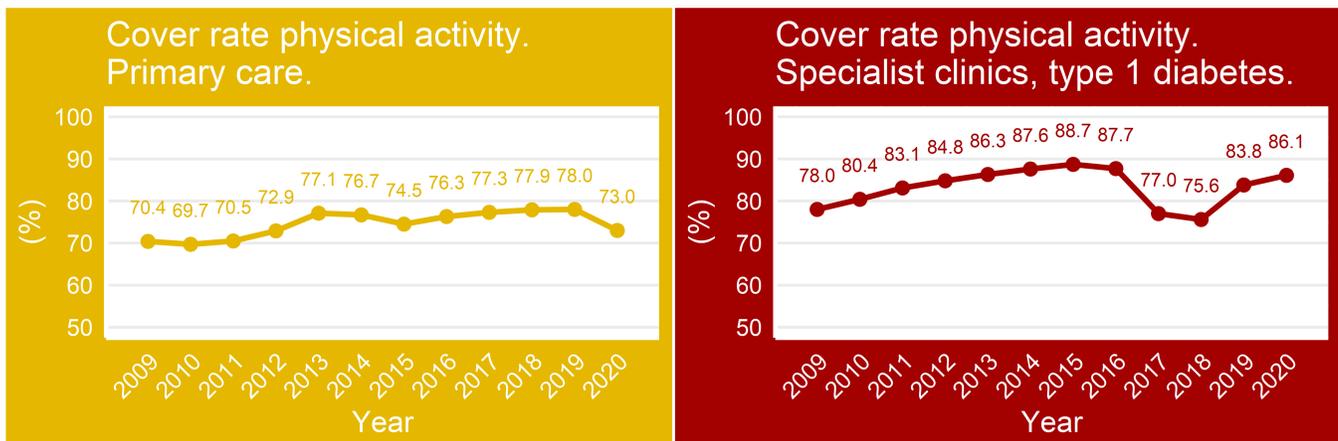


Figure 39. Retinopathy registered since 1996.

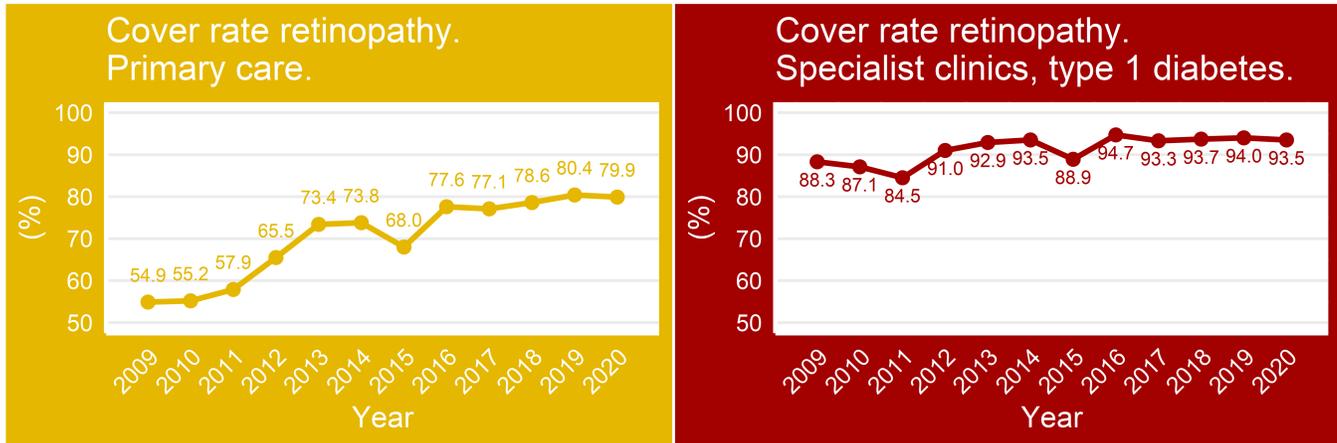


Figure 40. Foot Examination registered since 1996.

