# **SWEDIABKIDS**

Swedish National Diabetes Register (NDR), diabetes in children and adolescents

**ANNUAL REPORT 2020** 





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# Annual report 2020

Swedish National Diabetes Register (NDR), diabetes in children and adolescents www.ndr.nu

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Thanks to James Birchall for the translation into English.

Feel free to use material from the annual report but do not forget to state the reference: Swediabkids Annual Report 2020.

The digital report can be found at the NDR's homepage: https://www.ndr.nu/pdfs/Annual\_Report\_Swediabkids\_2020.pdf

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# Introduction

2020 has been a year unlike any other year. The pandemic caused by covid-19 has meant that many healthcare professionals have worked more than ever and that planned healthcare often has been left behind for the care of acutely ill patients. When Swediabkid's annual report for this year is compiled, we can state that the care for children and young people with diabetes in Sweden nevertheless remains of the same high quality and that metabolic control has not deteriorated. We also do not note any real increase in severe hypoglycaemia. In 2019, we saw a lower proportion of the newly diagnosed children who had ketoacidosis at diagnosis, but this year we are back at the same level as 2018. Although it is a marginal increase, you can of course wonder if the pandemic made people wait longer before seeking medical care.

On two occasions during the year 2020, validations against SmiNet and the cause of death register have been made. This to evaluate whether children and young people with diabetes are at a greater risk than other persons of the same age to be diagnosed with, cared for as an inpatient or to die due to the Covid-19 infection. No increased risk has been found for young people with diabetes without other risk factors and this is welcome news for all children and young people with diabetes.

The proportion of young people who by 2020 has some type of continuous glucose meter is even higher than in previous years and over 70% of children and young people with type 1 diabetes have an insulin pump.

A great daily job is done, not least by children and young people with diabetes but also the people close to them, to achieve such good results. The pediatric diabetes clinics have continued to do a fantastic job when educating how to use modern technology as well as how to manage the disease.

It is a challenge for pediatric diabetes care to be constantly improved and the hope is that Swediabkids, through easily accessible data, can be used as a tool in the improvement work.

Swediabkid's annual report is published online at www.ndr.nu. Swediabkid's annual report 2020 will function as a complement to the data that are continuously updated on the website (www.ndr.nu) and results that cannot be produced and shown on www.ndr.nu/#/knappen are reported. The register is since a couple of years prepared for direct transfer of data from the medical record. Data from three departments of pediatric in Sweden are currently entered via direct transfer. The purpose of the annual report is to present data that is useful in diabetes care and each year, the steering group reviews comments from users of the register and tries in the best way to improve the presentation in the annual report. This year, among other things, the figure "Distribution of the proportion of time with glucose values within the range 4-8 mmol/l" is new. Our hope is that Swediabkids is a useful tool in the improvement work and a useful contributor towards even higher quality of care for all people with diabetes in Sweden!

If you have questions or suggestions for improvements, you are very welcome to contact me or the register's development manager Ebba Linder.

Karin Åkesson, register director for Swediabkids

# Results 2020

There is an increased number of patients registered in Swediabkids. Figure 1 shows all the children and adolescents under 18 years of age registered, regardless of diabetes type. Figure 2 shows all patients, even those born in '99-01 to show that data on a few people is registered in Swediabkids even after they have turned 18 years old. Data on these older individuals are not included in the rest of the annual report.

As of Figure 5, only data on persons younger than 18 years of age and with type 1 diabetes are included. In Figure 5, the mean value for HbA1c is calculated on each individual's annual mean. Other figures are based on everyone's last visit in 2020. In all figures, data on at least 20 patients are required to be reported, to have the figures be displayed. This annual report shows data for 2020, taken out in February 2021. The figures may therefore differ slightly from the data in NDR's statistics tool "Knappen" where data is updated daily.

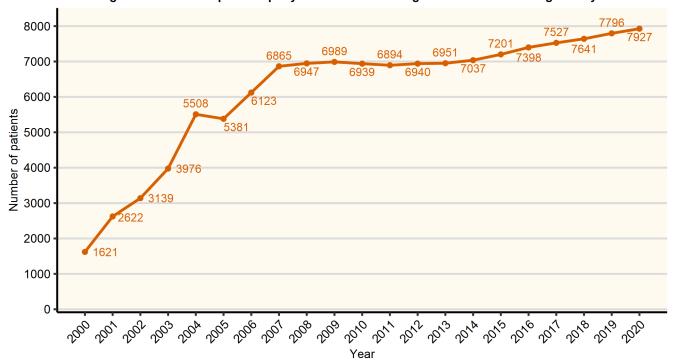


Figure 1. Number of patients per year. All diabetes diagnoses are included. Age < 18 years.

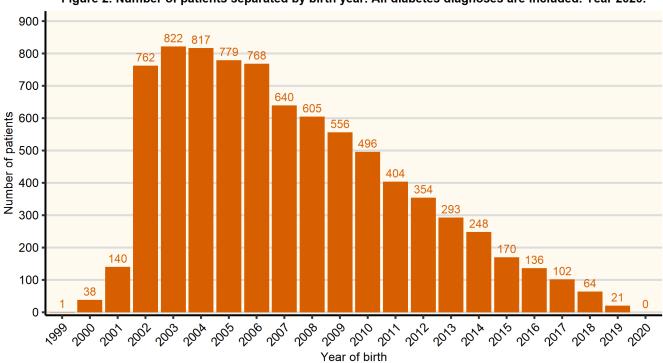
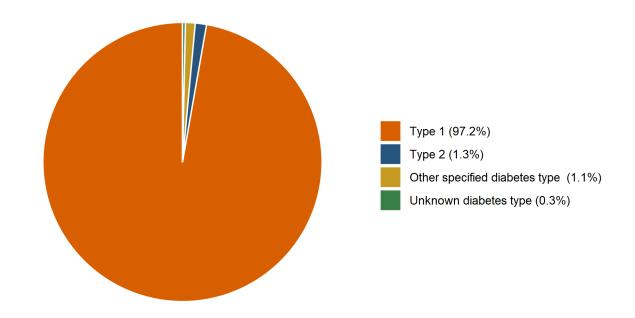


Figure 2. Number of patients separated by birth year. All diabetes diagnoses are included. Year 2020.

Figure 3. The proportion of diabetes diagnoses. Year 2020.



# Coverage rate

The coverage rate is based on the number of people registered within Swediabkids divided by the number of people who retrieved a prescription for insulin in 2019 (data taken from the Medicines Register).

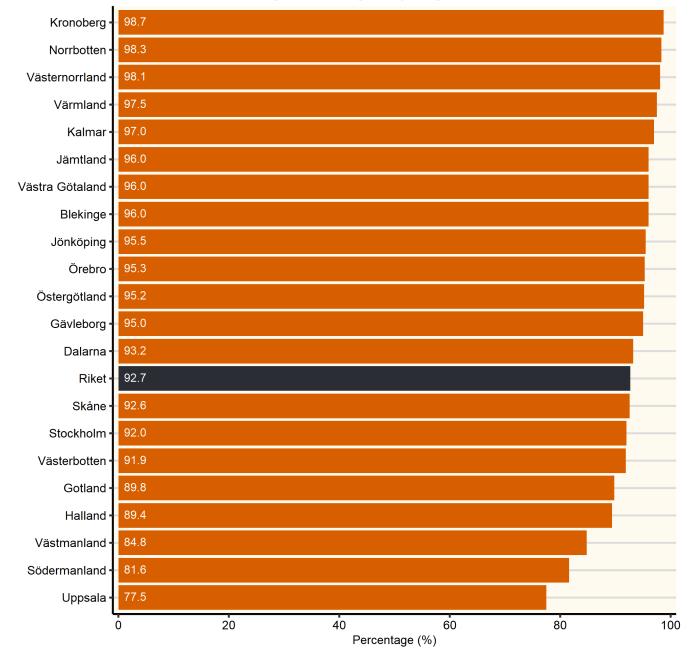


Figure 4. Coverage rate per region. Year 2019.

# HbA1c

Average-HbA1c has continued to stay at a low level during 2020 and the results are almost identical to 2019. The national target for HbA1c for children and adolescents is  $\leq$  48 mmol/mol.

