Nationwide results 1996 – 2019

NDR NATIONELLA DIABETESREGISTRET
SWEDISH NATIONAL DIABETES REGISTER

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This report can be downloaded digitally on NDR's website:
https://www.ndr.nu/pdfs/NationWideResults_1996-2019.pdf

Contents

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 − 2019

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 97% 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 90 specialist clinics, as well as the majority of primary care clinics (in all, 1268 units 2019). Hence, 100% of specialist clinics and 95% 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 socioeconomic 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 2019, 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 small increase in the number of patients reported each year, and in 2019 more than 440 000 patients with diabetes were reported to the NDR.

Figure 1. Number of patients reported to the NDR each year from 1996 to 2019.
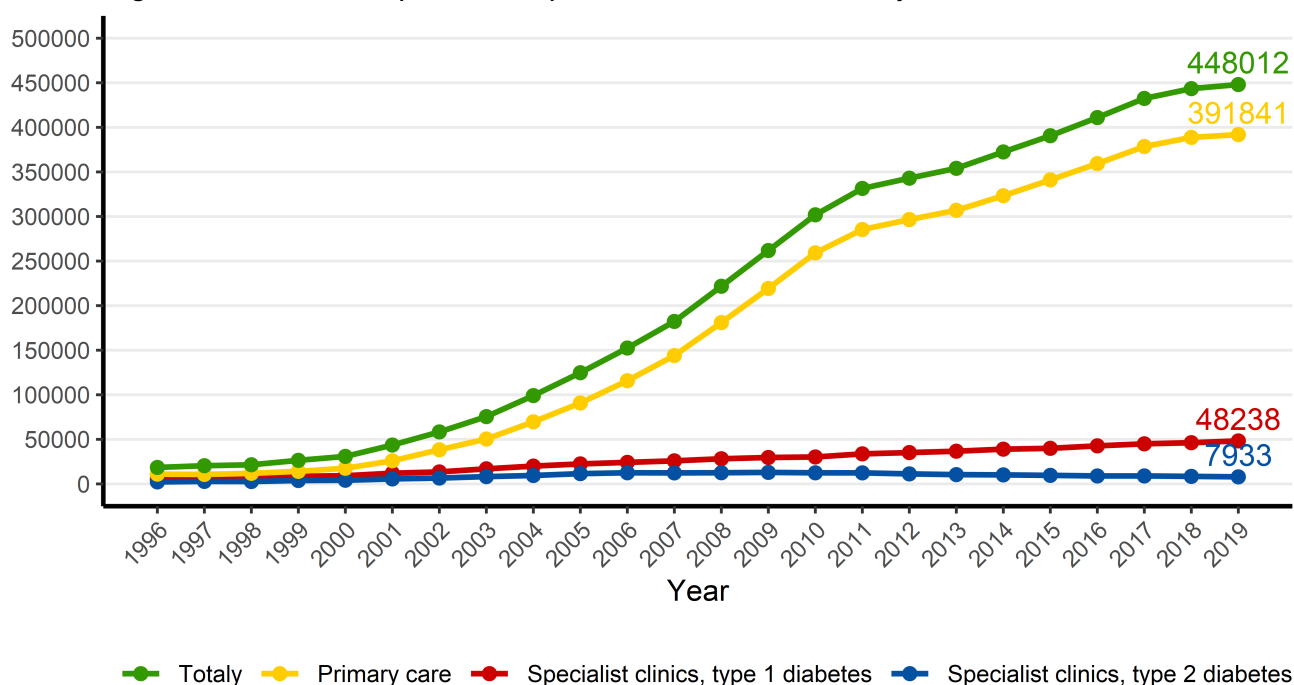
Coverage of the NDR

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 in both the NDR, 50-80 years of age, alive by Dec 31 2018 and with a registration in the NDR during the past 18 months and with a filled prescription of any glucose lowering drug (ACT code A10) in the SPDR were compared to all patients in the SPDR with a filled prescription of any glucose lowering drug. The coverage for the NDR in 2019 was 88%.

Clinical characteristics of patients in primary care (type 2 diabetes) and in patients with type 1 diabetes and in type 2 diabetes in specialist clinics

Tables 1, 2 and 3 describe 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. The fact that specialist clinics report decreasing numbers of patients with of type 2 diabetes, 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 2019, type of diabetes was reported in all patients, and the year of onset of diabetes was reported for more than 95% in all patients. The figures 2-4 show the distributions of age in the different populations in 2019.

Table1. Patients with diabetes in primary care.

Year	Number	Mean age years (SD)	Mean duration years (SD)	Men (%)
1996	10935	68.3 (12.1)	9.3 (8.1)	5671 (51.9)
1997	10649	67.3 (13.1)	9.9 (8.8)	5483 (51.5)
1998	11870	68.3 (12.2)	9.4 (8.1)	6106 (51.4)
1999	14110	68.5 (12.0)	9.1 (7.9)	7499 (53.1)
2000	17554	68.3 (12.3)	9.1 (8.3)	9127 (52.0)
2001	25962	68.0 (12.3)	8.8 (8.2)	13534 (52.1)
2002	38306	68.1 (12.1)	9.0 (8.5)	20394 (53.2)
2003	50382	67.6 (12.0)	8.7 (8.2)	27160 (53.9)
2004	69626	67.6 (11.8)	8.5 (7.8)	37547 (53.9)
2005	90777	67.5 (11.8)	8.6 (7.9)	49067 (54.1)
2006	115783	67.6 (11.7)	8.7 (7.8)	63253 (54.6)
2007	144021	67.4 (11.8)	8.7 (7.8)	79177 (55.0)
2008	180965	67.4 (11.8)	8.7 (7.9)	99819 (55.2)
2009	219255	67.4 (11.9)	8.8 (7.9)	121454 (55.4)
2010	259211	67.5 (12.1)	8.9 (8.1)	143760 (55.5)
2011	285388	67.7 (12.1)	9.0 (8.1)	159252 (55.8)
2012	296564	67.8 (12.0)	9.2 (8.2)	166698 (56.2)
2013	306935	67.9 (12.0)	9.4 (8.2)	174034 (56.7)
2014	323285	68.1 (11.9)	9.5 (8.2)	184241 (57.0)
2015	341060	68.2 (11.9)	9.6 (8.2)	195472 (57.3)
2016	359334	68.3 (12.0)	9.7 (8.2)	206799 (57.6)
2017	378521	68.4 (12.0)	9.8 (8.3)	218341 (57.7)
2018	388731	68.5 (12.1)	10.0 (8.3)	224896 (57.9)
2019	391841	68.6 (12.1)	10.1 (8.3)	227418 (58.0)

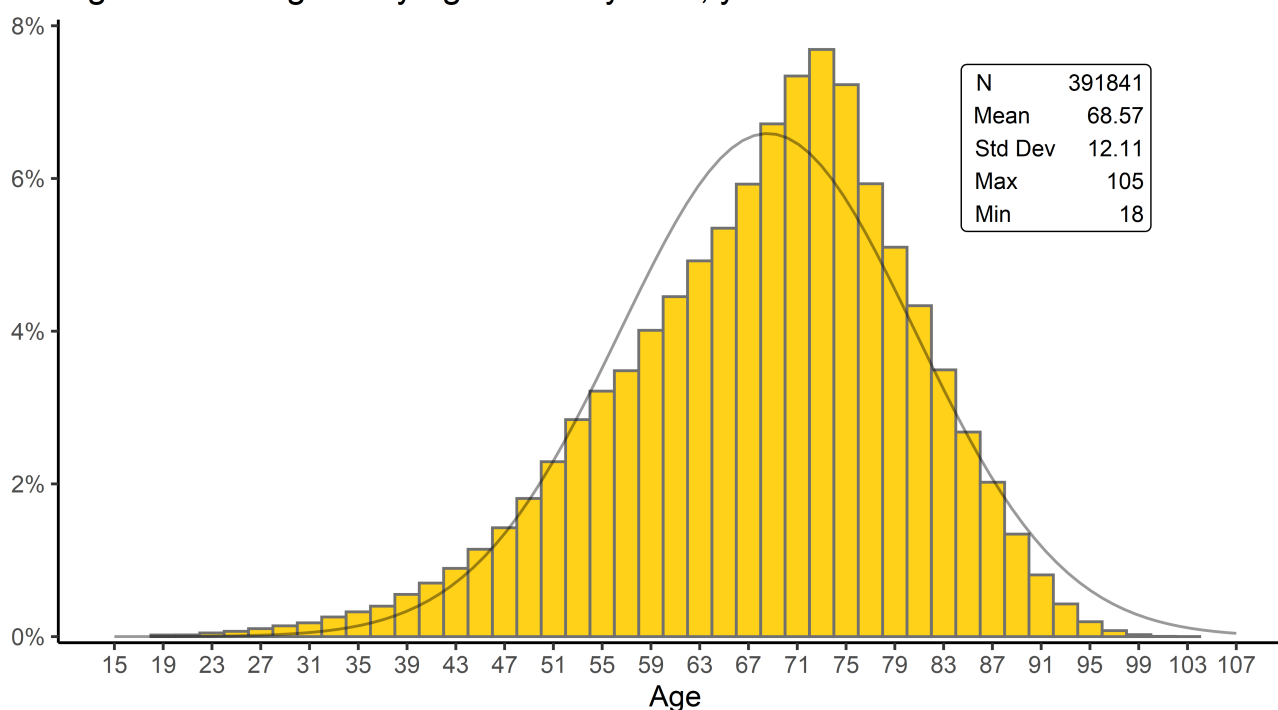Figure 2. Histogram by age. Primary care, year 2019.

N	391841
Mean	68.57
Std Dev	12.11
Max	105
Min	18

The Swedish National Diabetes Register (NDR) - Nationwide results 1996-2019

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

Year	Number	Mean age years (SD)	Mean duration years (SD)	Men (%)
1996	5316	41.7 (13.2)	20.2 (12.3)	2933 (55.2)
1997	6932	41.1 (13.2)	20.1 (12.5)	3780 (54.5)
1998	6899	41.6 (13.3)	20.2 (12.6)	3755 (54.4)
1999	8536	42.4 (13.4)	21.2 (12.8)	4673 (54.7)
2000	9192	42.9 (13.5)	21.2 (12.9)	5122 (55.7)
2001	12021	43.4 (13.9)	21.5 (13.3)	6677 (55.5)
2002	13461	44.0 (14.1)	21.8 (13.5)	7519 (55.9)
2003	16928	44.3 (14.4)	22.1 (13.7)	9352 (55.2)
2004	19993	44.7 (14.6)	22.2 (13.9)	11148 (55.8)
2005	22443	45.2 (14.8)	22.7 (14.2)	12402 (55.3)
2006	24169	45.4 (15.1)	22.9 (14.3)	13345 (55.2)
2007	25873	45.5 (15.3)	23.1 (14.5)	14348 (55.5)
2008	28232	45.5 (15.4)	23.1 (14.5)	15664 (55.5)
2009	29641	45.6 (15.7)	23.1 (14.7)	16445 (55.5)
2010	30232	45.5 (16.0)	23.1 (14.8)	16821 (55.6)
2011	33719	45.4 (16.3)	23.1 (14.9)	18970 (56.3)
2012	35170	45.4 (16.5)	23.2 (15.0)	19725 (56.1)
2013	36686	45.6 (16.7)	23.4 (15.1)	20525 (55.9)
2014	38993	45.9 (16.8)	23.6 (15.2)	21774 (55.8)
2015	39926	46.2 (16.9)	23.8 (15.3)	22234 (55.7)
2016	42701	46.4 (17.1)	24.0 (15.4)	23633 (55.3)
2017	44977	46.7 (17.2)	23.7 (15.7)	25039 (55.7)
2018	46249	47.0 (17.4)	23.7 (15.8)	25748 (55.7)
2019	48238	47.5 (17.6)	24.5 (15.7)	26909 (55.8)

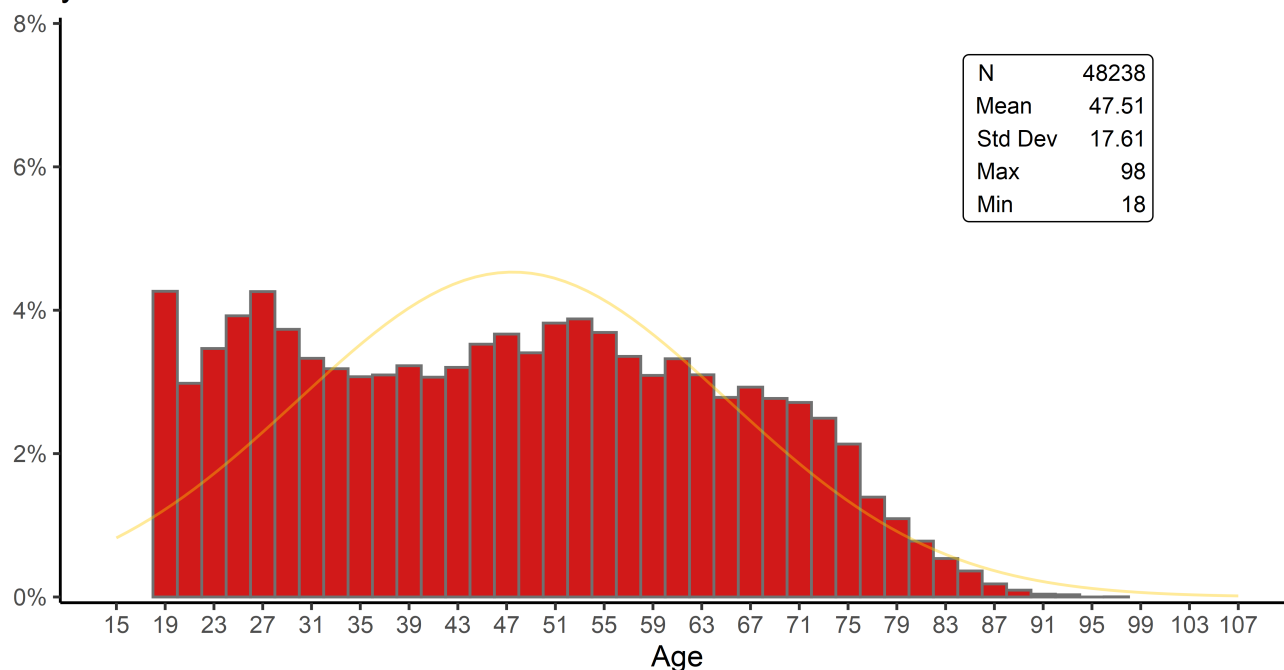Figur 3. Histogram by age. Patients with typ 1 diabetes at specialist clinics, year 2019.