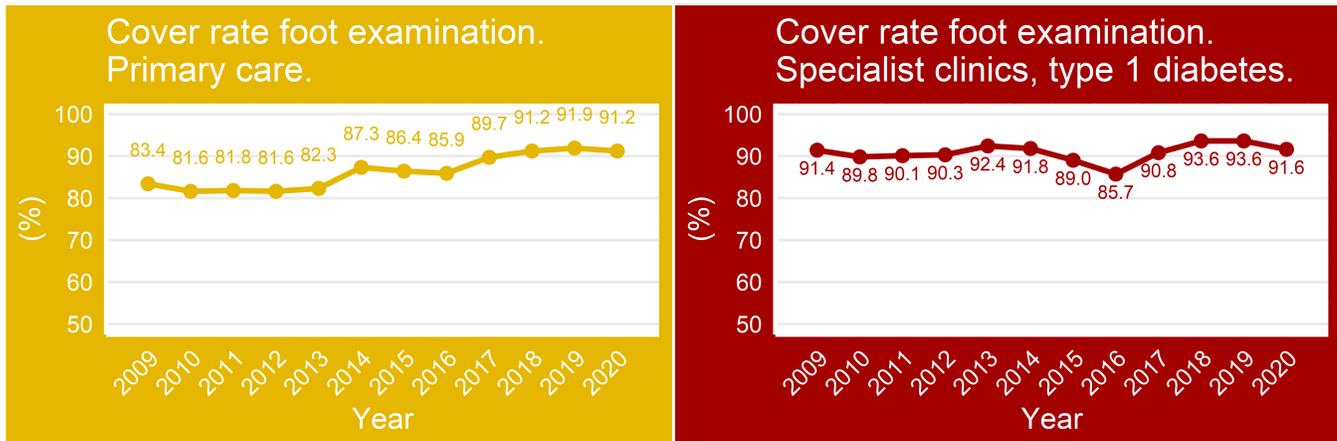


Figure 41. Foot risk registered since 1996.

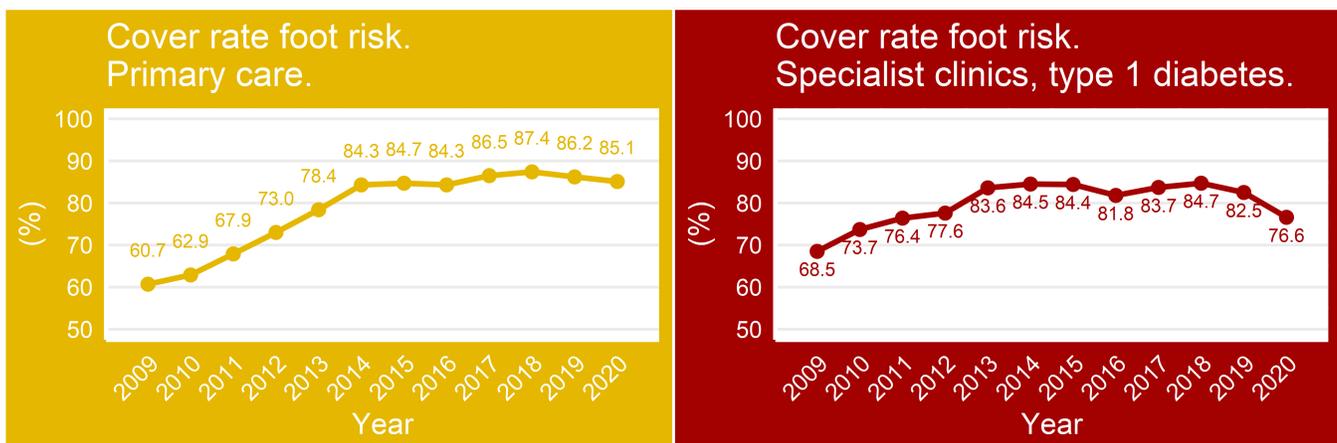


Figure 42. Smoking registered since 1996.