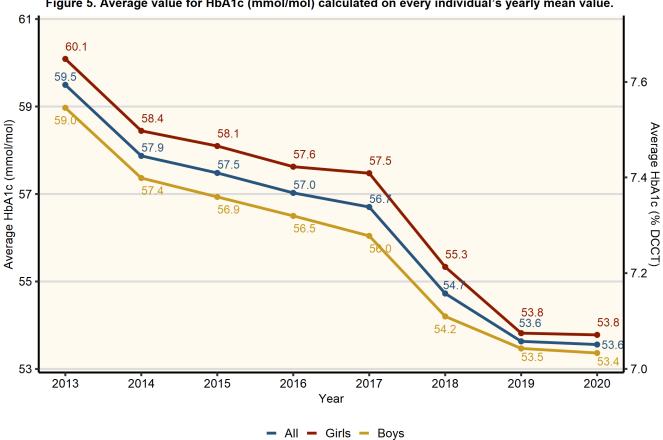


Figure 5. Average value for HbA1c (mmol/mol) calculated on every individual's yearly mean value.

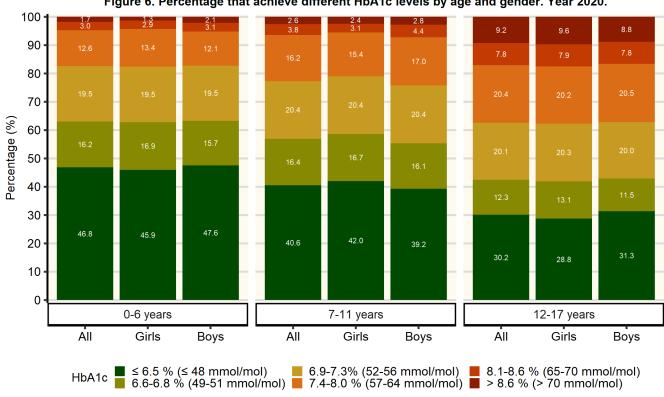


Figure 6. Percentage that achieve different HbA1c levels by age and gender. Year 2020.

HbA1c values in patients with a diabetes duration of less than 3 months have been excluded.

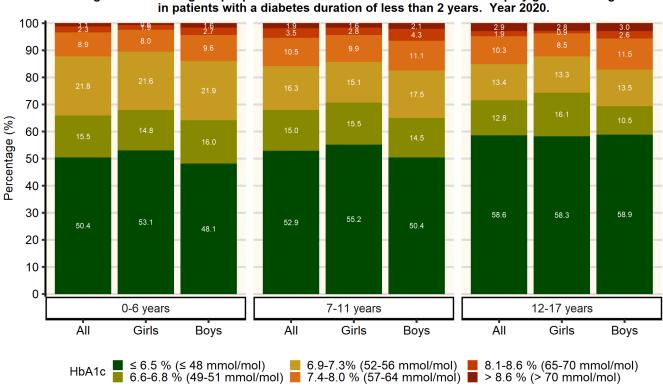


Figure 7. Percentage of people and their different HbA1c levels divided up by gender and age in patients with a diabetes duration of less than 2 years. Year 2020.

There is approximately the same year on year percentage increase in HbA1c during adolescence. At the lowest ages there are only a few individuals; therefore it is impossible to draw any valid conclusions about the youngest children.

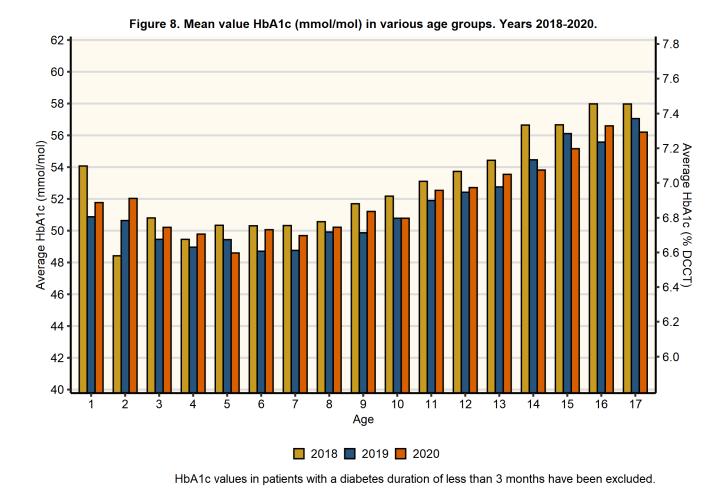


Figure 9 clearly shows how the proportion with HbA1c> 70 mmol/mol continuously decreased while the proportion with good metabolic control increased. 2020 continues to show these fine results.

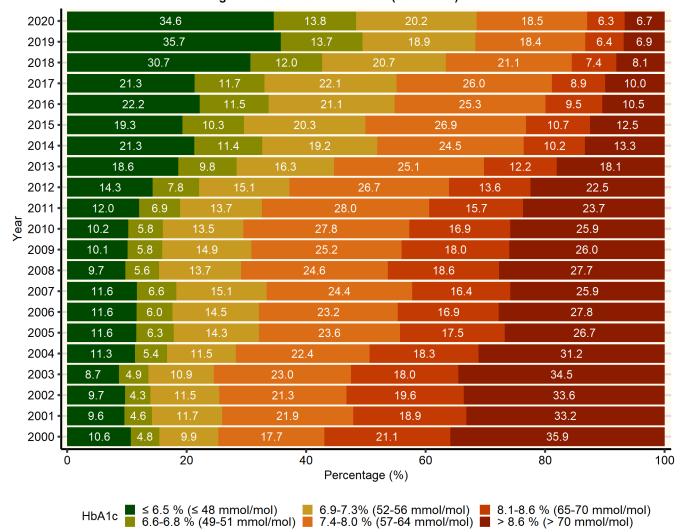


Figure 9. Distribution of HbA1c (mmol/mol) over time.

2020 26.4 28.1 14.3 2019 28.8 29.3 10.3 2018 25.4 29.3 12.5 3.3 2.9 2017 15.7 27.2 14.9 15.2 3.8 3.6 2016 19.9 25.3 13.7 16.9 3.5 3.4 2015 18.3 24.4 5.1 3.7 23.8 15.1 4.6 3.6 2014 23.4 13.3 24.7 4.5 4.5 2013 20.0 14.2 16.1 2012 18.2 21.8 17.8 6.1 12.6 5.6 7.2 7.8 2011 18.9 17.8 2010 14.4 15.7 9.5 22.4 8.1 10.7 13.7 16.1 10.2 8.8 2009 20.7 10.7 10.4 2008 13.0 16.3 9.2 23.7 10.4 2007 14.5 16.9 10.7 18.7 19.7 9.2 10.3 2006 14.3 16.7 11.4 11.4 2005 15.3 13.3 13.7 12.6 2004 14.0 15.3 8.3 19.9 13.5 13.6 2003 12.9 12.4 7.8 23.3 13.5 16.6 2002 15.7 22.2 14.6 16.7 11.1 23.5 13.6 2001 9.5 14.7 7.9 16.2 12.8 2000 15.2 19.0 8.2 13.3 17.7 13.9 Ō 20 40 60 80 100 Percentage (%) ■ > 8.6 % (> 70 mmol/mol) HbA1c

Figure 10. The proportion of HbA1c (mmol/lmol) over time in patients with a diabetes duration of less than 2 years.

Figures 11-17 and Figure 19 present results per clinic. The results show that there is a persistent difference between clinics and clarifies the importance of analyzing the results by individual clinic in order for care to be of increasing high-quality and more equal.