N	48238
Mean	47.51
Std Dev	17.61
Max	98
Min	18

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

Year	Number	Mean age years (SD)	Mean duration years (SD)	Men (%)
1996	2242	56.8 (11.3)	11.2 (8.4)	1356 (60.5)
1997	2849	57.3 (11.1)	11.3 (8.1)	1754 (61.6)
1998	2710	57.2 (11.1)	11.5 (8.3)	1619 (59.7)
1999	3815	57.8 (11.3)	11.7 (8.7)	2355 (61.7)
2000	4140	58.4 (11.3)	11.9 (8.7)	2573 (62.1)
2001	5627	58.7 (11.7)	11.9 (8.9)	3551 (63.1)
2002	6571	59.3 (11.8)	12.1 (9.0)	4158 (63.3)
2003	8193	59.9 (11.9)	12.5 (9.1)	5233 (63.9)
2004	9460	60.4 (12.0)	12.8 (9.1)	6085 (64.3)
2005	11532	61.3 (12.3)	13.0 (9.3)	7376 (64.0)
2006	12497	61.7 (12.2)	13.2 (9.4)	8058 (64.5)
2007	12367	62.1 (12.3)	13.6 (9.6)	7932 (64.1)
2008	12531	62.0 (12.5)	13.8 (9.7)	8024 (64.0)
2009	12912	62.2 (12.5)	13.8 (9.7)	8310 (64.4)
2010	12442	62.5 (12.4)	13.9 (9.7)	8071 (64.9)
2011	12390	62.3 (12.6)	14.3 (9.9)	7961 (64.3)
2012	11244	62.4 (12.7)	14.9 (10.0)	7285 (64.8)
2013	10421	62.3 (12.9)	15.1 (10.0)	6690 (64.2)
2014	10136	62.7 (13.0)	15.5 (10.0)	6498 (64.1)
2015	9599	63.0 (13.2)	16.0 (10.1)	6186 (64.4)
2016	8931	62.7 (13.5)	16.4 (10.4)	5763 (64.5)
2017	8949	62.9 (13.6)	16.6 (10.4)	5701 (63.7)
2018	8458	63.0 (13.7)	16.9 (10.3)	5416 (64.0)
2019	7933	63.0 (13.8)	17.3 (10.3)	5087 (64.1)

Figure 4. Histogram by age. Patients with typ 2 diabetes at specialist clinics, year 2019.

N	7933
Mean	62.98
Std Dev	13.81
Max	97
Min	18
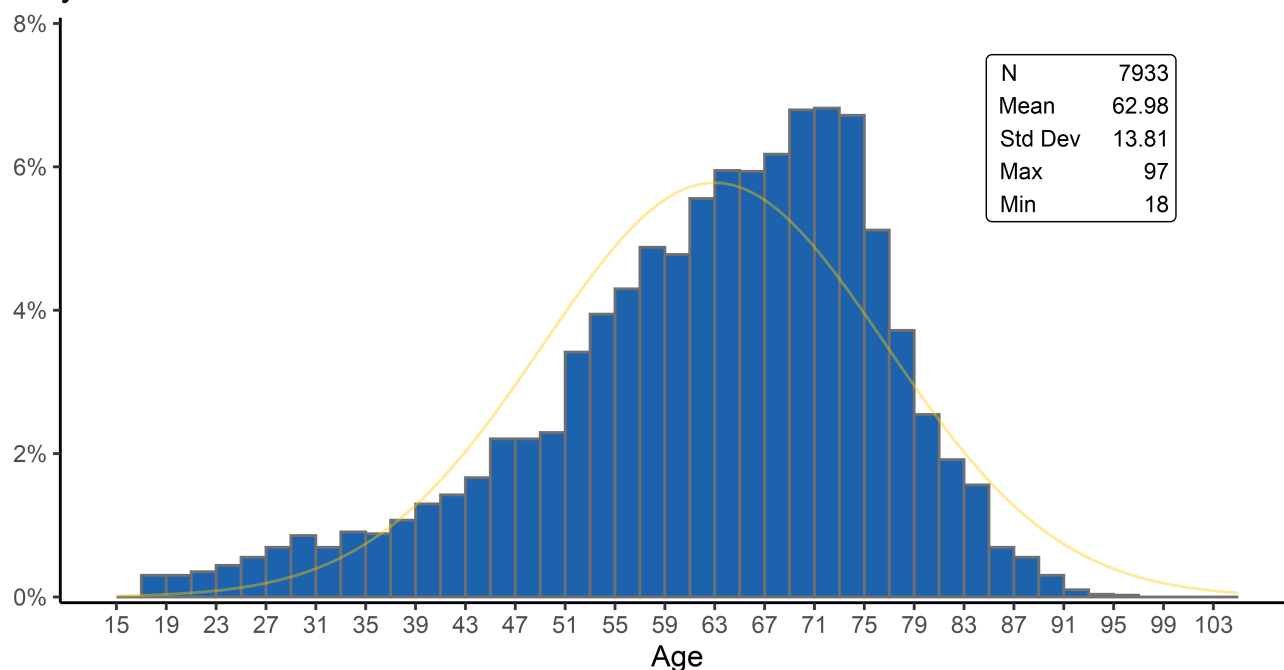
Lifestyle factors in primary care (type 2 diabetes) and in type 1 diabetes

Body Mass Index (BMI)

BMI is a measure of body composition, and is calculated as weight/$height^2$ (kg/m^2). BMI has been reported in NDR since 1996, and was reported in 81% of the patients in primary care and in 77% of all patients with type 1 diabetes in 2019.

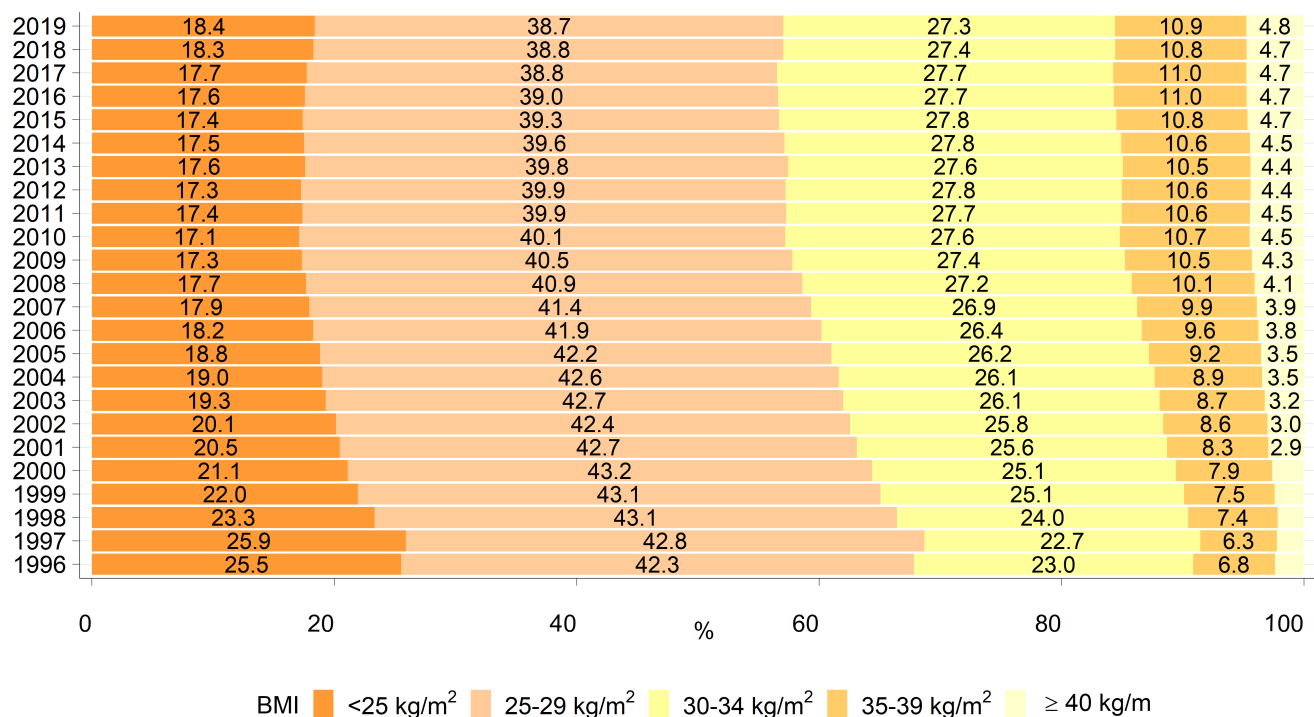### Figure 5. Proportions of patients by BMI intervals over time. Primary care.

Year	<25 kg/m²	25-29 kg/m²	30-34 kg/m²	35-39 kg/m²	≥ 40 kg/m²
2019	18.4	38.7	27.3	10.9	4.8
2018	18.3	38.8	27.4	10.8	4.7
2017	17.7	38.8	27.7	11.0	4.7
2016	17.6	39.0	27.7	11.0	4.7
2015	17.4	39.3	27.8	10.8	4.7
2014	17.5	39.6	27.8	10.6	4.5
2013	17.6	39.8	27.6	10.5	4.4
2012	17.3	39.9	27.8	10.6	4.4
2011	17.4	39.9	27.7	10.6	4.5
2010	17.1	40.1	27.6	10.7	4.5
2009	17.3	40.5	27.4	10.5	4.3
2008	17.7	40.9	27.2	10.1	4.1
2007	17.9	41.4	26.9	9.9	3.9
2006	18.2	41.9	26.4	9.6	3.8
2005	18.8	42.2	26.2	9.2	3.5
2004	19.0	42.6	26.1	8.9	3.5
2003	19.3	42.7	26.1	8.7	3.2
2002	20.1	42.4	25.8	8.6	3.0
2001	20.5	42.7	25.6	8.3	2.9
2000	21.1	43.2	25.1	7.9	
1999	22.0	43.1	25.1	7.5	
1998	23.3	43.1	24.0	7.4	
1997	25.9	42.8	22.7	6.3	
1996	25.5	42.3	23.0	6.8	

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

Year	<25 kg/m²	25-29 kg/m²	30-34 kg/m²	35-39 kg/m²	≥ 40 kg/m²
2019	43.6	37.1	14.4	3.8	
2018	44.0	37.6	13.7	3.7	
2017	44.0	38.1	13.7	3.3	
2016	44.7	38.2	13.1	3.1	
2015	45.4	38.3	12.7	2.8	
2014	46.1	38.4	12.2		
2013	46.4	38.6	11.8		
2012	46.6	38.7	11.6		
2011	46.9	38.8	11.3		
2010	47.2	38.7	11.1		
2009	47.5	38.9	10.8		
2008	48.4	38.6	10.5		
2007	49.3	38.2	10.0		
2006	50.2	38.1	9.7		
2005	51.8	37.4	8.8		
2004	51.3	38.3	8.5		
2003	52.6	37.5	8.1		
2002	52.3	38.1	8.1		
2001	53.0	37.9	7.8		
2000	53.7	38.0	7.1		
1999	56.5	35.6	6.7		
1998	55.6	36.6	6.6		
1997	58.7	34.5	5.6		
1996	61.0	33.4	4.9		

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. This variable has been registered in the NDR since 2004. Cover rate has improved over time and was reported in 85% in type 1 diabetes and in 74 % in primary care in 2019.