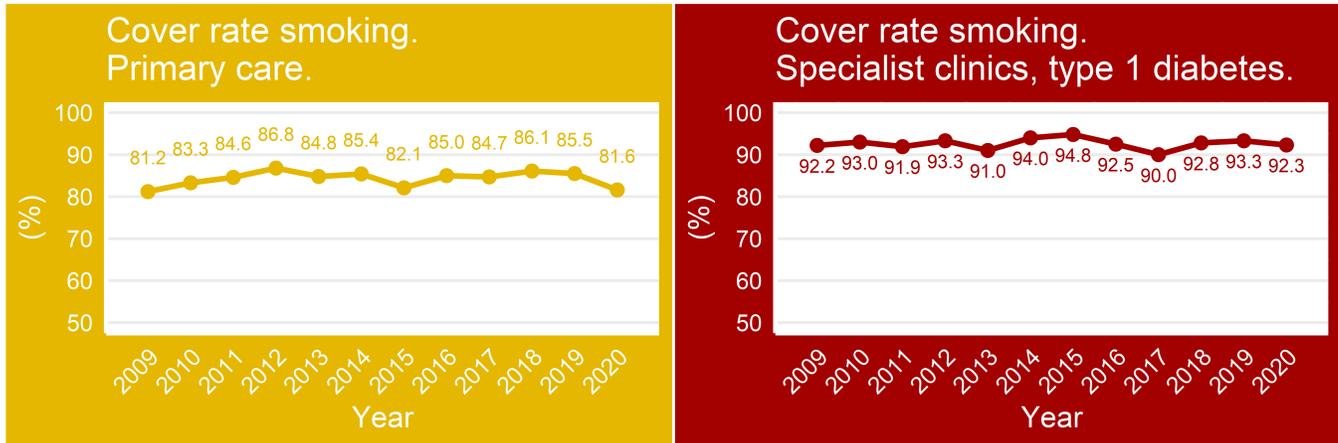


Figure 43. BMI registered since 1996.

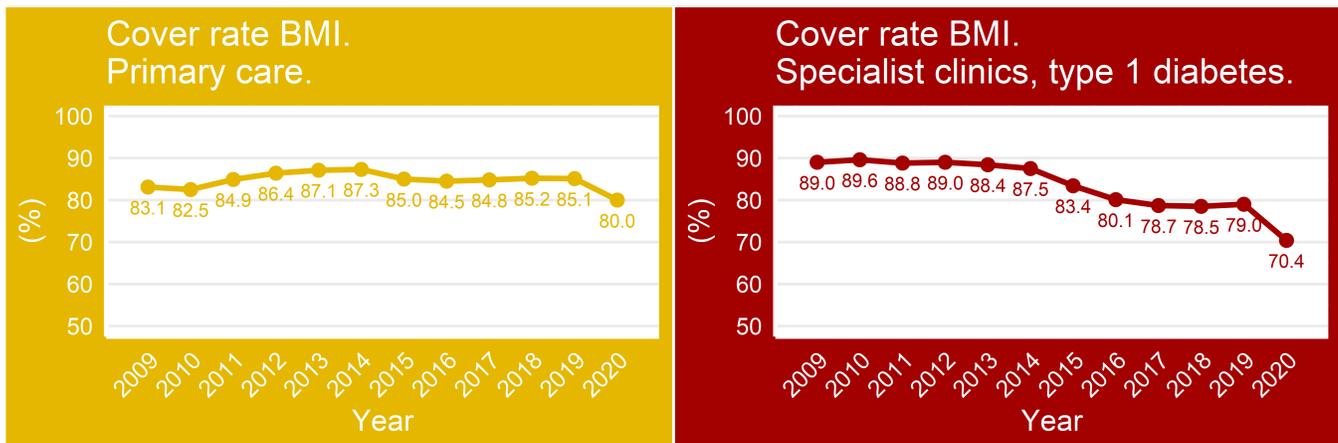
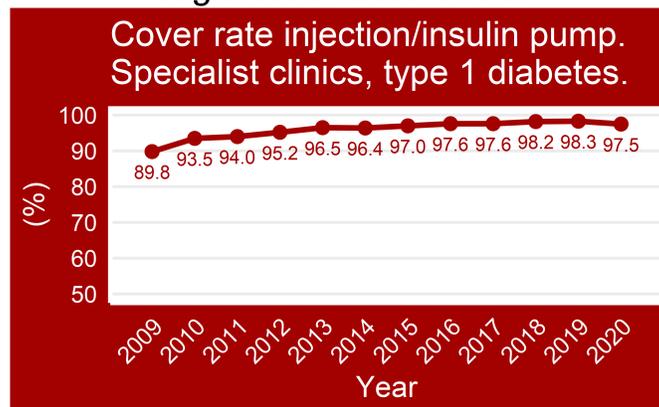


Figure 44. Method of insulin administration (injection/pump) registered since 1996.