Uddevalla Barnklinik Örnsköldsvik Barnklinik 24.1 24.1 20.4 18.5 9.3 Ystad Barnklinik 28.6 8.6 4.3 10.0 17.1 Lidköping Barnklinik 18.8 26.1 14.5 15.9 Örebro Barnklinik 16.3 28.5 12.7 13.1 5.9 4.5 Linköping Barnklinik 16.3 28.2 11.9 16.7 Kungsbacka Barnklinik 16.2 27.0 14.4 21.6 Skellefteå Barnklinik 33.8 11.3 21.1 4.2 8.5 Barndiabetes SUS Lund 18.8 21.5 13.5 16.2 15.8 8.1 Barndiabetes SUS Malmö 16.1 24.0 12.2 20.1 16.5 6.7 4.3 DSBUS Göteborg Barnklinik 15.9 23.4 10.9 22.4 16.9 3.8 6.7 Hudiksvall Barnklinik 25.0 15.0 18.8 20.0 5.0 13.8 Sachsska Barnklinik 18.3 20.4 13.8 19.2 16.3 8.1 Borås Barnklinik 14.6 23.8 20.4 3.3 17.9 17.5 Jönköping Barnklinik 12.7 25.3 15.1 18.5 18.8 5.1 4.5 Visby Barnklinik 8.2 28.6 14.3 22.4 18.4 6.1 Trollhättan Barnklinik 20.1 14.2 16.4 9.0 15.7 7.5 Skövde Barnklinik 14.1 16.3 3.7 21.5 11.9 96 18.7 24.3 15.9 2.82.8 Kalmar Barnklinik 13.1 22.4 All pediatric clinics 12.8 21.8 13.8 20.2 18.5 6.3 6.7 ALB Solna Barnklinik 12.9 12.2 15.8 20.0 9.4 21.7 Västerås Barnklinik 14.9 6.3 15.3 18.5 144 23.6 16.4 4.3 3.6 Sundsvall Barnklinik 9.3 24.3 186 Kristianstad Barnklinik 9.0 14.6 11.1 21.5 11.8 146 12.6 7.7 Uppsala Barnklinik 10.9 21.4 168 19.0 5.0 Karlskrona Barnklinik 15.7 16.5 12.4 28.9 Sollefteå Barnklinik 8.0 24.0 4.0 28.0 16.0 8.0 23.6 8.6 6.3 Helsingborg Barnklinik 6.9 24.7 16.1 ALB Huddinge Barnklinik 19.9 13.2 18.0 10.6 20.3 5.8 12.2 Östersund Barnklinik 13.3 15.3 18.4 14.3 23.5 6.1 9.2 Norrköping Barnklinik 8.4 19.6 18.2 21.7 5.6 4.9 Luleå Barnklinik 9.7 18.1 12.5 20.8 10.4 7.6 21.3 20.0 Växjö Barnklinik 7.1 20.6 12.9 7 7 10.3 20.5 19.7 Eskilstuna Barnklinik 6.6 20.5 12.3 98 10.7 Gävle Barnklinik 4.6 21.9 27.2 8.6 4.4 5.2 Umeå Barnklinik 14.8 28.1 27.4 5.3 3.6 Halmstad Barnklinik 5.9 18.9 18.9 33 7 Nyköping Barnklinik 14.1 14.1 31.2 20.3 9.4 8.0 Falun Barnklinik 4.0 16.1 21.3 28.2 Karlstad Barnklinik 13.7 18.6 22.5 6.9 4.9 28.1 3.13.1 Gällivare Barnklinik 18.8 25.0 Västervik Barnklinik - 6.2 7.7 6.2 20 40 60 80 100 Percentage (%) HbA1c 
■ ≤ 6.0 % (≤ 42 mmol/mol) 
■ 6.6-6.8 % (49-51 mmol/mol) 
■ 7.4-8.0 % (57-64 mmol/mol) 
■ 6.0-6.5 % (42-48 mmol/mol) 
■ 6.6-7.3% (52-56 mmol/mol) 
■ 8.1-8.6 % (65-70 mmol/mol) 6.6-6.8 % (49-51 mmol/mol) 7.4-8.0 % (57-64 mmol/mol) > 8.6

Figure 11. Variations in HbA1c (mmol/mol) across the various pediatric clinics. Year 2020

Barndiabetes SUS Lund 33.9 32.1 4.3 Karlskrona Barnklinik 39.1 26.1 17.4 34.8 Linköping Barnklinik 30.4 13.0 15.2 Borås Barnklinik 30.4 33.9 19.6 8.9 Jönköping Barnklinik 26.8 35.7 10.7 Umeå Barnklinik 29.0 32.3 12.9 25.8 DSBUS Göteborg Barnklinik 29.2 31.7 9.2 5.8 5.0 Barndiabetes SUS Malmö 23.2 37.5 5.4 14.3 10.7 8.9 Kristianstad Barnklinik 24.0 36.0 8.0 12.0 Skövde Barnklinik 34.4 21.9 6.2 3.1 25.0 9.4 Örebro Barnklinik 28.3 28.3 8.7 Sachsska Barnklinik 34.7 16.3 10.2 21.4 Norrköping Barnklinik 24.0 32.0 4.0 12.0 20.0 8.0 Västerås Barnklinik 28.9 26.3 7.9 5.3 All pediatric clinics 26.4 28.1 14.3 4.6 25.0 Uppsala Barnklinik 27.3 9.1 ALB Solna Barnklinik 24.5 25.5 13.6 17.3 9.1 Luleå Barnklinik 29.4 20.6 17.6 8.8 5.9 4.3 ALB Huddinge Barnklinik 21.3 27.7 12.8 8.5 5.0 5.0 Eskilstuna Barnklinik 20.0 25.0 30.0 10.3 10.3 6.9 Helsingborg Barnklinik 17.2 27.6 27.6 Halmstad Barnklinik 10.7 32.1 10.7 Sundsvall Barnklinik 16.7 23.3 16.7 20.0 10.0 Gävle Barnklinik 3.2 35.5 6.5 16.1 12.9 5.1 33.3 Karlstad Barnklinik 20.5 20.5 20 40 80 100 60 Percentage (%) 6.9-7.3% (52-56 mmol/mol) 7.4-8.0 % (57-64 mmol/mol) HbA1c

Figure 12. The distribution of HbA1c (mmol/mol) per care unit for patients with diabetes of less than 2 years. Year 2020.

Örnsköldsvik Barnklinik 49.1 Uddevalla Barnklinik 49.6 Lidköping Barnklinik Kungsbacka Barnklinik 50.6 51.1 Borås Barnklinik Örebro Barnklinik 51.2 51.3 Kalmar Barnklinik 51.4 Linköping Barnklinik 51.8 Hudiksvall Barnklinik 51.8 Karlskrona Barnklinik Ystad Barnklinik 51.8 Barndiabetes SUS Malmö 52.2 Jönköping Barnklinik 52.6 Skövde Barnklinik 52.6 DSBUS Göteborg Barnklinik Barndiabetes SUS Lund Sundsvall Barnklinik 52.7 Sachsska Barnklinik Västerås Barnklinik 52.9 53.0 Visby Barnklinik Halmstad Barnklinik 53.1 53.4 Skellefteå Barnklinik All pediatric clinics 53.4 Norrköping Barnklinik 53.8 Uppsala Barnklinik Umeå Barnklinik 54.0 Trollhättan Barnklinik 54.1 54.2 Helsingborg Barnklinik Gällivare Barnklinik 54.6 Nyköping Barnklinik Karlstad Barnklinik Östersund Barnklinik ALB Solna Barnklinik Luleå Barnklinik 55.1 Gävle Barnklinik 55.7 55.9 ALB Huddinge Barnklinik Växjö Barnklinik 56.0 Eskilstuna Barnklinik Kristianstad Barnklinik 56.0 Sollefteå Barnklinik Falun Barnklinik 56.8 Västervik Barnklinik 58.0 10 20 30 40 50 60 70

Figure 13. Average HbA1c per care unit. Year 2020.

mmol/mol

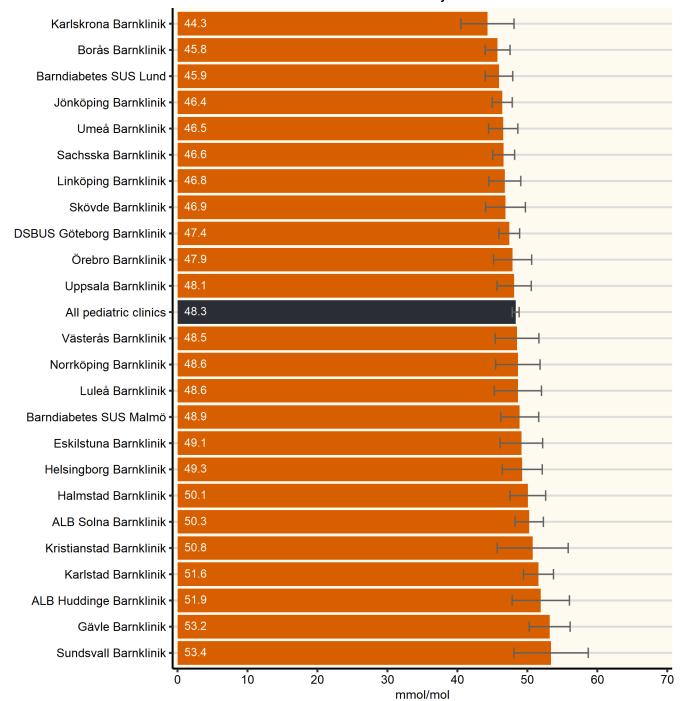


Figure 14. The average HbA1c per care unit for patients with diabetes of less than 2 years. Year 2020.