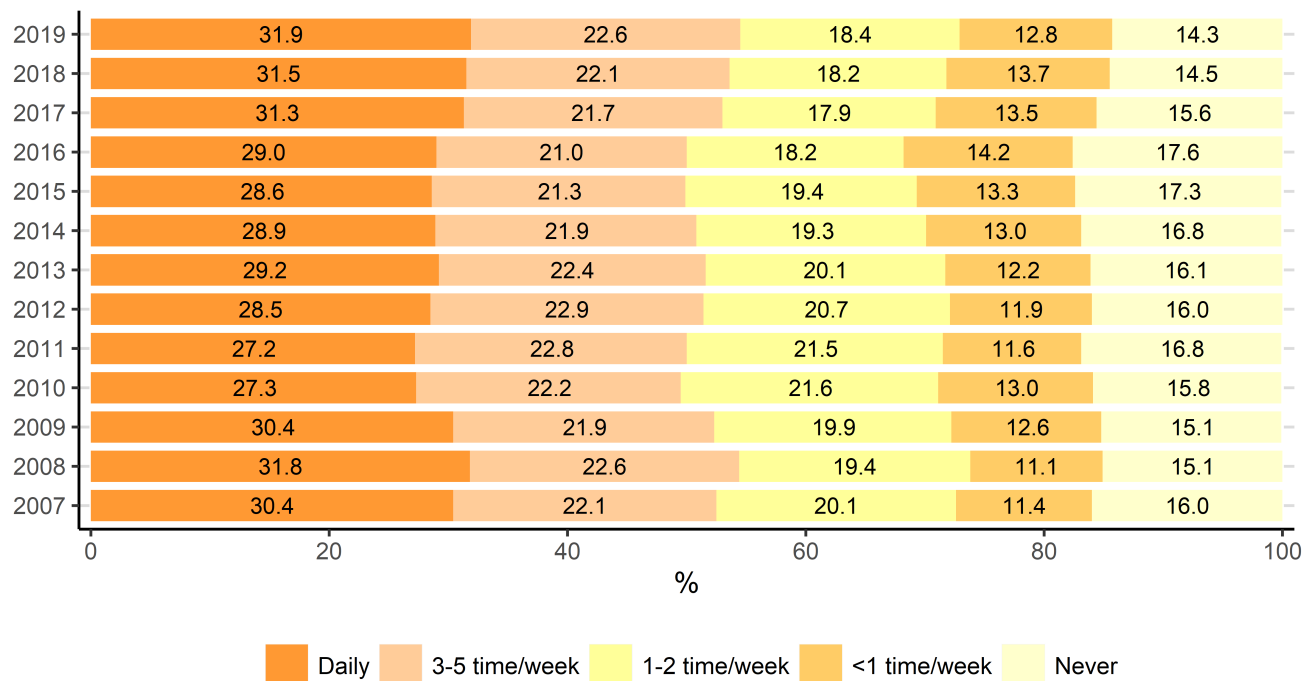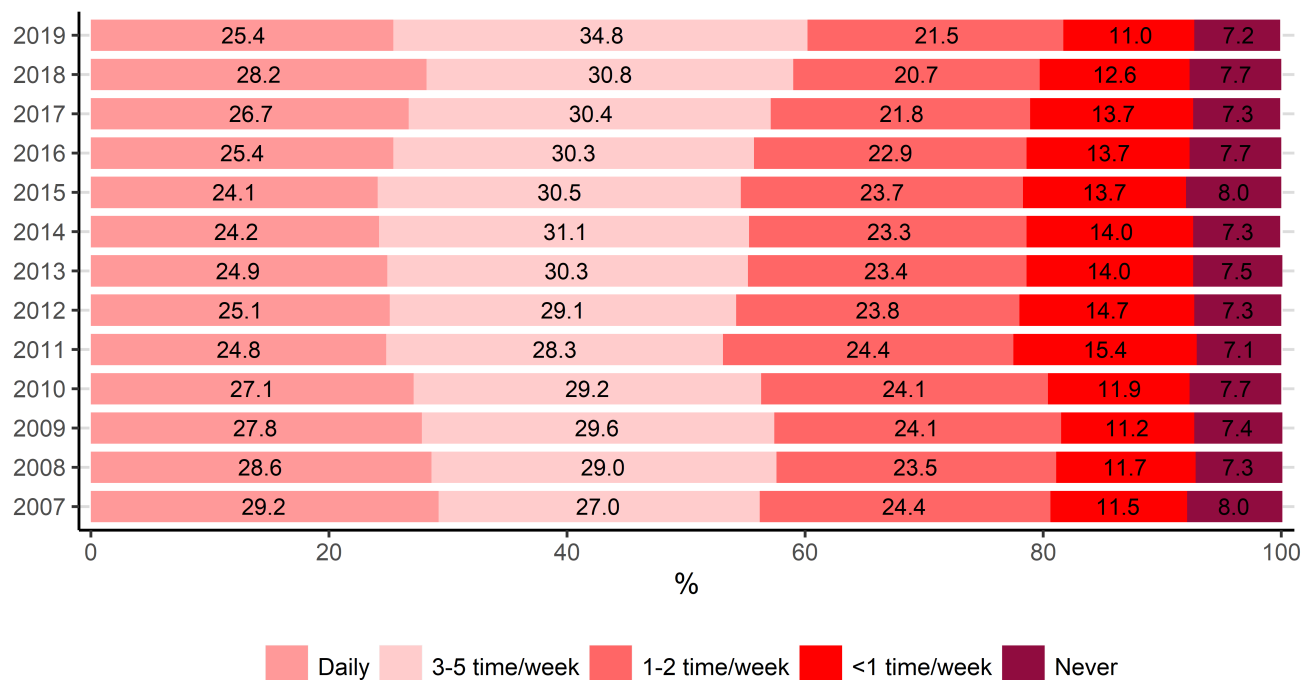Figure 7. Proportions of patients at different levels of physical leisure time activity. Primary care.

Year	Daily	3-5 time/week	1-2 time/week	<1 time/week	Never
2019	31.9	22.6	18.4	12.8	14.3
2018	31.5	22.1	18.2	13.7	14.5
2017	31.3	21.7	17.9	13.5	15.6
2016	29.0	21.0	18.2	14.2	17.6
2015	28.6	21.3	19.4	13.3	17.3
2014	28.9	21.9	19.3	13.0	16.8
2013	29.2	22.4	20.1	12.2	16.1
2012	28.5	22.9	20.7	11.9	16.0
2011	27.2	22.8	21.5	11.6	16.8
2010	27.3	22.2	21.6	13.0	15.8
2009	30.4	21.9	19.9	12.6	15.1
2008	31.8	22.6	19.4	11.1	15.1
2007	30.4	22.1	20.1	11.4	16.0

Legend: Daily, 3-5 time/week, 1-2 time/week, <1 time/week, Never

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

Year	Daily	3-5 time/week	1-2 time/week	<1 time/week	Never
2019	25.4	34.8	21.5	11.0	7.2
2018	28.2	30.8	20.7	12.6	7.7
2017	26.7	30.4	21.8	13.7	7.3
2016	25.4	30.3	22.9	13.7	7.7
2015	24.1	30.5	23.7	13.7	8.0
2014	24.2	31.1	23.3	14.0	7.3
2013	24.9	30.3	23.4	14.0	7.5
2012	25.1	29.1	23.8	14.7	7.3
2011	24.8	28.3	24.4	15.4	7.1
2010	27.1	29.2	24.1	11.9	7.7
2009	27.8	29.6	24.1	11.2	7.4
2008	28.6	29.0	23.5	11.7	7.3
2007	29.2	27.0	24.4	11.5	8.0

Legend: Daily, 3-5 time/week, 1-2 time/week, <1 time/week, Never

Smoking

In NDR, the definition of a smoker is person who is a current smoker or has stopped smoking during the last 3 months. Smoking has been registered since 1996 and was reported in 93% in type 1 diabetes and in 82% in primary care in 2019.

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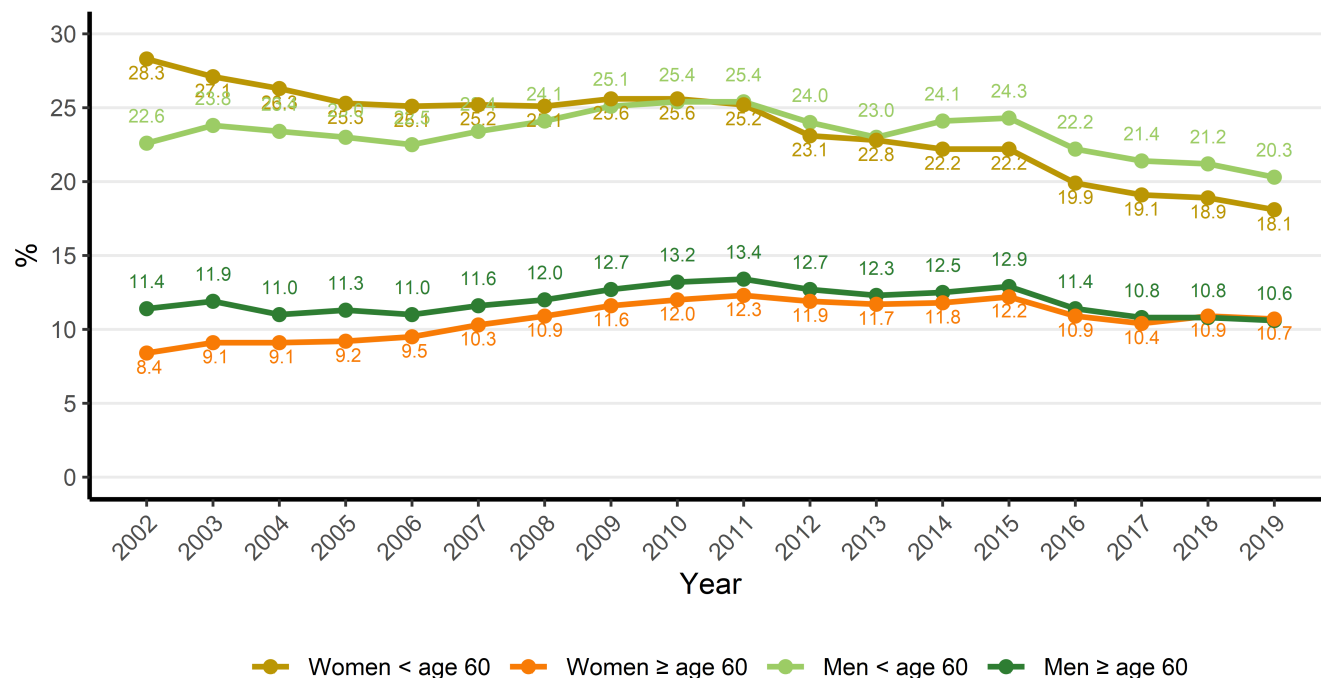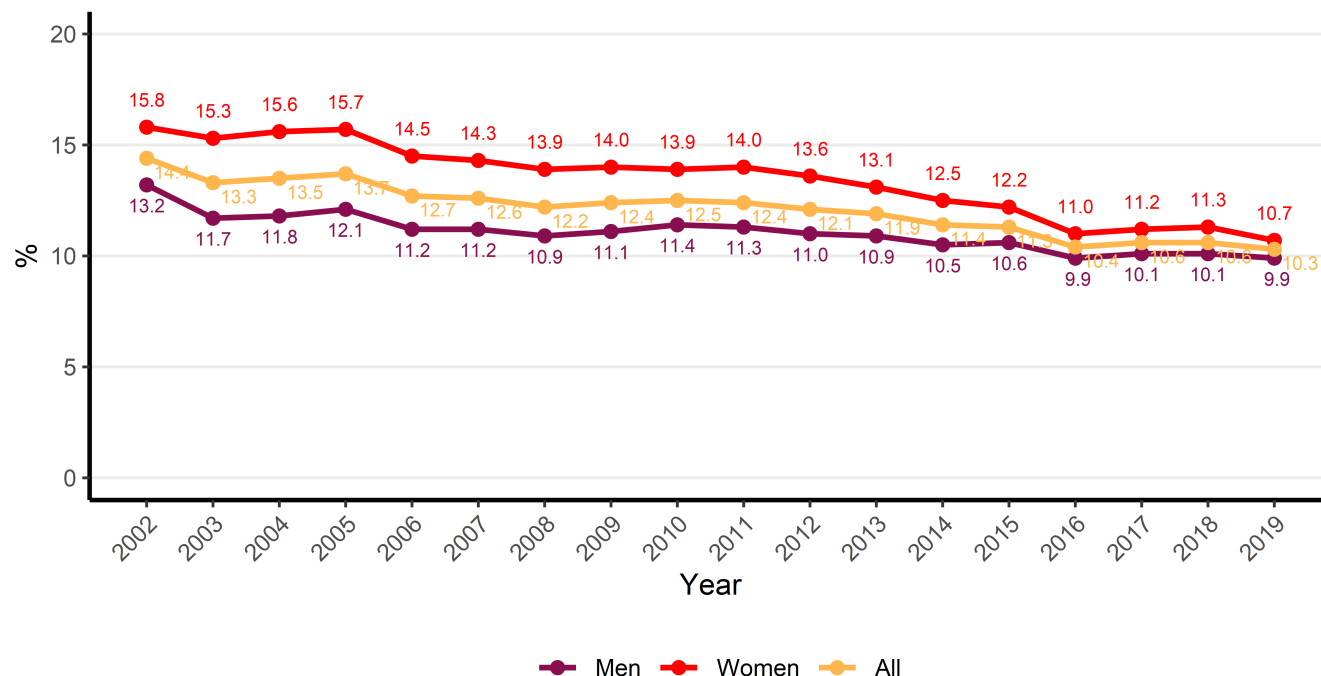

Figure 10. Proportions of women, men and in all, who smoke. Patients with type 1 diabetes at specialist clinics.

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. HbA1c has been registered since 1996, and was reported more than 95% of all patients in 2019.