Patient-reported outcome and experience measures (PROM and PREM)

To further improve and develop diabetes care it has long been a goal to add patient-reported outcome and experience measures (PROM and PREM) to the existing clinical variables in the NDR. A new diabetes-specific questionnaire has been developed and tested. Since 2017, 61

pilot units have started to use the digital version the Diabetes questionnaire in clinical practice. Structured and supported implementation in both primary care and in specialized clinics is ongoing, under continuous careful evaluation.

Scientific publications 2020

1. Hero C, Karlsson SA, Franzén S, Svensson A-M, Miftaraj M, Gudbjörnsdóttir S, m.fl. **Adherence to lipid-lowering therapy and risk for cardiovascular disease and death in type 1 diabetes mellitus: a population-based study from the Swedish National Diabetes Register.** *BMJ Open Diabetes Res Care.* januari 2020;8(1).
2. Taimour S, Franzén S, Zarrouk M, Acosta S, Nilsson P, Miftaraj M, m.fl. **Nationwide comparison of long-term survival and cardiovascular morbidity after acute aortic aneurysm repair in patients with and without type 2 diabetes.** *J Vasc Surg.* januari 2020;71(1):30-38.e3.
3. Sundbom M, Franzén S, Ottosson J, Svensson A-M. **Superior socioeconomic status in patients with type 2 diabetes having gastric bypass surgery: a case-control analysis of 10 642 individuals.** *BMJ Open Diabetes Res Care.* januari 2020;8(1).
4. Seyed Ahmadi S, Svensson A-M, Pivodic A, Rosengren A, Lind M. **Risk of atrial fibrillation in persons with type 2 diabetes and the excess risk in relation to glycaemic control and renal function: a Swedish cohort study.** *Cardiovasc Diabetol.* 18 januari 2020;19(1):9.
5. Zabala A, Darsalia V, Holzmann MJ, Franzén S, Svensson A-M, Eliasson B, m.fl. **Risk of first stroke in people with type 2 diabetes and its relation to glycaemic control: A nationwide observational study.** *Diabetes Obes Metab.* februari 2020;22(2):182–90.
6. Svensson A-M, Ekelund J, Miftaraj M, Eliasson B. **Efficacy and Safety of Treatment with New Basal Insulin Analogues in Type 1 Diabetes: Nation-Wide Survey.** *Diabetes Ther.* mars 2020;11(3):725–34.
7. Zimmerman M, Anker I, Karlsson A, Arner M, Svensson A-M, Eeg-Olofsson K, m.fl. **Ulnar Nerve Entrapment in Diabetes: Patient-reported Outcome after Surgery in National Quality Registries.** *Plast Reconstr Surg Glob Open.* april 2020;8(4):e2740.
8. Skov J, Eriksson D, Kuja-Halkola R, Höijer J, Gudbjörnsdóttir S, Svensson A-M, m.fl. **Co-aggregation and heritability of organ-specific autoimmunity: a population-based twin study.** *Eur J Endocrinol.* maj 2020;182(5):473–80.
9. Liakopoulos V, Franzén S, Svensson A-M, Sattar N, Miftaraj M, Björck S, m.fl. **Renal and Cardiovascular Outcomes After Weight Loss From Gastric Bypass Surgery in Type 2 Diabetes: Cardiorenal Risk Reductions Exceed Atherosclerotic Benefits.** *Diabetes Care.* juni 2020;43(6):1276–84.
10. Pasternak B, Wintzell V, Eliasson B, Svensson A-M, Franzén S, Gudbjörnsdóttir S, m.fl. **Use of Glucagon-Like Peptide 1 Receptor Agonists and Risk of Serious Renal Events: Scandinavian Cohort Study.** *Diabetes Care.* juni 2020;43(6):1326–35.
11. Eliasson B, Ekelund J, Miftaraj M, Ranthe MF, Mårdby A-C, Da Rocha Fernandes JD, m.fl. **Persistence with IDegLira in Patients in Clinical Practice: A Nationwide Observational Study in Sweden.** *Diabetes Ther.* augusti 2020;11(8):1807–20.
12. Tran-Duy A, Knight J, Palmer AJ, Petrie D, Lung TWC, Herman WH, m.fl. **A Patient-Level Model to Estimate Lifetime Health Outcomes of Patients With Type 1 Diabetes.** *Diabetes Care.* augusti 2020;43(8):1741–9.
13. Eeg-Olofsson K, Johansson UB, Linder E, Leksell J. **Patients' and Health Care Professionals' Perceptions of the Potential of Using the Digital Diabetes Questionnaire to Prepare for Diabetes Care Meetings: Qualitative Focus Group Interview Study.** *J Med Internet Res.* 2020 Aug 19;22(8):e17504.
14. Husdal R, Thors Adolffson E, Leksell J, Eliasson B, Jansson S, Jerdén L, m.fl. **Organisation of primary diabetes care in people with type 2 diabetes in relation to all-cause mortality: A nationwide register-based cohort study.** *Diabetes Res Clin Pract.* september 2020;167:108352.