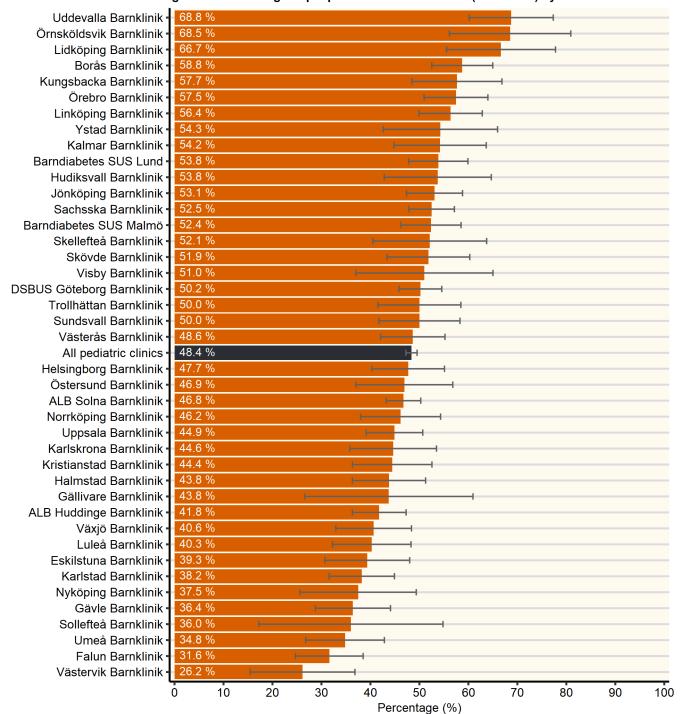


Figure 15. Percentage of people that have HbA1c <52 (mmol/mol) by care unit. Year 2020.

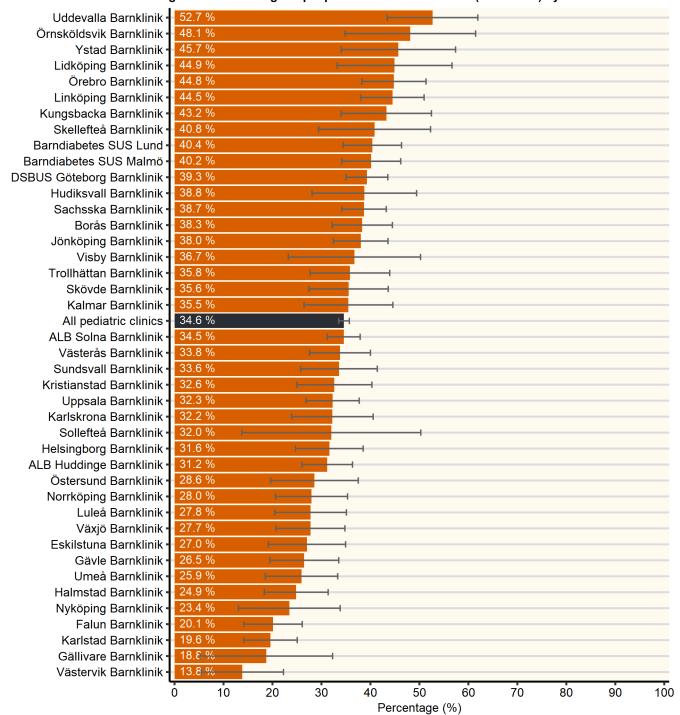


Figure 16. Percentage of people that have HbA1c ≤ 48 (mmol/mol) by care unit. Year 2020

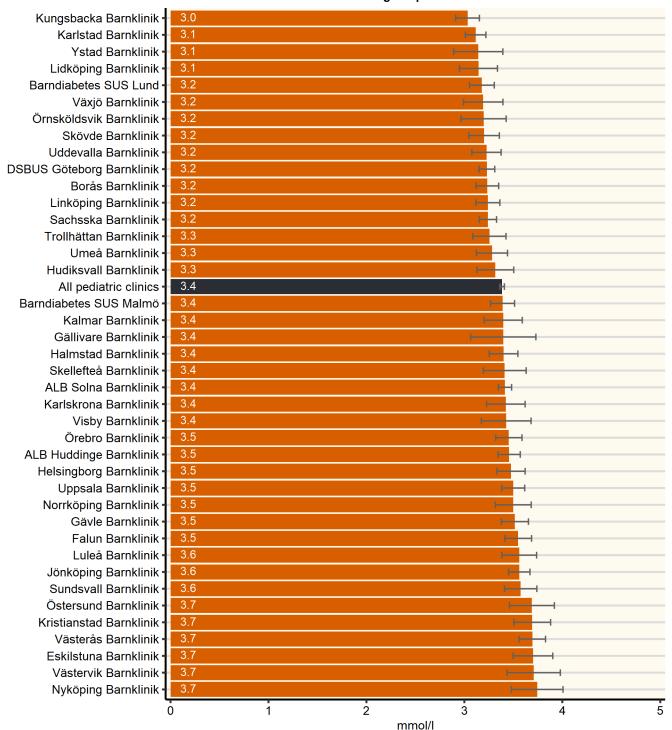


Figure 17. Mean value per care unit of individuals standard deviation of mean glucose in rtCGM / isCGM during the previous 2 weeks. Year 2020.

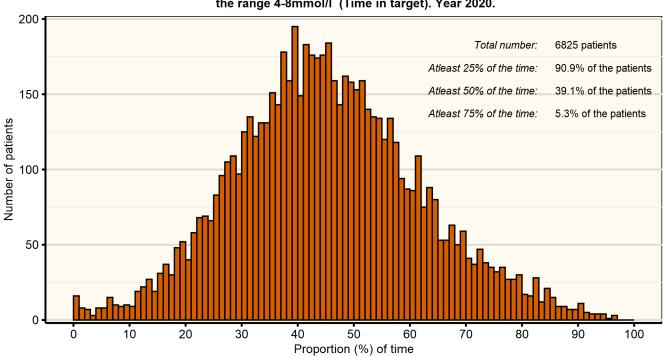


Figure 18. Distribution of the proportion of time, with glucose values within the range 4-8mmol/l (Time in target). Year 2020.