Figure 11. Mean HbA1c levels (IFCC, mmol/mol) over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.
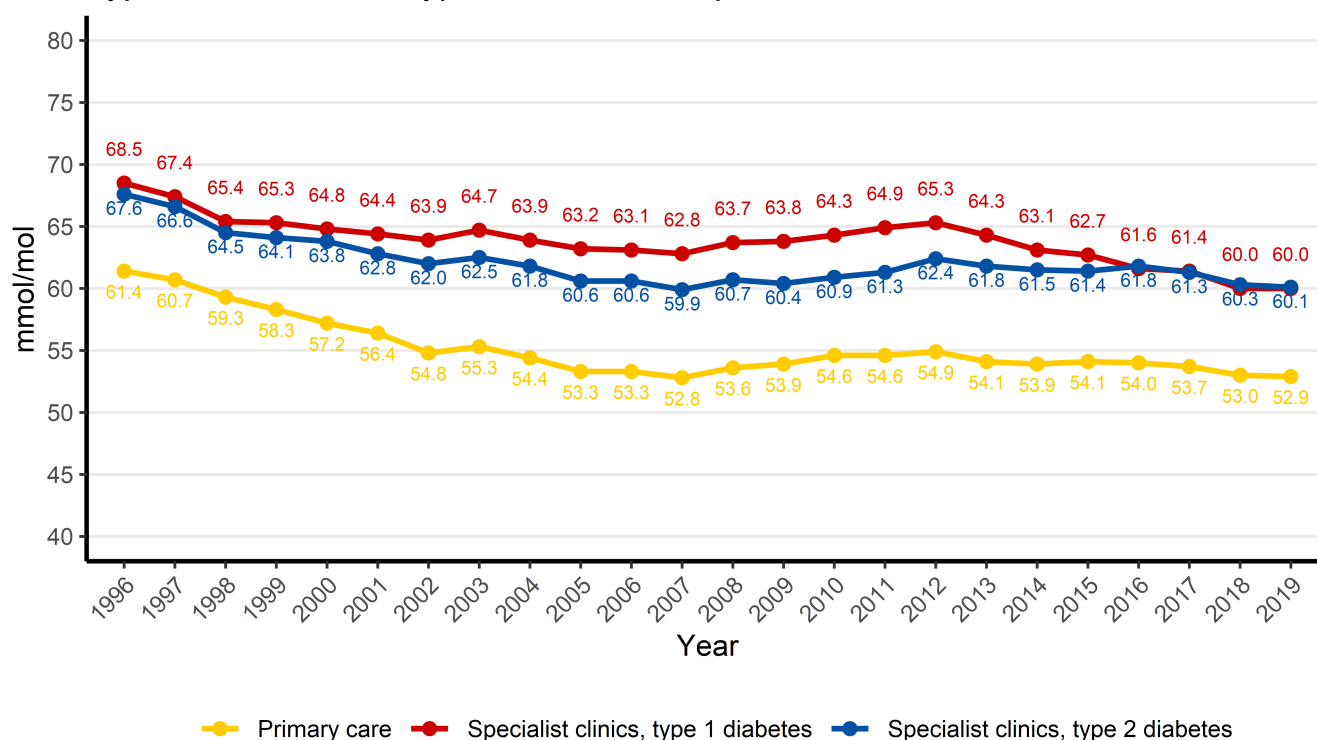
Figure 12. Mean HbA1c levels (NSPG, %) over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.
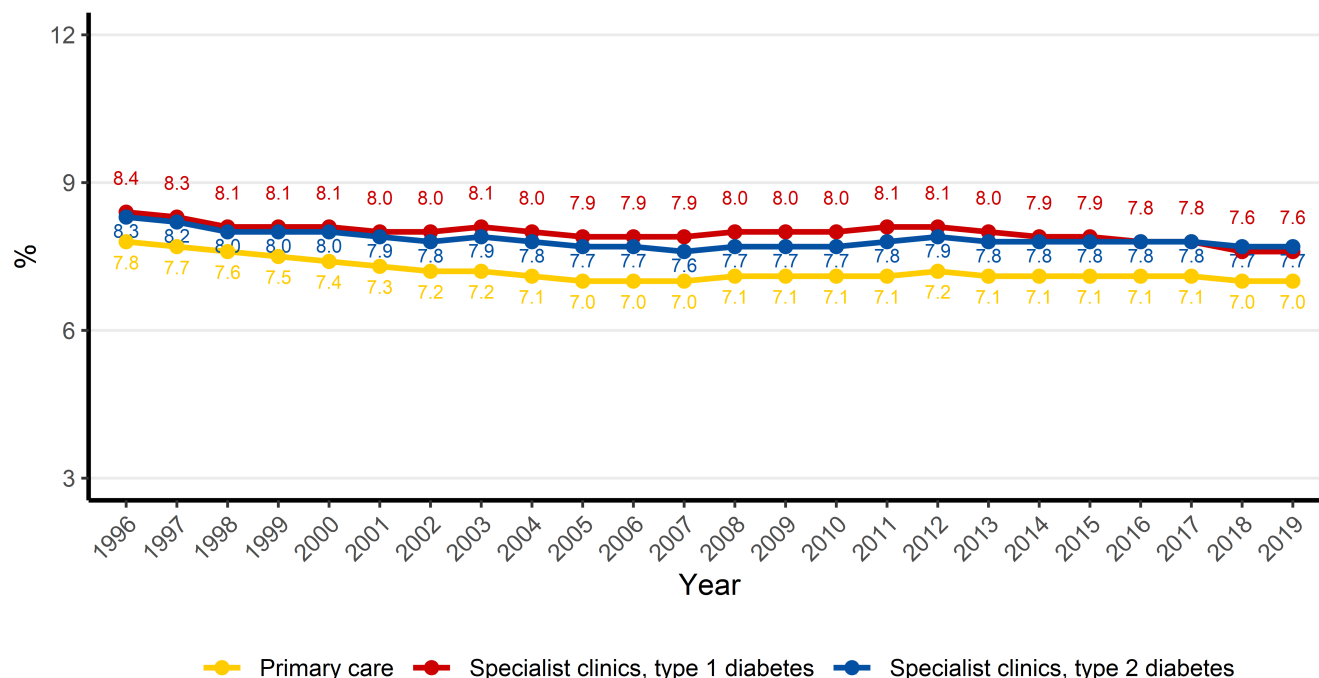
Figure 13. Proportions of patients with Hba1c < 52 mmol/mol (6.9% NGSP) over time in primary care, in type 1 diabetes and type 2 diabetes in specialist clinics.
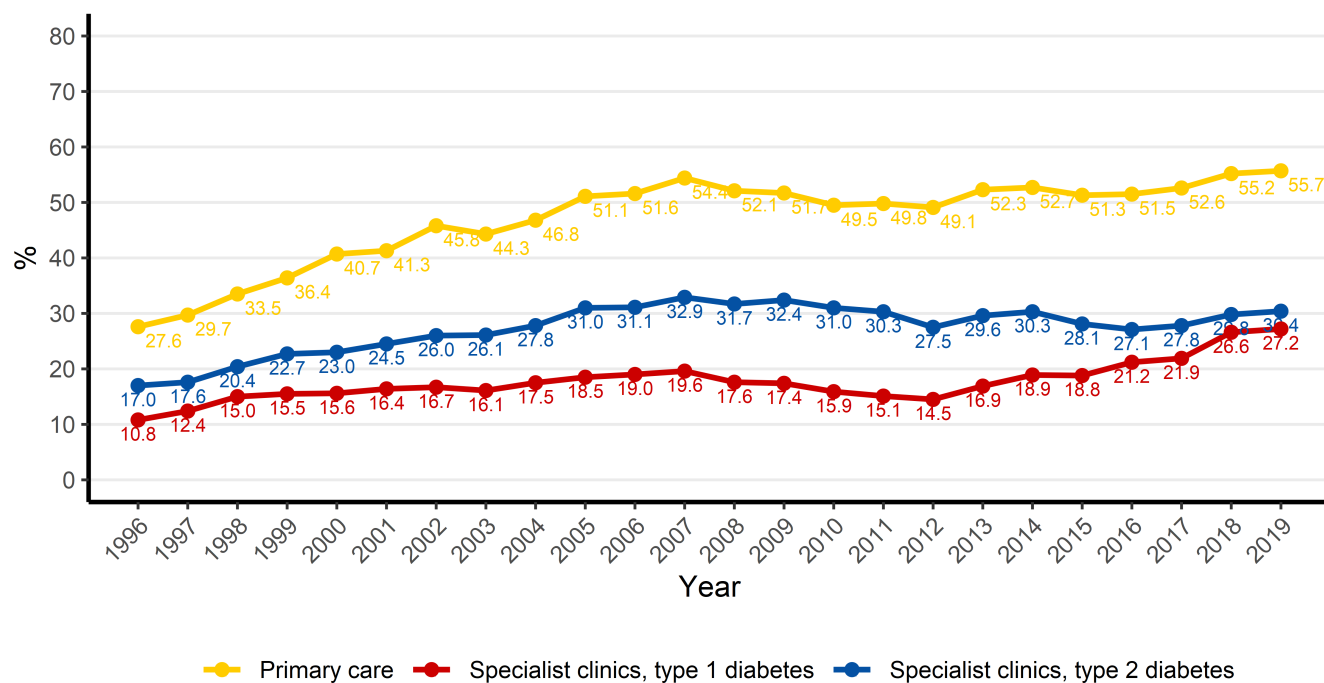
Figure 14. Proportions of patients with Hba1c > 70 mmol/mol (8.6% NGSP) over time in primary care, in type 1 diabetes and type 2 diabetes in specialist clinics.

Primary care — Specialist clinics, type 1 diabetes — Specialist clinics, type 2 diabetes

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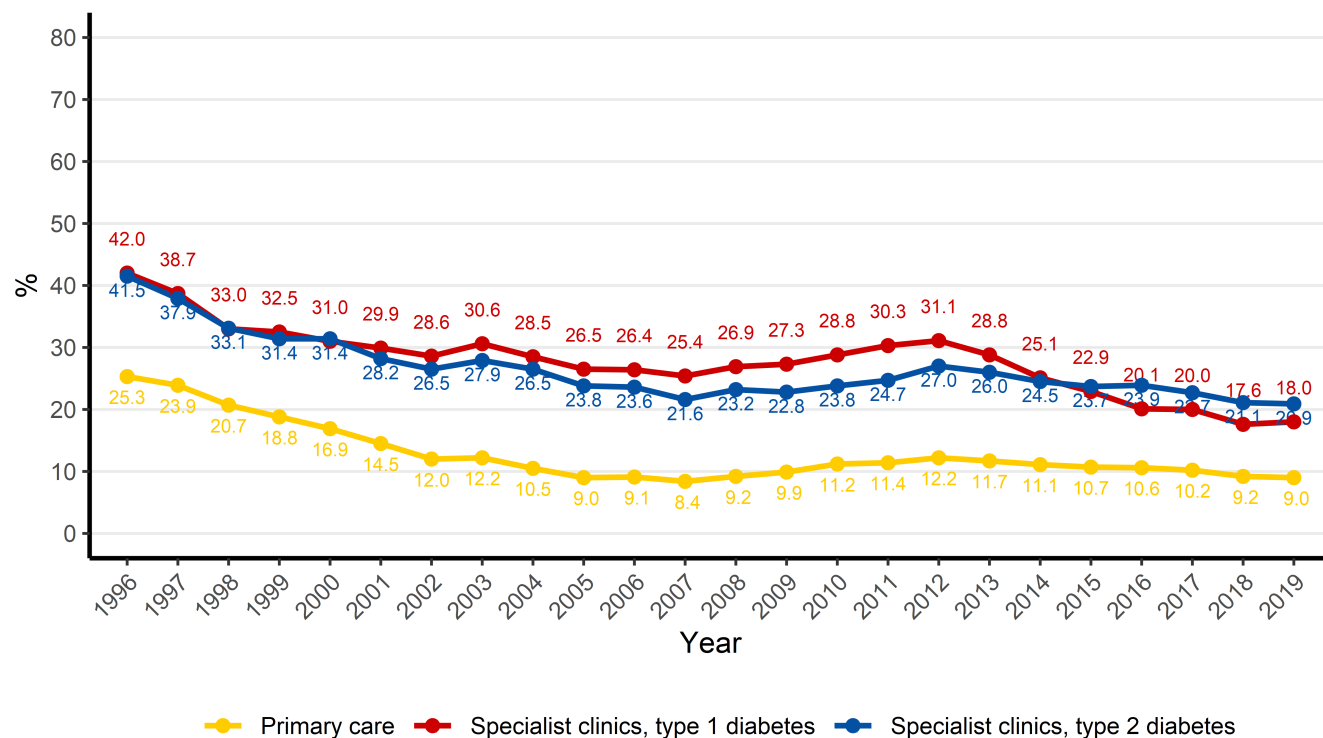
Technical devices in type 1 diabetes

The way insulin is administered, by multiple daily injections or by insulin pumps, have been registered in the NDR since 2002, and was reported in 98% of all patients with type 1 diabetes in 2019. 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 2019.