15. Bjornsdottir HH, Rawshani A, Rawshani A, Franzén S, Svensson A-M, Sattar N, m.fl. **A national observation study of cancer incidence and mortality risks in type 2 diabetes compared to the background population over time.** *Sci Rep.* 15 oktober 2020;10(1):17376.
16. Rautio E, Gadler F, Gudbjörnsdottir S, Franzén S, Rydén L, Svensson A-M, m.fl. **Patients With Type 2 Diabetes Have an Increased Demand for Pacemaker Treatment: A Comparison With Age- and Sex-Matched Control Subjects From the General Population.** *Diabetes Care.* november 2020;43(11):2853–8.
17. Rathsman B, Haas J, Persson M, Ludvigsson J, Svensson A-M, Lind M, m.fl. **LDL cholesterol level as a risk factor for retinopathy and nephropathy in children and adults with type 1 diabetes mellitus: A nationwide cohort study.** *J Intern Med.* 29 november 2020.
18. Svedbo Engström M, Leksell J, Johansson U-B, Borg S, Palaszewski B, Franzén S, m.fl. **New Diabetes Questionnaire to add patients' perspectives to diabetes care for adults with type 1 and type 2 diabetes: nationwide cross-sectional study of construct validity assessing associations with generic health-related quality of life and clinical variables.** *BMJ Open.* 17 november 2020;10(11):e038966.
19. Dakhel A, Zarrouk M, Ekelund J, Acosta S, Nilsson P, Miftaraj M, m.fl. **Worse cardiovascular prognosis after endovascular surgery for intermittent claudication caused by infrainguinal atherosclerotic disease in patients with diabetes.** *Ther Adv Endocrinol Metab.* 2020;11:2042018820960294.
20. Dakhel A, Zarrouk M, Ekelund J, Acosta S, Miftaraj M, Eliasson B, m.fl. **Higher long-term cardiovascular morbidity after open surgery for intermittent claudication caused by infrainguinal atherosclerotic disease in patients with diabetes - a nationwide observational cohort study.** *Vasa.* 18 december 2020;1–7.
21. Höskuldsdóttir G, Ekelund J, Miftaraj M, Wallenius V, Ottosson J, Näslund I, m.fl. **Potential Benefits and Harms of Gastric Bypass Surgery in Obese Individuals With Type 1 Diabetes: A Nationwide, Matched, Observational Cohort Study.** *Diabetes Care.* december 2020;43(12):3079–85.

NDR: the flagship register for Swedish diabetes care

- Enters an average of *1,400 patients daily* as reported by thousands of healthcare providers.
- Offers a clinical tool for risk assessment, monitoring and comparison.
- Promotes improvement through measurement.
- Encourages clinical research with a focus on patient benefit.



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