3.62.7 Uddevalla Barnklinik 13.6 35.5 10.0 16.3 5.9 5.2 Trollhättan Barnklinik 31.1 18.5 Kungsbacka Barnklinik 13.2 33.3 15.5 4.7 14.5 Lidköping Barnklinik 14.5 31.9 14.5 Kalmar Barnklinik 12.6 31.9 18.5 11.8 19.3 Linköping Barnklinik 18.9 25.0 10.1 Örebro Barnklinik 12.8 30.4 25.5 Örnsköldsvik Barnklinik 16.4 5.5 16.8 Barndiabetes SUS Lund 25.0 8.6 DSBUS Göteborg Barnklinik 16.5 24.4 13.5 14.7 5.4 5.4 15.6 Borås Barnklinik 18.4 21.3 19.0 19.0 Ystad Barnklinik 12.7 15.9 14.3 Gävle Barnklinik 19.0 19.0 12.4 20.3 9.2 5.2 Skellefteå Barnklinik 29.0 11.6 20.3 8.7 7.2 22.1 Sachsska Barnklinik 14.4 20.4 10.2 8.2 14.4 20.0 4.4 4.4 17.8 Hudiksvall Barnklinik 23.8 6.6 Karlskrona Barnklinik 18.0 16.4 5.7 18.0 20.5 All pediatric clinics 12.6 21.8 11.6 7.6 8.0 Uppsala Barnklinik 11.1 22.6 11.1 18.5 20.7 7.8 8.1 8.8 24.8 10.2 Umeå Barnklinik 13.1 19.0 22.2 6.6 Jönköping Barnklinik 12.8 18.8 11.5 5.6 3.0 Karlstad Barnklinik 27.4 13.7 25.4 22.3 Skövde Barnklinik 15.6 18.5 9.6 8.1 13.3 19.3 Gällivare Barnklinik 5.9 26.5 8.8 5.9 Helsingborg Barnklinik 10.6 21.7 9.0 9.0 5.7 4.6 8.6 23.6 Halmstad Barnklinik 14.9 Luleå Barnklinik 10.8 20.1 7.9 12.2 24.5 Östersund Barnklinik 11.8 17.6 7.8 12.7 10.4 18.8 8.3 8.3 Visby Barnklinik 13.5 15.5 ALB Huddinge Barnklinik 10.9 18.8 24.7 6.2 10.5 ALB Solna Barnklinik 11.1 17.1 10.7 21.6 11.4 11.1 Falun Barnklinik 10.2 18.1 12.4 22.6 22.6 8.5 5.6 13.9 Barndiabetes SUS Malmö 10.3 17.9 11.1 5.9 Sundsvall Barnklinik 19.0 Nyköping Barnklinik 6.3 9.5 Västerås Barnklinik 7.2 16.3 Kristianstad Barnklinik 7.6 14.6 11.1 18.8 22.2 8.9 12.5 13.4 Eskilstuna Barnklinik 10.9 Västervik Barnklinik 10.9 7.8 18.8 18.8 20 40 60 80 100 Percentage (%) ≤ 7,0 mmol/l ■ 8.0-8.3 mmol/l ■ 9.1-10.2 mmol/l >11.1 mmol/l Average glucose

Figure 19. Distribution of average glucose by care unit. Year 2020.

Care units with less than 20 patients or with a reporting rate less than 50% on the variable "average glucose" in rtCGM / isCGM during the previous 2 weeks have been excluded

7.1-7.9 mmol/l 8.4-9.0 mmol/l 10.3-11.1 mmol/l

Figure 20 and Table 1 show the relationship between the 24 pediatric clinics' mean HbA1c in patients with a duration of less than 2 years and the clinic's total mean HbA1c. The figure highlights the importance of early good metabolic control, as we see that clinics with low mean Hba1c in short-term patients also in many cases have a low total mean Hba1c.

Average-HbA1c. <u>4</u>2 4<u>4</u> Average-HbA1c. Duration less than 2 years.

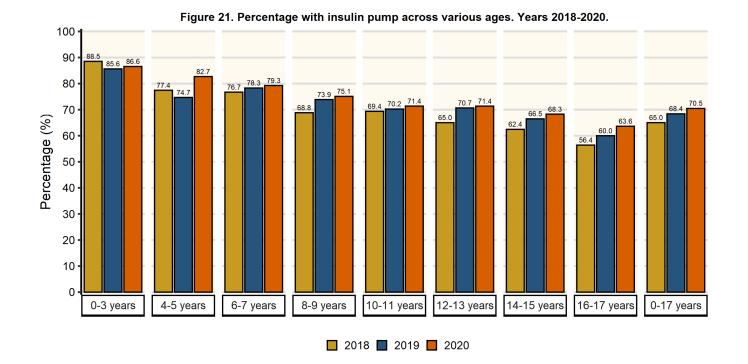
Figure 20. Average HbA1c by clinic versus the clinic's mean HbA1c for patients with diabetes duration <2.0 years. Year 2020.

Table 1. Average HbA1c by clinic versus the clinic's mean HbA1c for patients with diabetes duration <2.0 years. Year 2020.

		Dura	tion < 2,0 år		Totalt
ID	Care unit	Number	Average HbA1c	Number	Average HbA1c
1	Karlskrona Barnklinik	23	44.3	121	51.8
2	Borås Barnklinik	56	45.8	240	51.1
3	Barndiabetes SUS Lund	56	45.9	260	52.6
4	Jönköping Barnklinik	56	46.4	292	52.3
5	Umeå Barnklinik	31	46.5	135	54.0
6	Sachsska Barnklinik	98	46.7	442	52.7
7	Linköping Barnklinik	46	46.8	227	51.4
8	Skövde Barnklinik	32	46.9	135	52.6
9	DSBUS Göteborg Barnklinik	120	47.4	504	52.6
10	Örebro Barnklinik	46	47.9	221	51.2
11	Uppsala Barnklinik	44	48.1	285	53.8
12	Västerås Barnklinik	38	48.5	222	52.9
13	Norrköping Barnklinik	25	48.6	143	53.7
14	Luleå Barnklinik	34	48.6	144	55.1
15	Barndiabetes SUS Malmö	56	48.9	254	52.2
16	Eskilstuna Barnklinik	20	49.1	122	56.0
17	Helsingborg Barnklinik	29	49.3	174	54.2
18	Halmstad Barnklinik	28	50.1	169	53.1
19	ALB Solna Barnklinik	110	50.3	770	54.8
20	ALB Huddinge Barnklinik	47	50.5	311	55.9
21	Kristianstad Barnklinik	25	50.8	144	56.0
22	Karlstad Barnklinik	39	51.6	204	54.8
23	Gävle Barnklinik	31	53.1	151	55.7
24	Sundsvall Barnklinik	30	53.4	140	52.7
	All pediatric clinics	1346	48.3	7280	53.4

# Treatment with insulin pump and rtCGM / isCGM1

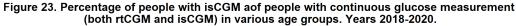
Proportion of people with a pump and a continuous glucose monitoring system (both rtCGM and isCGM) continues to increase. In Figure 21, the proportion with a pump is calculated in all individuals with type 1 diabetes, where data on the method of giving insulin has been documented in the register, and in Figure 22, the denominator is all people with type 1 diabetes.

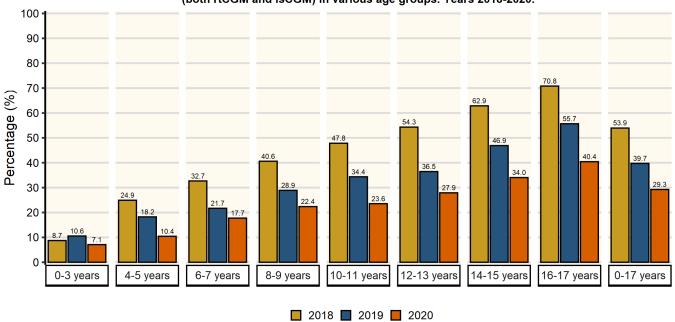


<sup>1</sup>rtCGM = real time CGM isCGM = intermittent scanning CGM

98.2 98.7 99.7 97.7 98.9 99.6 100 -94.1 94.6 97.0 91.6 90 80 70 Percentage (%) 60 50 40 30 20 10 0 0-3 years 6-7 years 14-15 years 16-17 years 0-17 years 4-5 years 8-9 years 10-11 years 12-13 years **2018 2019 2020** 

Figure 22. Percentage of people with continuous glucose measurement (both rtCGM and isCGM) in various age groups. Years 2018-2020.