Figure 15. Proportions of patients using insulin pumps among patients with type 1 diabetes over time in men, in women and in all.
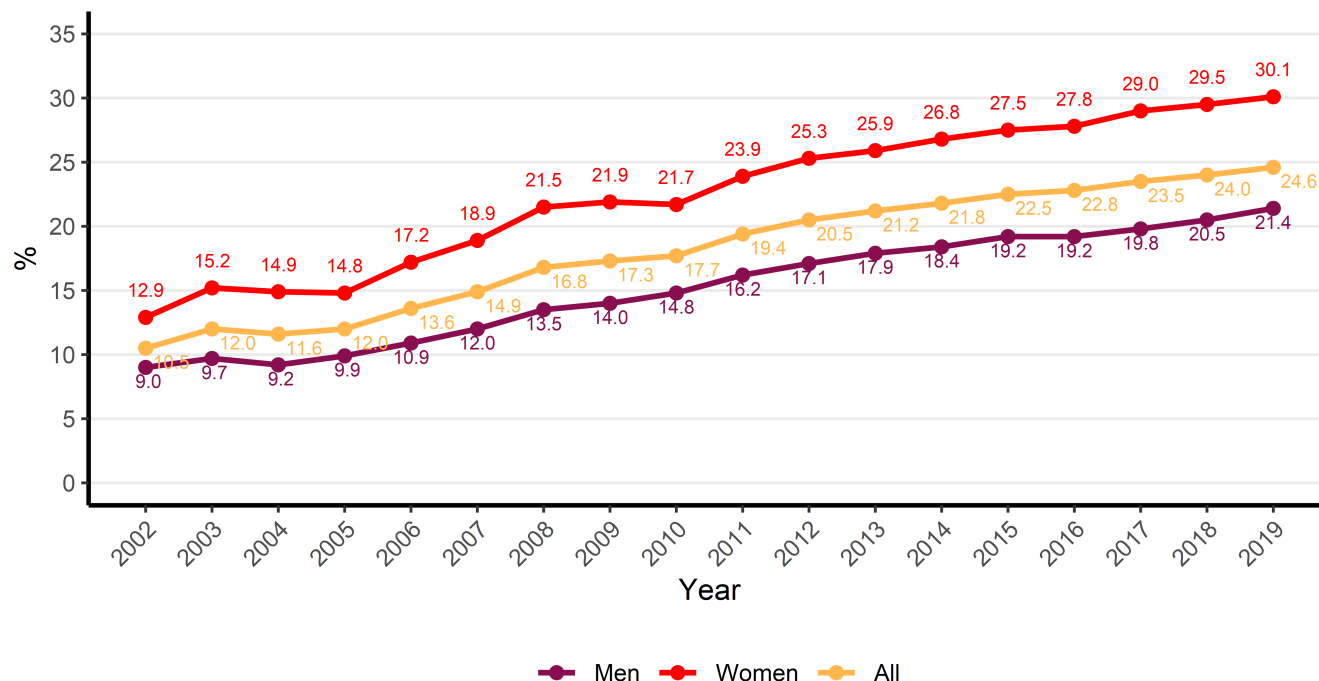
Figure 16. Proportions of patients using insulin pumps among patients with type 1 diabetes over time in different age groups.
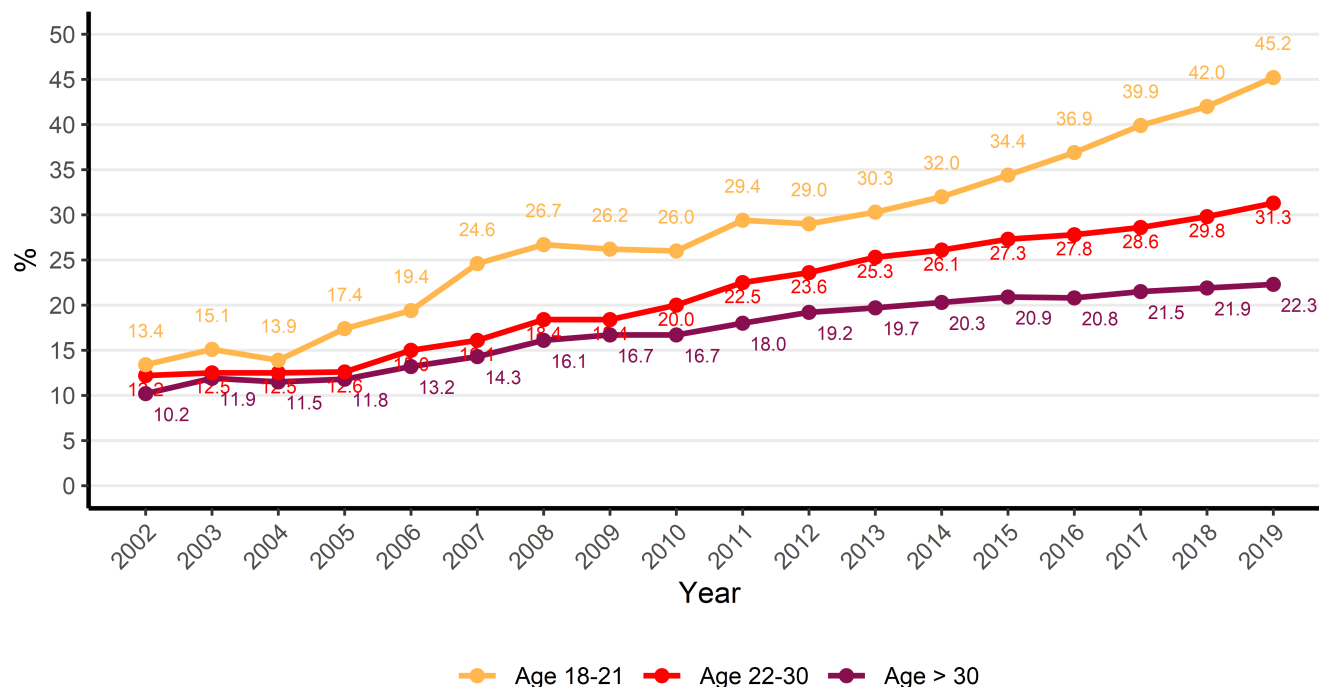
Figure 17. Proportion of patients with type 1 diabetes using sensor-based glucose monitoring, including both real-time and intermittent scanning devises.
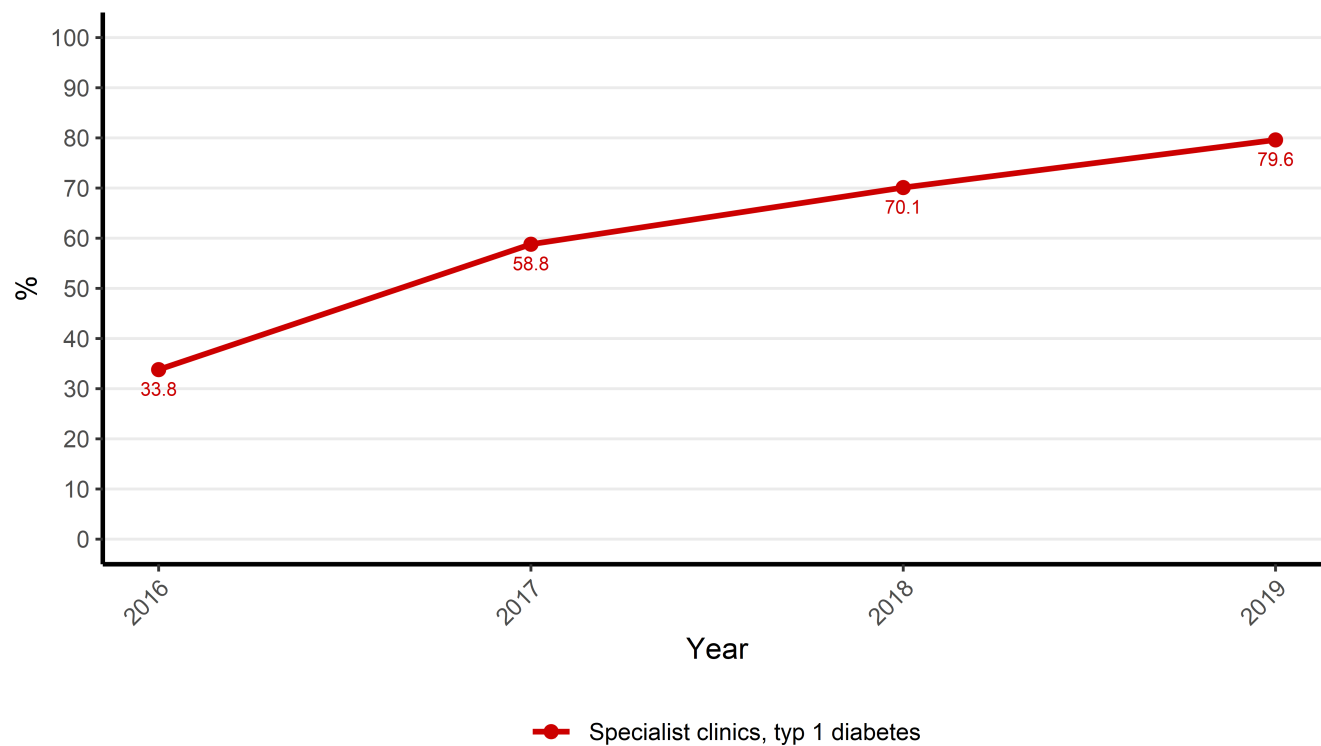
Blood pressure and blood lipid levels in primary care (type 2 diabetes) and in type 1 diabetes and type 2 diabetes in specialist clinics

Blood pressure levels and antihypertensive treatment

Blood pressure and use of antihypertensive treatment have been registered in the NDR since 1996 and were reported in over 90% of all patients in 2019. 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.
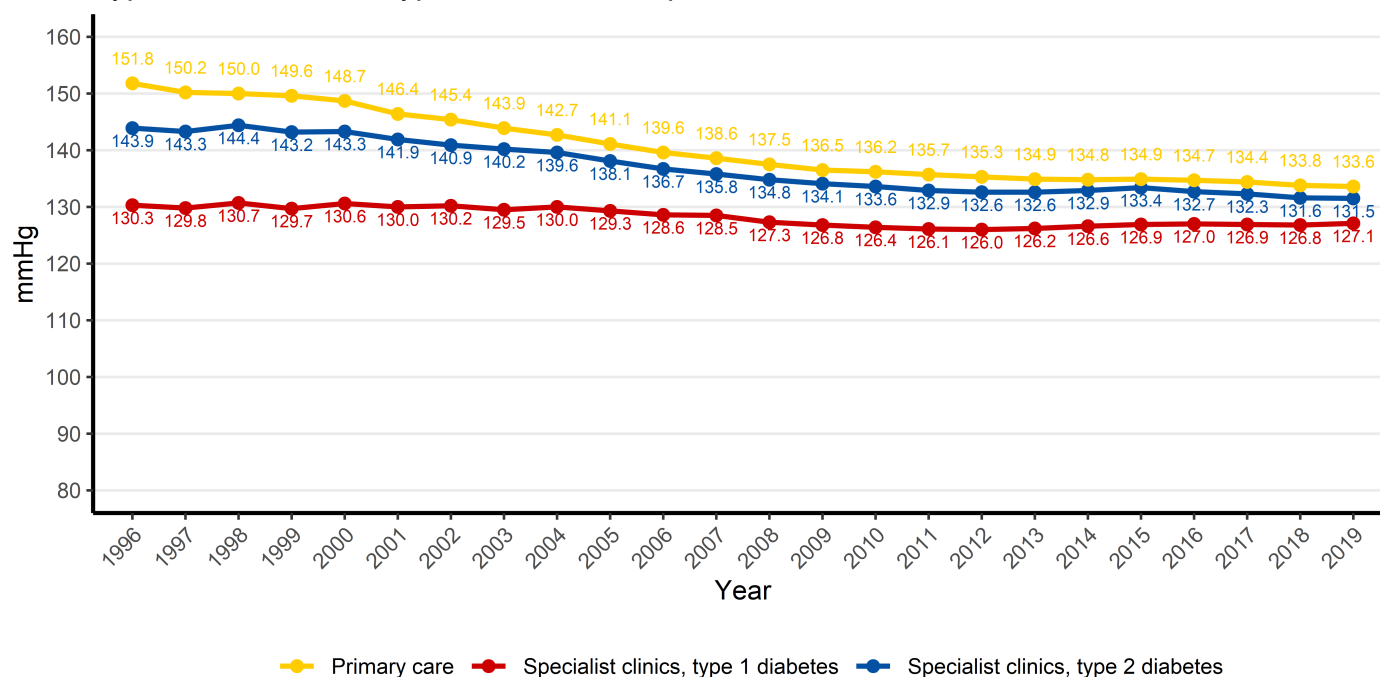
Figure 19. Mean diastolic blood pressure (mmHg) over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.
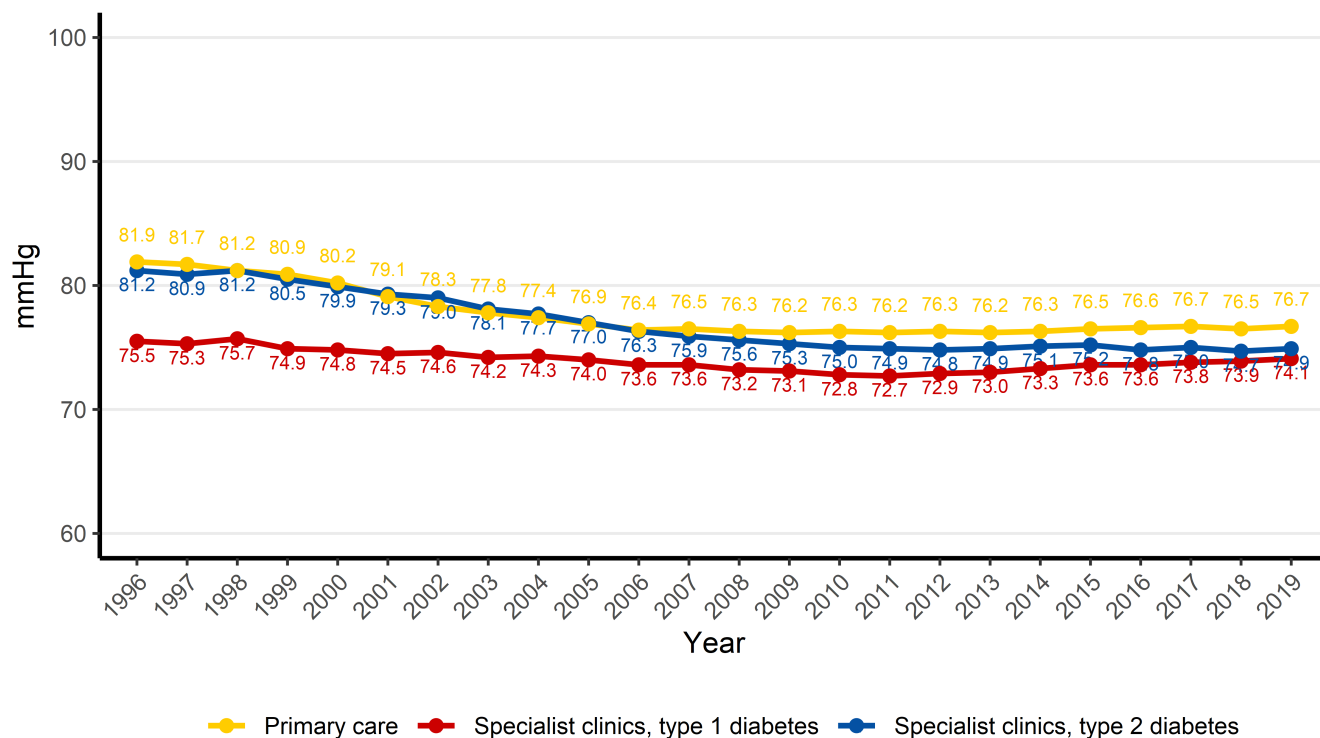