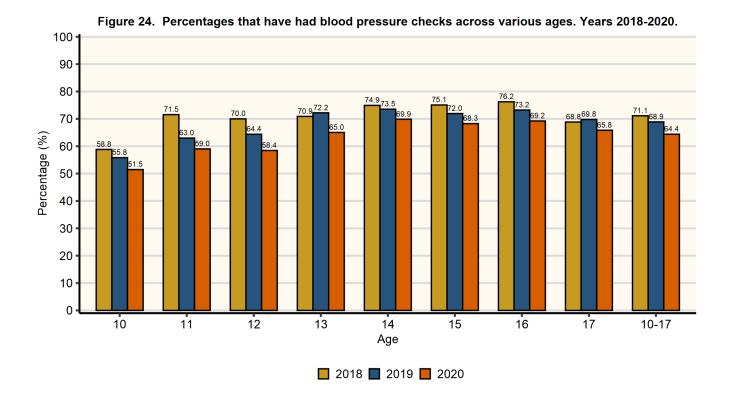


# Screening for complications

#### Control of blood pressure and albuminuria.

According to the Swedish Guidelines<sup>2</sup>, blood pressure and albuminuria should be checked annually from 10 years of age. Figures 24 and 25 show that the quality target of at least 80% of patients being checked annually has not been achieved. Blood pressure has been controlled in about 64% and albuminuria in almost 50% of the patients. It is unclear whether the low screening frequency is due to the values not being registered in Swediabkids or whether annual checks are not carried out at all.

Screening for complications is an important area that needs to be improved. In Figure 24–25, the denominator is all unique patients who are 10 years and older and have type 1 diabetes. Figure 25 is based on the patients who have either a value on the variable albuminuria or on u-Alb / Creatinine and the denominator is all unique patients who are 10 years and older and have type 1 diabetes.



<sup>2</sup>Swedish Guidelines 2016/2017, Pediatric Physician's Association's (BLF in Sweden) sub-association for endocrinology and diabetes.

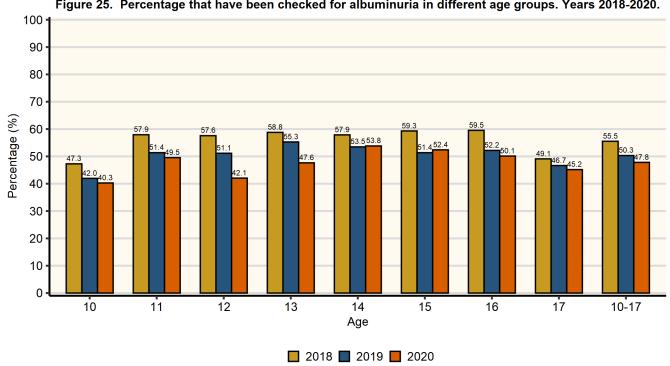


Figure 25. Percentage that have been checked for albuminuria in different age groups. Years 2018-2020.

Table 2. Albumin/creatinine ratio (ACR). Age group 10-17 years. Years 2018-2020.

		2018		2019	2020		
	Number	Percentage (%)	Number	Percentage (%)	Number	Percentage (%)	
Number of patients 10-17 years	5669		5716		5829		
Number/proportion with ACR	2823	49.8	2587	45.3	2604	44.7	
<3.5 mg/mmol	2650	93.9	2433	94.0	2483	95.4	
3.5-25 mg/mmol	158	5.6	142	5.5	109	4.2	
>25 mg/mmol	15	0.5	12	0.5	12	0.5	

Table 3. Proportion of patients with albuminuria. Age group 10-17 years. Years 2018-2020.

		2018		2019	2020		
	Number	Percentage (%)	Number	Percentage (%)	Number	Percentage (%)	
Number of patients 10-17 years	5669		5716		5829		
Number/proportion with value	2635	46.5	2205	38.6	1791	30.7	
No	2569	97.5	2135	96.8	1737	97.0	
Normal value	17	0.6	21	1.0	19	1.1	
Microalbuminuria	43	1.6	41	1.9	29	1.6	
Macroalbuminuri	6	0.2	8	0.4	6	0.3	

## **Retinal examinations**

Fundus photography starts routinely after 2 years of diabetes duration, earliest at the age of 10 years, and is repeated every other year. In case of pathological findings, more frequent examinations are made.

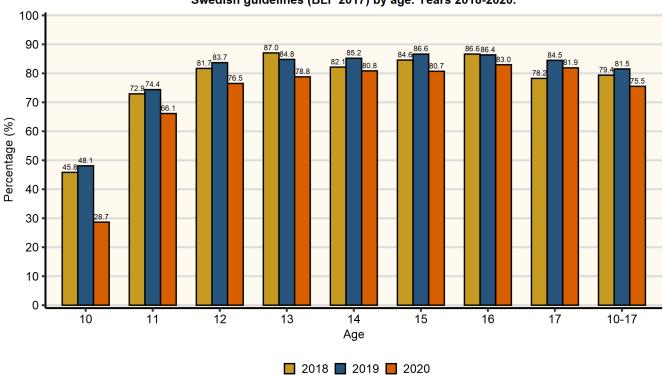
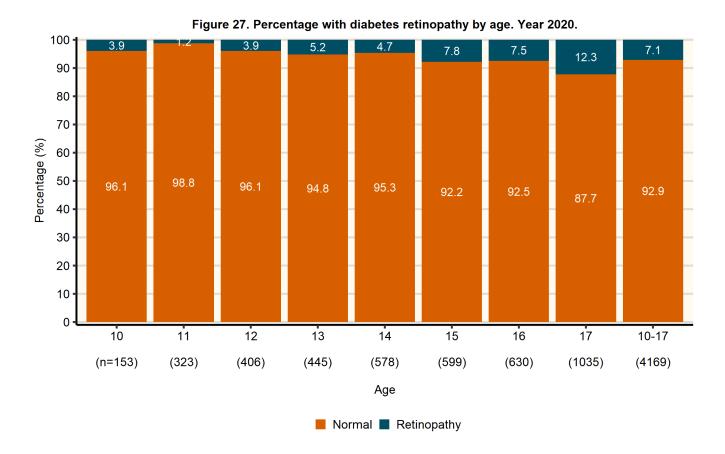
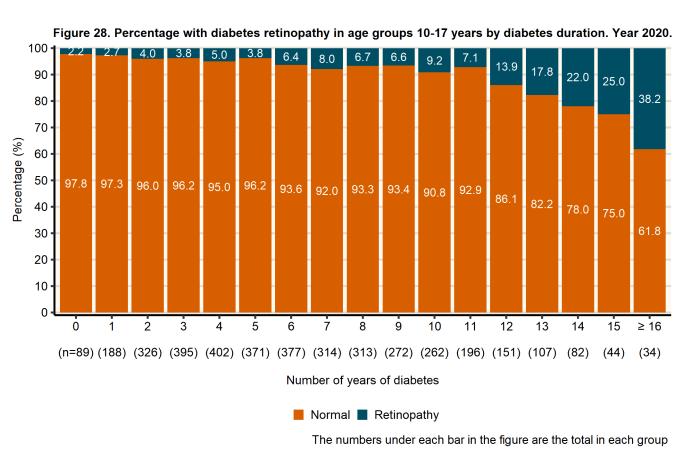


Figure 26. Percentage with examinations for retinal changes according to Swedish guidelines (BLF 2017) by age. Years 2018-2020.





# Living habits

According to BLF's Guidelines for children and adolescents in Sweden, teens with diabetes should be asked about smoking from the age of 13 years. In 2020, 78% of teens diagnosed with diabetes aged 13–17 years were asked about smoking. The data is based on what the teens have answered to questions about smoking at a visit to a diabetic clinic. At a group level, those who smoke have a significantly higher mean HbA1c than non-smokers. Those listed in the figures as smokers include everyone that smokes, regardless of whether they stated that they smoke daily, occasionally or that they stopped smoking during the current year. The denominator is all individuals 13-17 years of age, with type 1 diabetes where data on smoking habits is registered.