Figure 20. Proportions of patients using antihypertensive treatment over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.
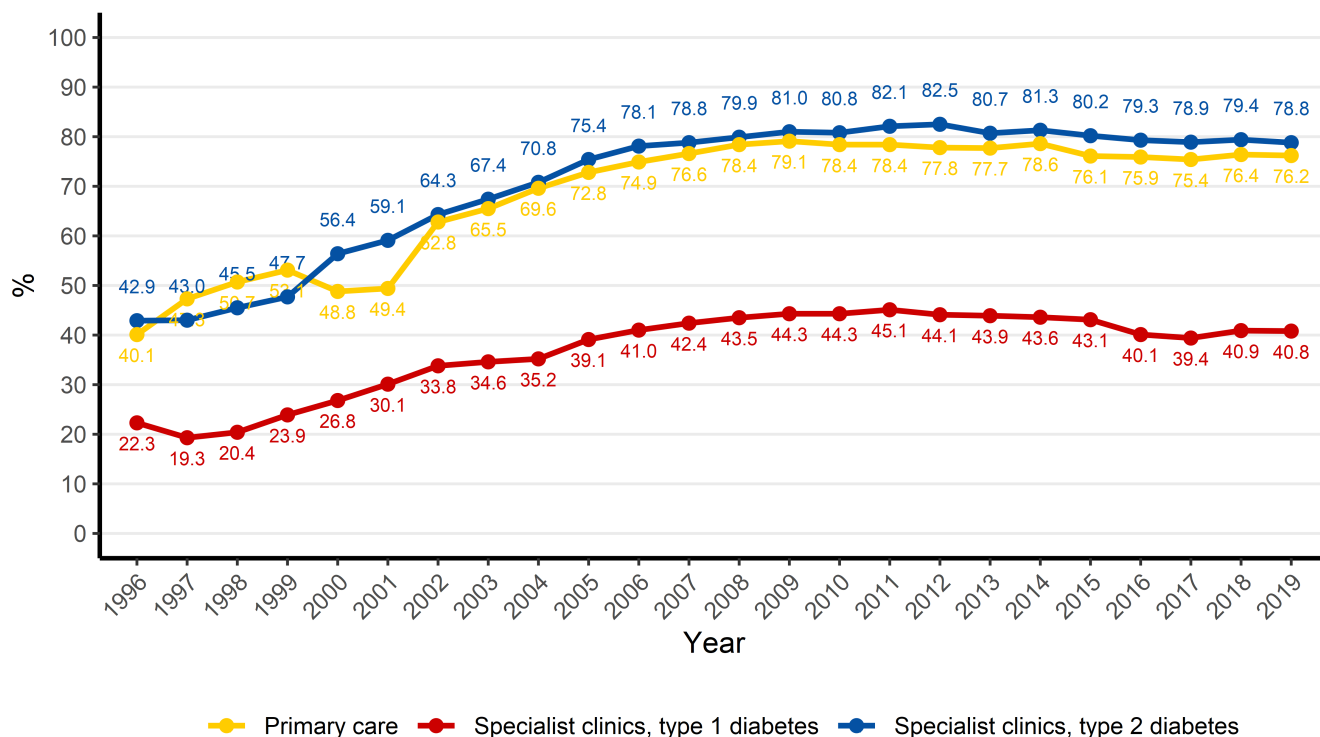
Figure 21. Proportions of patients with blood pressure <140/85 mmHg over time primary care, type 1 diabetes and type 2 diabetes in specialist clinics.
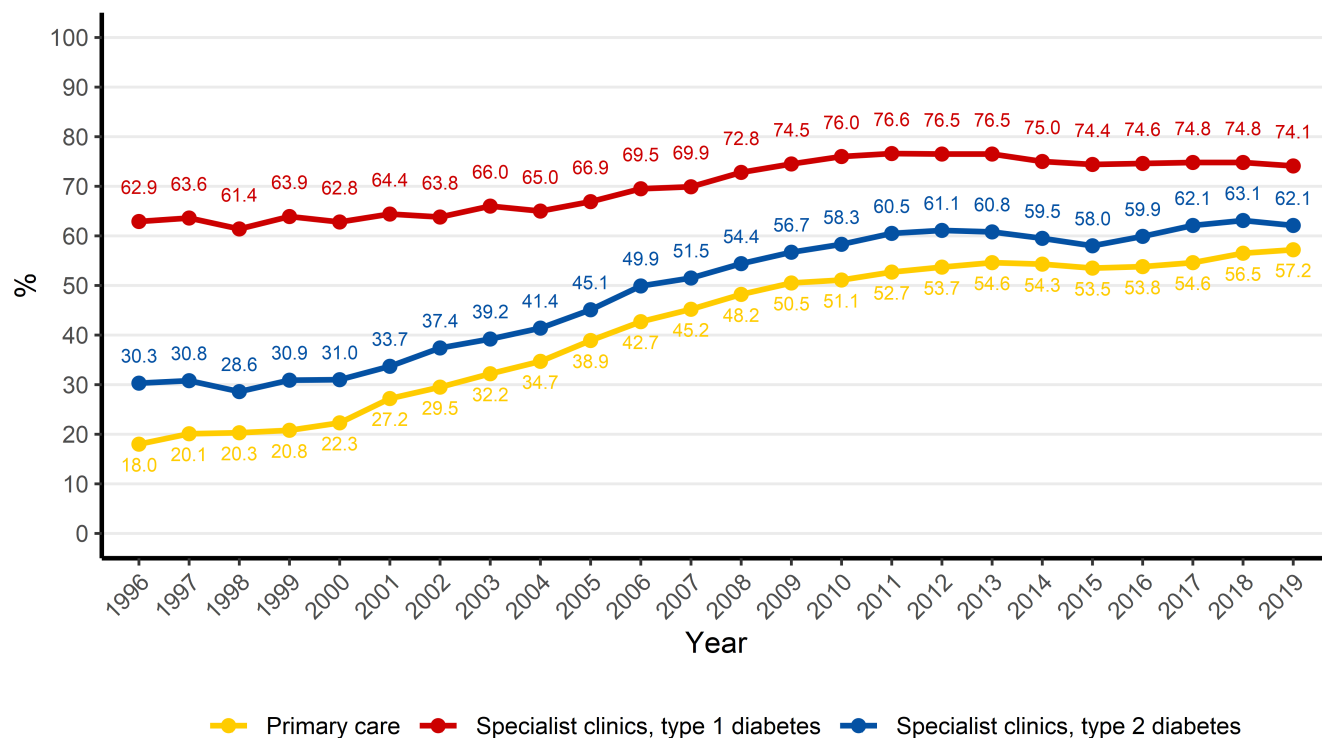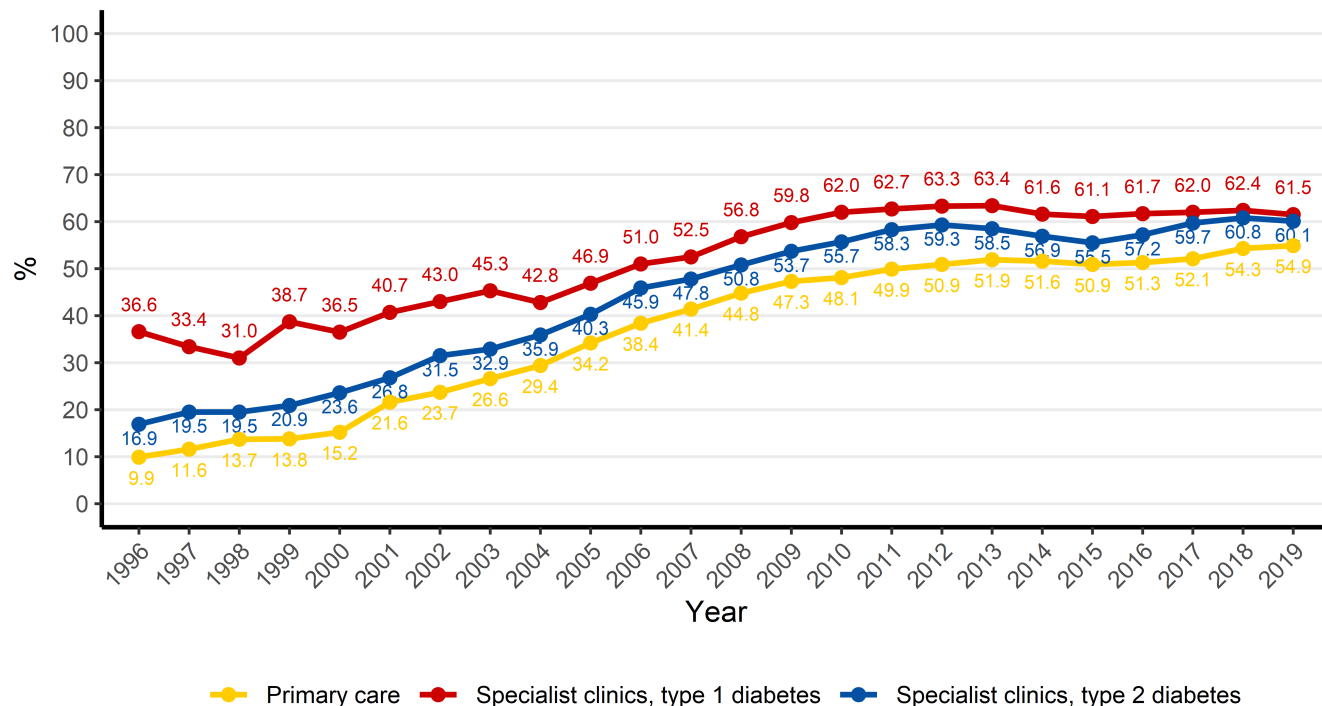

Figure 21. Proportions of patients with blood pressure <140/85 mmHg over time primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

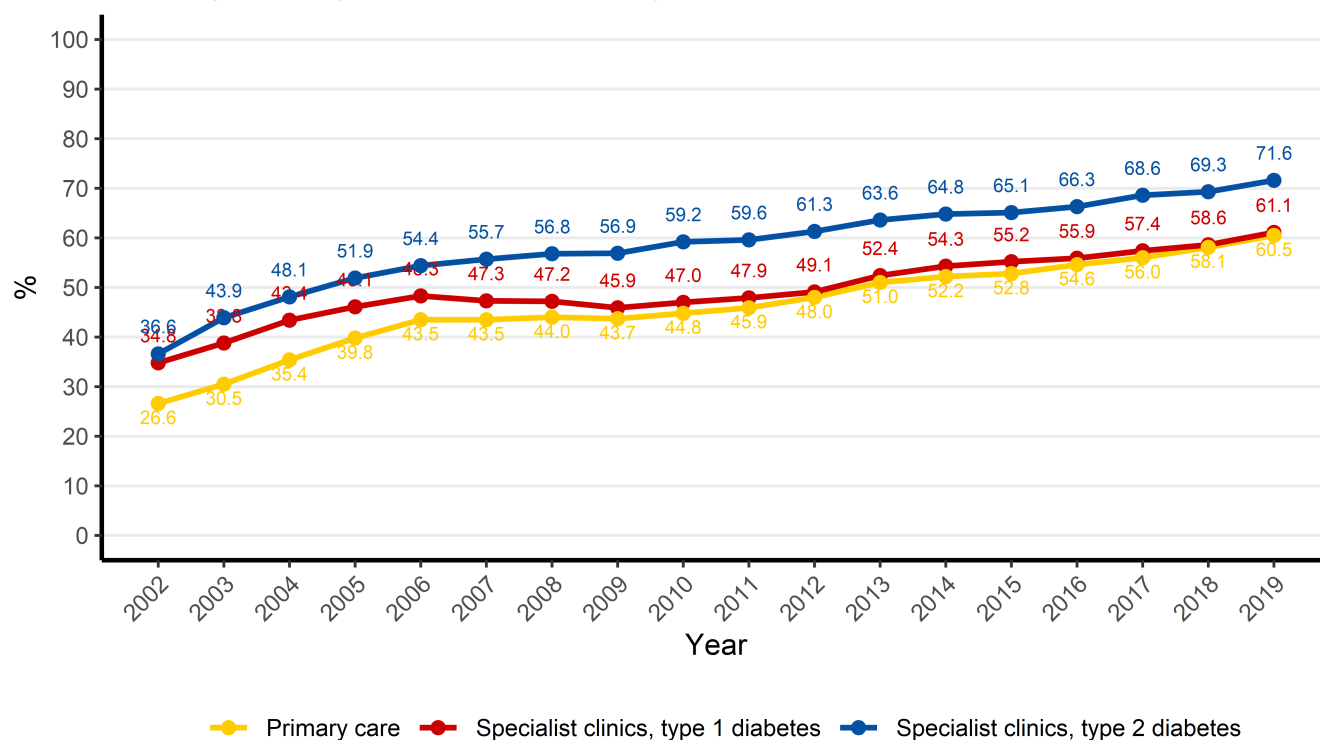## Figure 22. Proportions of patients with antihypertensive treatment and blood pressure < 140/85 mmHg over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

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. In 2019, lipid-lowering medication were reported in more than 95% of all patients and blood lipid levels where reported in around 75% of all patients.