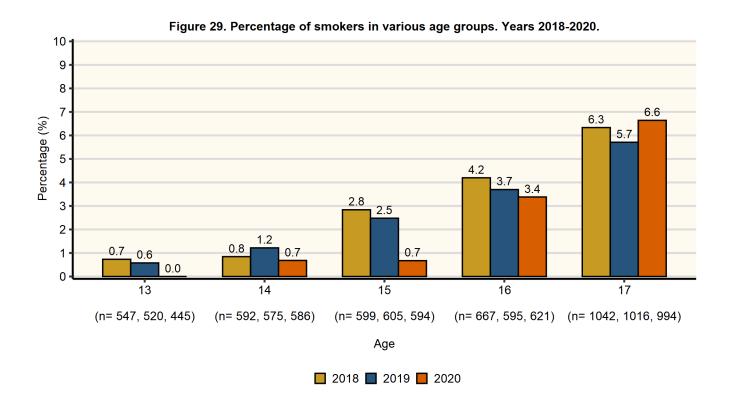
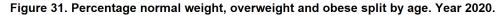


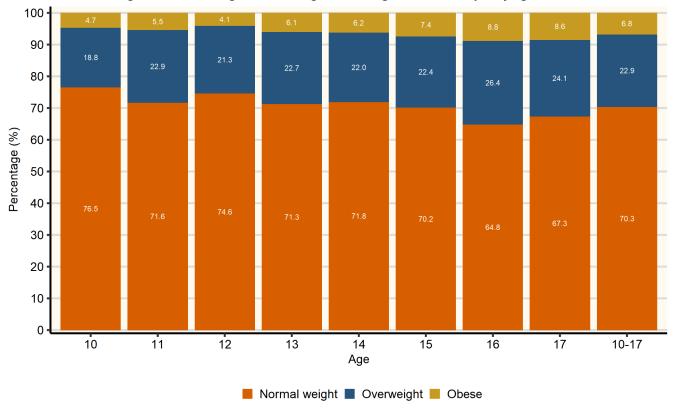
Table 4. Smoking and average HbA1c levels (IFCC=mmol/mol, DCCT=%). Age group 13-17 years. Year 2020.

Smoking habits	Number of patients	Mean HbA1c (CI) IFCC	Mean HbA1c (CI) DCCT
Have not smoked during the year	3145	54.8 (54.4 - 55.2)	7.16% (7.12 - 7.20)
Smokes occationally or daily	95	69.7 (66.1 - 73.3)	8.53% (8.20 - 8.86)
Lacks reported information	927	55.4 (54.6 - 56.2)	7.22% (7.15 - 7.29)

30 25 Percentage (%) 01 01 02 18.5 18.4 14.0 12.1 11.6 11.4 11.2 10.2 9.7 10.8 10.1 9.4 10 8.3 7.3 8.1 7.3 8.4 7.6 5 0 10 11 12 13 14 15 16 17 10-17 Age ■ Girls ■ Boys

Figure 30. The percentage of children with at least 60 minutes of physical activity, every day, 7 days a week. Divided by age and gender. Year 2020.





# Hypoglycaemia and ketoacidosis

Table 5. Number and percentage of patients who have had hypoglycaemia including unconsciousness with or without seizures.

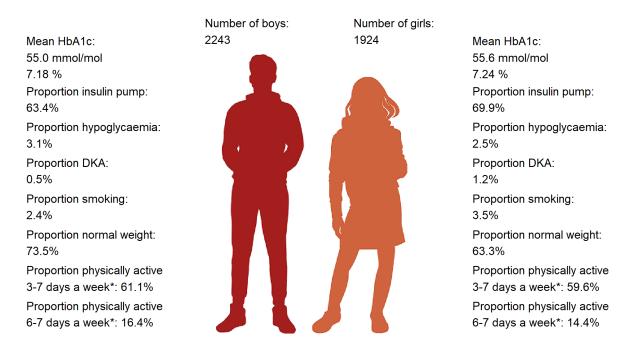
Year	Number of patients	Number of patients with hypoglycaemia	Proportion (%)	Number of episodes
2019	7543	213	2.8	244
2020	7639	174	2.3	215

Table 6. Number and percentage of patients who have had diabetes ketoacidosis (DKA).

Year	Number of patients	Number of patients with DKA	Proportion (%)	Number of episodes
2019	7543	55	0.7	56
2020	7639	55	0.7	60

#### **Gender differences**

Figure 32. Boys and Girls, 13-17 years. Clinical characteristics. Year 2020.



HbA1c-värden vid diabetesduration < 3 månader har exkluderats.

<sup>\*</sup>The goal, for all children and adolescents, is to be physically active at least 60 minutes per day. The Public Health Authority report "School children's health habits in Sweden 2017/18" shows that 13% of 15-year-old boys and 9% of 15-year-old girls are active every day.

# **New onset diabetes**

There is a backlog in the registration of newly diagnosed individuals. Therefore, reporting on patients for 2020 is incomplete.

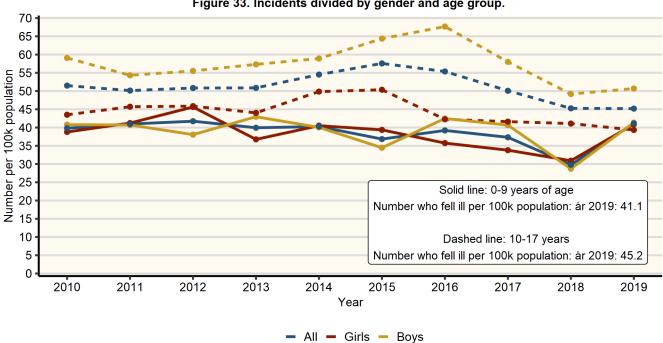


Figure 33. Incidents divided by gender and age group.

Information on Sweden's population aged 0-9 years old and 10 to 17 is taken from Statistics Sweden (15-1-2021)

		0-4 ye	ars	5-9 ye	ars	10-14 y	ears	15-17 y	ears	0-17 ye	ears
Diagnosis year	Gender	Number	%	Number	%	Number	%	Number	%	Number	%
	All	168		293		344		140		945	
2016	Girls	74	44.0	130	44.4	134	39.0	45	32.1	383	40.5
	Boys	94	56.0	163	55.6	210	61.0	95	67.9	562	59.5
2017	All	155		291		338		115		899	
	Girls	65	41.9	131	45.0	135	39.9	47	40.9	378	42.0
	Boys	90	58.1	160	55.0	203	60.1	68	59.1	521	58.0
	All	134		225		309		112		780	
2018	Girls	71	53.0	110	48.9	140	45.3	45	40.2	366	46.9
	Boys	63	47.0	115	51.1	169	54.7	67	59.8	414	53.1
	All	189		308		308		123		928	
2019	Girls	74	39.2	166	53.9	129	41.9	53	43.1	422	45.5
	Boys	115	60.8	142	46.1	179	58.1	70	56.9	506	54.5
0000	All	114		221		271		95		701	
2020	Girls	44	38.6	112	50.7	133	49.1	29	30.5	318	45.4
	Boys	70	61.4	109	49.3	138	50.9	66	69.5	383	54.6

Table 7. New onset diabetes. Years 2016-2020.

Table 8. Mean HbA1c (IFCC=mmol/mol, DCCT=%) at diagnosis. Years 2016-2020.