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.
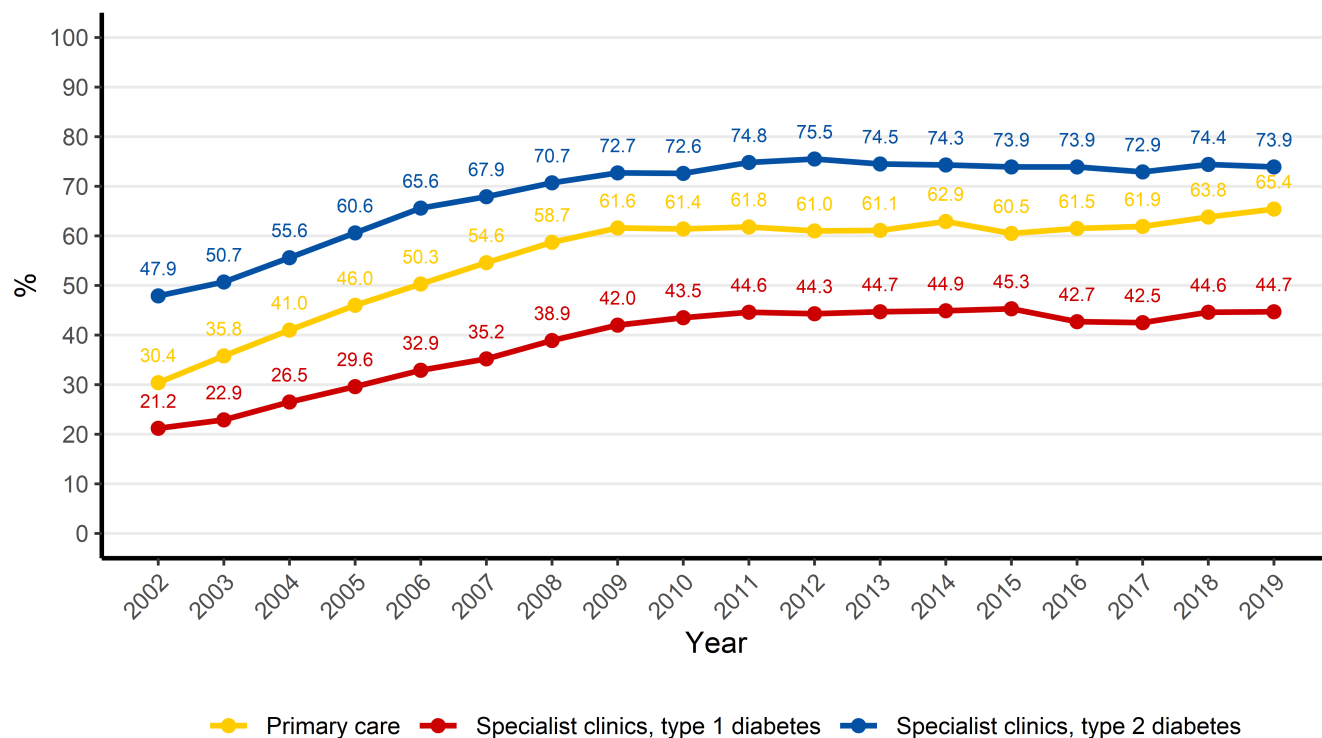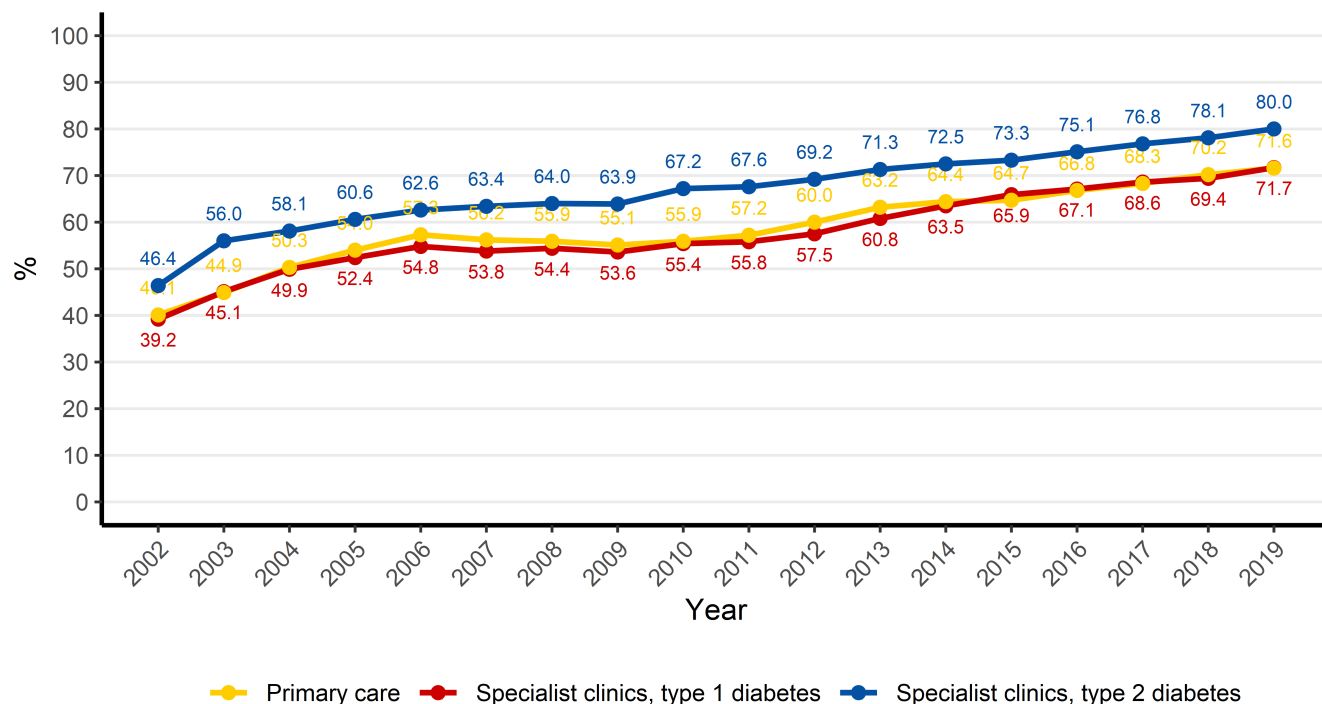

Figure 25. Proportions of patients treated with lipid-lowering medication and with LDL cholesterol < 2.5 mmol/L over time in primary care, type 1 diabetes and type 2 diabetes in specialist clinics.

Process measures of diabetes complications including abuminuria, retinopathy and recommended eye and foot examinations

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 μg/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 μg/min (>300 mg/L). Albuminuria has been reported since 2002, and the response rate in all patients was 70% in year 2019.

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.
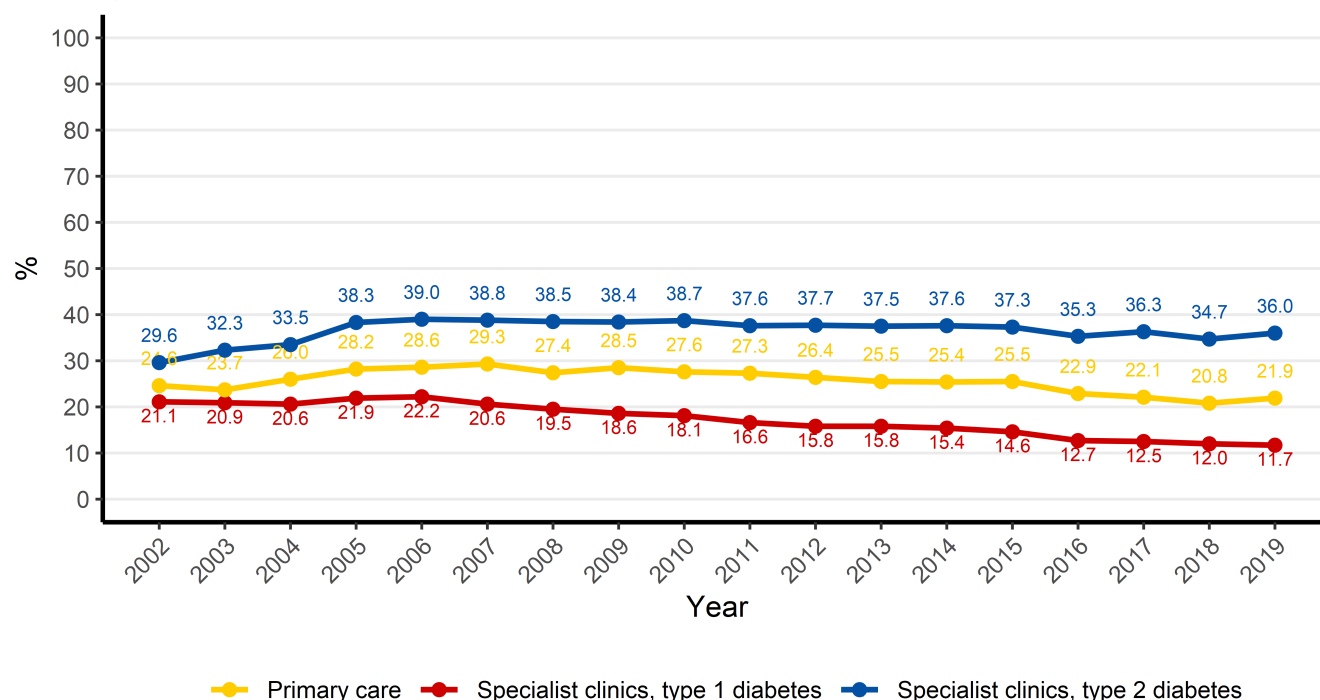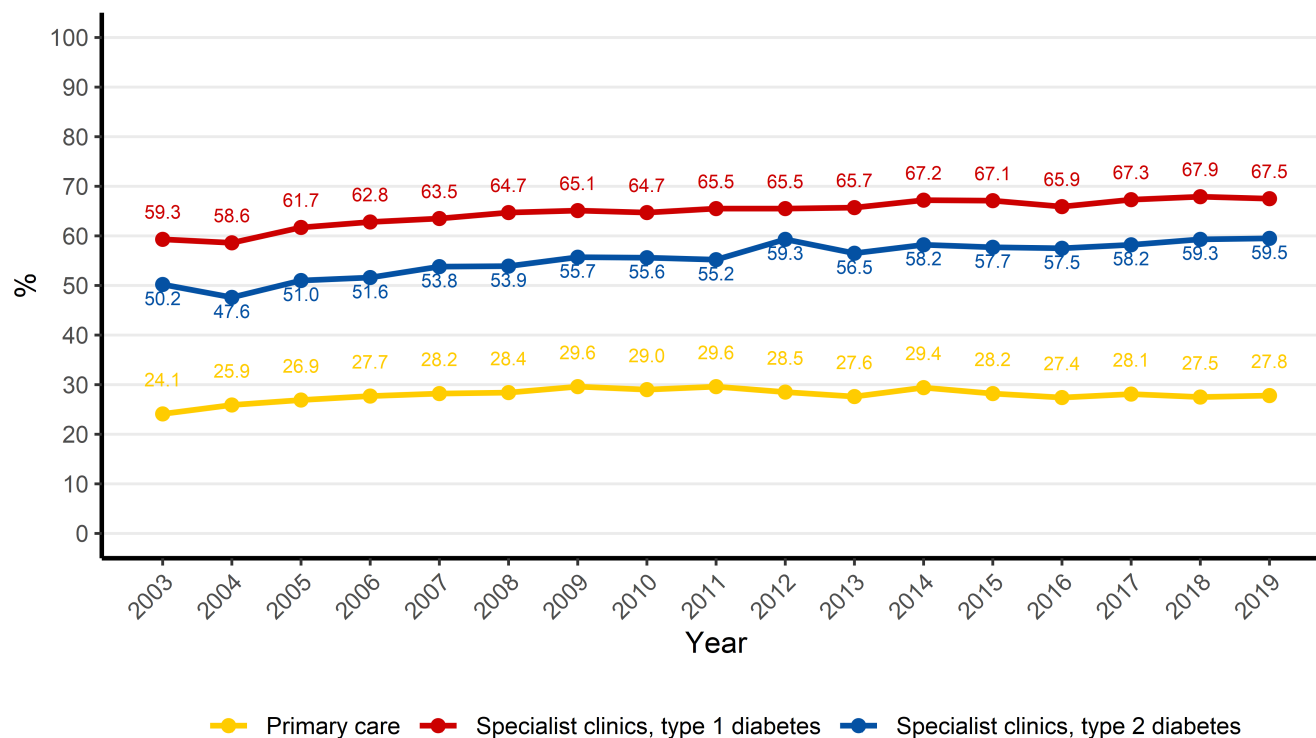
Retinopathy

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. In 2019 grading of retinopathy has been reported in 90% of all patients with type 1 diabetes, and in 80% of all type 2 diabetes patients.

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

Control of the 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 year for patients with type 1 diabetes, and every three years for patients with type 2 diabetes. Patient with mild to moderate retinopathy are recommended examinations every year, and patients with more severe retinopathy more often based on individual conditions. Examinations of the retina were reported in more than 90 % of all patients with type 1 diabetes and in more than 80% in primary care in 2019.