Diagnosis year		0-4 years	5-9 years	10-14 years	15-17 years	0-17 years
	Number	125	236	278	111	750
2016	Mean HbA1c (CI) IFCC	79.3 (76.2 - 82.4)	89.6 (86.7 - 92.4)	101.9 (98.6 - 105.1)	101.2 (95.5 - 106.8)	94.1 (92.2 - 96.0)
	Mean HbA1c (CI) DCCT	9.41% (9.12 - 9.69)	10.35% (10.08 - 10.61)	11.47% (11.17 - 11.77)	11.41% (10.89 - 11.92)	10.76% (10.59 - 10.94)
	Number	129	241	287	94	751
2017	Mean HbA1c (CI) IFCC	78.9 (75.7 - 82.1)	91.9 (89.0 - 94.8)	100.5 (97.3 - 103.8)	104.4 (97.7 - 111.2)	94.6 (92.6 - 96.5)
	Mean HbA1c (CI) DCCT	9.37% (9.08 - 9.66)	10.56% (10.30 - 10.83)	11.35% (11.05 - 11.65)	11.70% (11.09 - 12.32)	10.80% (10.62 - 10.98)
	Number	124	208	279	99	710
2018	Mean HbA1c (CI) IFCC	83.9 (79.8 - 88.0)	90.9 (87.8 - 93.9)	101.7 (98.5 - 105.0)	103.7 (98.0 - 109.5)	95.7 (93.7 - 97.7)
	Mean HbA1c (CI) DCCT	9.82% (9.45 - 10.20)	10.47% (10.19 - 10.75)	11.46% (11.16 - 11.76)	11.64% (11.12 - 12.17)	10.91% (10.73 - 11.09)
	Number	155	265	264	99	783
2019	Mean HbA1c (CI) IFCC	79.9 (77.2 - 82.7)	93.9 (91.2 - 96.6)	103.5 (100.2 - 106.8)	100.2 (94.2 - 106.2)	95.2 (93.3 - 97.0)
	Mean HbA1c (CI) DCCT	9.46% (9.21 - 9.71)	10.74% (10.49 - 10.99)	11.62% (11.32 - 11.92)	11.32% (10.77 - 11.87)	10.86% (10.69 - 11.02)
	Number	109	213	257	85	664
2020	Mean HbA1c (CI) IFCC	81.7 (77.7 - 85.8)	95.2 (92.0 - 98.3)	105.6 (102.0 - 109.3)	107.8 (101.6 - 114.0)	98.6 (96.5 - 100.8)
	Mean HbA1c (CI) DCCT	9.63% (9.26 - 10.00)	10.86% (10.57 - 11.15)	11.82% (11.48 - 12.15)	12.02% (11.45 - 12.58)	11.18% (10.98 - 11.37)

#### Metabolic acidosis

Metabolic acidosis (diabetic ketoacidosis, DKA) is defined as pH <7.30. In 2019, the proportion who had metabolic acidosis at diagnosis decreased. In 2020, the proportion is slightly higher but comparable with 2018. The reasons for the increase could be due to several mitigating factors and it needs to be analyzed further.

About 50% of cases have had contact with someone in healthcare before the admission for DKA. Of these, about 1/3 have not been handled correctly, i.e. referred to the pediatric clinic on the same day<sup>3</sup>. Increased knowledge of the symptoms of diabetes and ketoacidosis amongst the general population and within primary care areas could significantly reduce the development of ketoacidosis at onset.

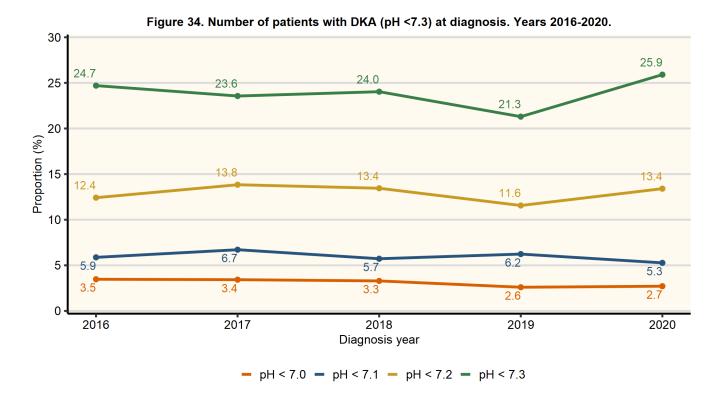


Figure 35. The percentage with DKA (pH<7,30) at diagnosis by age group. Years 2016-2020. 60 55 51.1 50.0 48.1 50 44.0 45 40 35.3 Proportion (%) 35 30.4 28.0 26.7 25.2 25.9 24.7 24.0 23.6 20 21.3 15.9 14.3 13.9 12.6 15 9.2 10 5 0 2016 2017 2018 2019 2020 Diagnosis year <2 years = 2-7 years = 8-17 years = 0-17 years</p>

<sup>3</sup>Wersäll J H, Hanas R et al. ISPAD 2017, abstract eP173; Contacts with health care services for diabetes-related symptoms before admission for DKA among peadiatric patients in Sweden. A two-year national survey.

Table 9. Number of patients with DKA (pH <7.3) at diagnosis. Years 2016-2020.

Diagnosis year	Age group	Number of patients	Number of pH	Number of pH < 7.3	Proportion (%) pH < 7.3
	0-1 years	43	34	12	35.3
0040	2-4 years	125	95	13	13.7
2016	5-9 years	293	237	55	23.2
	10-14 years	344	277	83	30.0
	15-17 years	140	106	22	20.8
	0-17 years	945	749	185	24.7
	0-1 years	34	27	13	48.1
00.47	2-4 years	121	104	9	8.7
2017	5-9 years	291	236	48	20.3
	10-14 years	338	278	85	30.6
	15-17 years	115	85	17	20.0
	0-17 years	899	730	172	23.6
	0-1 years	33	32	16	50.0
0040	2-4 years	101	93	13	14.0
2018	5-9 years	225	209	37	17.7
	10-14 years	309	271	77	28.4
	15-17 years	112	94	25	26.6
	0-17 years	780	699	168	24.0
	0-1 years	55	45	23	51.1
0010	2-4 years	134	108	8	7.4
2019	5-9 years	308	268	39	14.6
	10-14 years	308	259	68	26.3
	15-17 years	123	90	26	28.9
	0-17 years	928	770	164	21.3
	0-1 years	25	25	11	44.0
	2-4 years	89	82	8	9.8
2020	5-9 years	221	211	41	19.4
	10-14 years	271	258	85	32.9
	15-17 years	95	88	27	30.7
	0-17 years	701	664	172	25.9

# **Publications in 2020**

- 1. Samuelsson J, Samuelsson U, Hanberger L, Bladh M, Åkesson K. Poor metabolic control in childhood strongly correlates to diabetes-related premature death in persons <30years of age-A population-based cohort study. Pediatr Diabetes. 2020 Jan 14
- Cherubini V, Grimsmann JM, Åkesson K, Birkebæk NH, Cinek O, Dovč K, Gesuita R, Gregory JW, Hanas R, Hofer SE, Holl RW, Jefferies C, Joner G, King BR, Mayer-Davis EJ, Peña AS, Rami-Merhar B, Schierloh U, Skrivarhaug T, Sumnik Z, Svensson J, Warner JT, Bratina N, Dabelea D. Temporal trends in diabetic ketoacidosis at diagnosis of paediatric type 1 diabetes between 2006 and 2016: results from 13 countries in three continents. Diabetologia. 2020 Aug;63(8):1530-1541.
- 3. Anderzén J, Hermann JM, Samuelsson U, Charalampopoulos D, Svensson J, Skrivarhaug T, Fröhlich-Reiterer E, Maahs DM, Akesson K, Kapellen T, Fritsch M, Birkebaek NH, Drivvoll AK, Miller K, Stephenson T, Hofer SE, Fredheim S, Kummernes SJ, Foster N, Amin R, Hilgard D, Rami-Merhar B, Dahl-Jørgensen K, Clements M, Hanas R, Holl RW, Warner JT. International benchmarking in type 1 diabetes: Large difference in childhood HbA1c between 8 high-income countries but similar rise during adolescence-A quality registry study. Pediatr Diabetes. 2020 Apr 6.
- 4. Svensson J, Møller Sildorf S, Bøjstrup J, Kreine S, Skrivarhaug T, Hanberger L, Petersson C, Åkesson K, Frøisland D H, Chaplin J The DISABKIDS© generic and diabetes specific modules are valid but not directly comparable between Denmark, Sweden and Norway Pediatr Diabetes. 2020 Aug;21(5):900-908.





# National Diabetes Registry (NDR) goal is better diabetic care.

Diabetes is a serious chronic disease with an increased risk of cardiovascular disease and premature death. There is a very strong scientific support that good multifactorial diabetes treatment can delay and prevent diabetes complications in a cost-effective way. This is a daily challenge for diabetes care. National Diabetes Register (NDR) is a tool to drive the improvement work and follow how it goes, as well as identifying additional challenges. It is a tool that in part benefits daily improvement work but also since the data is public it can also be used as a foundation for national improvement.

NDR is an international model for improvement work and how we learn more and more about diabetes. The effect of the registration and the results generated by the register has undoubtedly been a part of the improved risk factor control and the reduction in cardiovascular morbidity and mortality rates in both type 1 and type 2 diabetes that can be observed. The register's work should continue to focus on yet further improvements.