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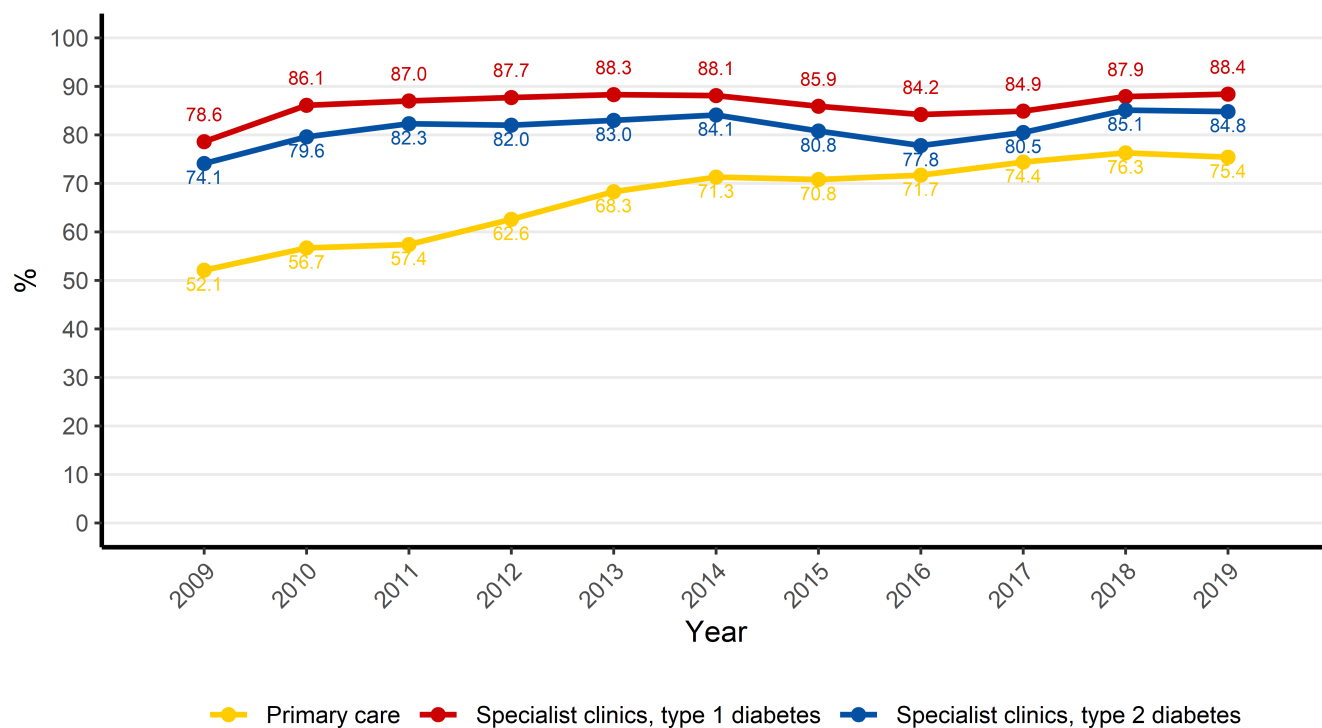
Control of foot status

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, and has been reported since 2002. It was reported in almost 90% of all patients in 2019.

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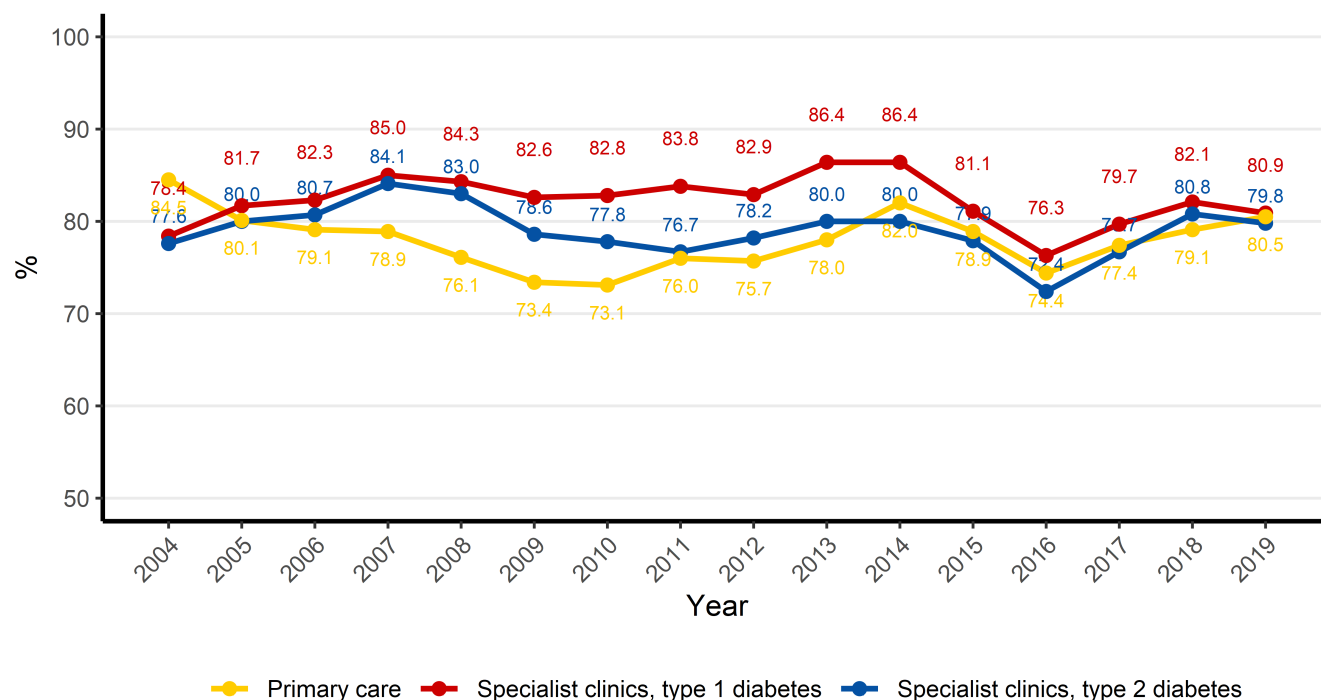
Patient-reported outcome and experience measures (PROM and PREM)

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 the developed and tested. Since 2017, 40 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 specialised clinics is ongoing, under continuous careful evaluation.

Scientific publications 2019

1. **Quality of life in chronic conditions using patient-reported measures and biomarkers: a DEA analysis in type 1 diabetes.** Borg S, Gerdtham UG, Eeg-Olofsson K, Palaszewski B, Gudbjörnsdottir S Health Econ Rev. November 2019

2. **Contrasting Associations of Body Mass Index and Hemoglobin A1c on the Excess Risk of Acute Myocardial Infarction and Heart Failure in Type 2 Diabetes Mellitus.** Edqvist J, Rawshani A, Adiels M, Björck L, Lind M, Svensson AM, Gudbjörnsdottir S, Sattar N, Rosengren A J Am Heart Assoc. December 2019

3. **Geographical variation in the incidence of type 1 diabetes in the Nordic countries: A study within NordicDiabKids.** Samuelsson U, Westerberg L, Aakesson K, Birkebaek N, Bjarnason R, Drivvoll AK, Skrivarhaug T, Svensson J, Thorsson A, Hanberger L, Nordic Childhood Diabetes Registry Study Group, NordicDiabKids Pediatr Diabetes. Epub November 2019

4. **Glycaemic control and excess risk of major coronary events in patients with type 2 diabetes: a population-based study.** Tancredi M, Rosengren A, Svensson A-M, Pivodic A, Gudbjörnsdottir S, Wedel H, Lind M Open Heart. September 2019

5. **Prediction of individual life-years gained without cardiovascular events from lipid, blood pressure, glucose, and aspirin treatment based on data of more than 500 000 patients with Type 2 diabetes mellitus.** Berkelmans GFN, Gudbjörnsdottir S, Visseren FLJ, Wild SH, Franzen S, Chalmers J, Davis BR, Poulter NR, Spijkerman AM, Woodward M, Pressel SL, Gupta AK, van der Schouw YT, Svensson AM, van der Graaf Y, Read SH, Eliasson B, Dorresteijn JAN Eur Heart J. September 2019

6. **Open carpal tunnel release and diabetes: a retrospective study using PROMs and national quality registries.** Zimmerman M, Eeg-Olofsson K, Svensson AM, Åström M, Arner M, Dahlin L BMJ Open. September 2019

7. **Use of sodium glucose cotransporter 2 inhibitors and risk of major cardiovascular events and heart failure: Scandinavian register based cohort study.** Pasternak B, Ueda P, Eliasson B, Svensson AM, Franzén S, Gudbjörnsdottir S, Hveem K, Jonasson C, Wintzell V, Melbye M, Svanström H BMJ. August 2019

8. **HbA1c level as a risk factor for retinopathy and nephropathy in children and adults with type 1 diabetes: Swedish population based cohort study.** Lind M, Pivodic A, Svensson AM, Ólafsdóttir AF, Wedel H, Ludvigsson J BMJ. August 2019

9. **Survival, cardiovascular morbidity, and reinterventions after elective endovascular aortic aneurysm repair in patients with and without diabetes: A nationwide propensity-adjusted analysis.** Taimour S, Avdic T, Franzén S, Zarrouk M, Acosta S, Nilsson P, Miftaraj M, Eliasson B, Svensson AM, Gottsäter A Vasc Med. August 2019

10. **Health-related quality of life and glycaemic control among adults with type 1 and type 2 diabetes - a nationwide cross-sectional study.** Svedbo Engström M, Leksell J, Johansson UB, Borg S, Palaszewski B, Franzén S, Gudbjörnsdottir S, Eeg-Olofsson K Health Qual Life Outcomes. August 2019

11. **Risk Factors for Atrial Fibrillation in People With Type 1 Diabetes: An Observational Cohort Study of 36,258 Patients From the Swedish National Diabetes Registry.** Hallström S, Pivodic A Rosengren A, Ólafsdóttir AF, Svensson AM, Lind M Diabetes Care. August 2019

12. **Age at Diagnosis of Type 2 Diabetes Mellitus and Associations With Cardiovascular and Mortality Risks.** Sattar N, Rawshani A, Franzén S, Rawshani A, Svensson AM, Rosengren A, McGuire D, Eliasson B, Gudbjörnsdottir S Circulation. May 2019

13. **Nationwide comparison of long-term survival and cardiovascular morbidity after acute aortic aneurysm repair in patients with and without type 2 diabetes.** Taimour S, Franzén S, Zarrouk M, Acosta S, Nilsson P, Miftaraj M, Eliasson B, Svensson AM, Gottsäter A J Vasc Surg. May 2019

14. **BMI, Mortality, and Cardiovascular Outcomes in Type 1 Diabetes: Findings Against an Obesity Paradox.** Edqvist J, Rawshani A, Adiels M, Björck L, Lind M1, Svensson AM, Gudbjörnsdottir S, Sattar N, Rosengren A Diabetes Care. July 2019

15. **Glucagon-Like Peptide 1 Receptor Agonists and Risk of Diabetic Retinopathy Complications: Cohort Study in Nationwide Registers From Two Countries.** Ueda P, Pasternak B, Eliasson B, Svensson AM, Franzén S, Gudbjörnsdottir S, Hveem K, Jonasson C, Melbye M, Svanström H Diabetes Care. June 2019

16. **Long term survival and cardiovascular morbidity after elective open aortic aneurysm repair in patients with and without type 2 diabetes: a nationwide propensity-adjusted analysis.** Zarrouk M, Franzén S, Acosta S, Nilsson

P, Miftaraj M, Eliasson B, Svensson AM, Gottsäter A Ann Vasc Surg. April 2019

17. **Maternal Glycemic Control in Type 1 Diabetes and the Risk for Preterm Birth A Population-Based Cohort Study.** Ludvigsson JF, Neovius M, Söderling J, Gudbjörnsdottir S, Svensson AM, Franzén S, Stephansson O, Pasternak B Ann Intern Med. April 2019

18. **Risk Factors for Severe Liver Disease in Patients With Type 2 Diabetes.** Björkström K, Franzen S, Eliasson B, Miftaraj M, Gudbjörnsdottir S, Trolle-Lagerros Y, Svensson AM, Hagström H Clin Gastroenterol Hepatol. April 2019

19. **Relative Prognostic Importance and Optimal Levels of Risk Factors for Mortality and Cardiovascular Outcomes in Type 1 Diabetes Mellitus.** Rawshani A, Rawshani A, Sattar N, Franzén S, McGuire DK, Eliasson B, Svensson AM, Zethelius B, Miftaraj M, Rosengren A, Gudbjörnsdottir S Circulation. April 2019

20. **Excess risk of lower extremity amputations in people with type 1 diabetes compared with the general population: amputations and type 1 diabetes.** Ólafsdóttir AF, Svensson AM, Pivodic A, Gudbjörnsdottir S, Nyström T, Wedel H, Rosengren A, Lind M BMJ Open Diabetes Res Care. April 2019

21. **Excess mortality and cardiovascular disease risk in type 1 diabetes - Authors' reply.** Rawshani A, Sattar N, Franzén S, Rawshani A, Gudbjörnsdottir S Lancet. Mars 2019

22. **Center Size and Glycemic Control: An International Study With 504 Centers From Seven Countries.** Birkebaek NH, Hermann JM, Hanberger L, Charalampopoulos D, Holl RW, Skrivarhaug T, Aakesson K, Justin T. Warner J T, Drivvoll A K, Svensson A M, Stephenson T, Hofer S E, Fredheim S , Kummernes S J, Amin R, Rami-Merhar B, Johansen A, Kapellen T M, Hilgard D, Dahl-Jørgensen K, Froehlich-Reiterer E, Fritsch M, Hanas R, Svensson J Diabetes Care 2019

23. **Use of liraglutide and risk of major cardiovascular events: a register-based cohort study in Denmark and Sweden.** Svanström H, Ueda P, Melbye M, Eliasson B, Svensson AM, Franzén S, Gudbjörnsdottir S, Hveem K, Jonasson C, Pasternak B Lancet Diabetes Endocrinol. February 2019

24. **Real-World Costs of Continuous Insulin Pump Therapy and Multiple Daily Injections for Type 1 Diabetes: A Population-Based and Propensity-Matched Cohort From the Swedish National Diabetes Register.** Toresson Grip E, Svensson AM, Miftaraj M, Eliasson B, Franzén S, Gudbjörnsdottir S, Steen Carlsson K Diabetes Care. January 2019

25. **Pros and cons of gastric bypass surgery in individuals with obesity and type 2 diabetes: nationwide, matched, observational cohort study.** Liakopoulos V, Stefan Franzén S, Svensson A M, Miftaraj M, Ottosson J, Näslund I, Gudbjörnsdottir S, Eliasson B BMJ Open January 2019

26. **Patient-reported outcome and experience measures for diabetes: development of scale models, differences between patient groups and relationships with cardiovascular and diabetes complication risk factors, in a combined registry and survey study in Sweden.** Borg S, Eeg-Olofsson K, Palaszewski B, Svedbo Engström M, Gerdtham UG, Gudbjörnsdottir S BMJ Open. January 2019