

National Diabetes Audit, 2017-21Diabetes UKAdolescent and Young Adult Type 1 DiabetesDiabetes

England 16 June 2022

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AYA 2017-21: Type 1 Diabetes

Executive summary and recommendations





Executive summary

Background

Type 1 diabetes often starts in childhood. It is widely recognised that adolescence and young adulthood is a period during which delivery of routine care and achievement of treatment targets is least satisfactory.

Key findings:

- In people with type 1 diabetes aged 15 to 25 years old:
 - There were more males than females (55.2% vs. 44.8%), and more than expected lived in areas of social deprivation.
 - The proportion of people who were living with overweight and obesity increased progressively from the age of 18 years old.
 - Recorded completion of most annual, National Institute for Health and Care Excellence (NICE) recommended care
 processes dropped steadily between the ages of 17 and 20 years and then plateaued. Low rates of Urine Albumin
 Creatinine Ratio (UACR) checks were notable at all ages.
 - Mean/median HbA1c and the proportion of people achieving HbA1c treatment targets deteriorated steadily between the ages of 15 and 20 years old and improved steadily thereafter.
 - For 15 to 20 year olds, the mean/median HbA1c was similar at all ages of leaving paediatric services.
 - Diabetic ketoacidosis (DKA) frequency (single and multiple inpatient admissions with episode of DKA) started to rise at 16 years old, peaked at 18 years old and then fell slowly but progressively.
 - 81.9% of adolescents using insulin pumps continue to do so in young adulthood. Insulin pump usage rates dropped by almost two thirds (33.3% to 12.1%) between the ages of 15 and 25 years. At all ages pump users were more likely to achieve HbA1c treatment targets and less likely to experience DKA.

Recommendations

Recommendation 1

Adult services, both specialist and primary care, should develop systems to ensure that all adolescents and young adults continue to receive NICE recommended health checks after discharge from paediatric care.

Recommendation 2

Specialist paediatric and adult services should collaborate to develop systems of care that are aligned with the multiple life changes which accompany late adolescence/early adulthood in order to minimise age associated deteriorations in level of glucose control (15-20 years old) and frequency of diabetic ketoacidosis (15-18 years old).

Recommendation 3

Young adults with type 1 diabetes transferring from paediatric services and using insulin pump therapy should be supported by adult specialist services to continue and those who are eligible by NICE criteria should be offered insulin pump treatment.

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Experts By Experience

Below are quotes from young adults with lived experience of type 1 diabetes and transferring from paediatric diabetes services to adult diabetes services:

"Whilst perhaps unsurprising, it is still worrying that there is a steep fall-off in the completion of healthcare checks and a rise in Hb1Ac during the period where transition from paediatric to adult services is likely to have occurred. Moving from paediatric to adult services can be a daunting prospect, as well as a logistical challenge. This decline in care and outcomes over the transition age highlights the need for specialised care and support for adolescents and young adults. There needs to be better coordination between paediatric and adult services, as well as improved education programmes for adolescents and young adults.

As the transition to adult services can also coincide with other life changes and increasing independence, specialised transition services are needed so that we, as young adults, feel prepared to manage our diabetes. Attending and engaging with diabetes care during periods of changes between teams and locations, especially when leaving home, can be challenging. Leaving established relationships and familiar systems during transfer can be confusing and difficult to navigate without adequate support. The specific challenges faced during this period while living with diabetes cannot be underestimated and needs to be reflected in the care and support offered."



AYA 2017-21: Type 1 Diabetes

Introduction





Introduction

The Adolescent and Young Adult Type 1 Diabetes Audit (AYA) links datasets from the adult and paediatric national diabetes audits. The AYA audit has been designed to audit care provision during the period when young people with diabetes move from paediatric to adult based clinical care. The audit covers the period 01 January 2017 to 31 March 2021.

The National Diabetes Audit (NDA) provides a comprehensive view of diabetes care in England and Wales. It measures the effectiveness of diabetes healthcare against NICE Clinical Guidelines and NICE Quality Standards^{*,**}.

The National Paediatric Diabetes Audit (NPDA) was established to compare the care and outcomes of all children and young people with diabetes receiving care from Paediatric Diabetes Units (PDUs) in England and Wales.

At the time of producing this report the Welsh NPDA data was not available to NHS Digital. Therefore, to ensure timescales for publication of this population level report were met, only England data is included (94.7% of the combined data***). Welsh NPDA data has since become available meaning Welsh data is included in the national and locality level dashboard accompanying this report. Consequently, the combined England and Wales national results in the dashboard may be slightly different to the England national results in this report.

Why is transfer from Paediatric to Adult Care important?

- Diabetes is a very difficult condition to manage. From the point of diagnosis onwards, diabetes has a major impact on the life of a
 young person, placing an enormous 24/7 burden on them and their family or carers. Supporting lifelong management of the condition
 is essential in achieving the most positive outcomes for the individual.
- Adolescents making the transfer from childhood to adulthood are particularly at risk of disruption in care, with both short and long-term health effects. It is therefore very important that the handover of care from paediatric to adult services defends against this and does not intensify the risk.
- Care during this period needs collaborative support from medical, educational and psychological services. Engagement between
 paediatric and young adult services to provide continuity of care, and give young adults confidence to continue to manage their
 diabetes is pivotal. Falling short of this can lead to serious and lasting consequences, resulting in increased morbidity and mortality.

Introduction

Adolescent and Young Adult Type 1 Diabetes cohort

A new diagnosis validation process* has been introduced to this report. Therefore the type 1 cohort used for this report will not be the same as the type 1 cohort used in previous NDA reports. The cohort used for this report consists of people:

- Recorded as being diagnosed with type 1 diabetes within the 2017-18 to 2019-20 NPDA audits or 2017-18 to 2020-21 NDA core audits.
- Record of insulin treatment within audit year, either:
 - Prescribed insulin treatment consistent with one of the following regimens:
 - Insulin pump**
 - Basal-bolus
 - Fixed mix.
 - On insulin treatment according to a NPDA submission.
 - On an insulin pump according to a NDA submission from a specialist service.
- Aged between 15 and 25 years at any point during the audit period (01 January 2017 to 31 March 2021).

National Diabetes Transition Audit (NDTA) becomes the AYA Type 1 Diabetes audit

The AYA audit was previously referred to as the National Diabetes Transition Audit (NDTA), but has been renamed to AYA to reflect the change in approach to auditing care provision of young people with type 1 diabetes. The NDTA measured changes in glycaemic control and care provision across the period of transfer, looking only at people who had records of transfer from paediatric services to adult specialist services. However, AYA measures care provided and treatment outcomes across the age range 15 to 25 years, including everyone within this age range in NPDA and NDA during the AYA audit period. This approach aims to describe the trajectory of care, identify age groups which should be a priority for improvement, and create a framework for monitoring improvement action plans.

57,060 people with type 1 diabetes were aged between 15 and 25 years old during the AYA period. A third were known to paediatric services (34.3%).

AYA 2017-21: Type 1 Diabetes

What are the characteristics of adolescents and young adults diagnosed with type 1 diabetes?





AYA: Sex, Ethnicity, Deprivation

- More adolescents and young adults with type 1 diabetes were male than female. •
- The proportion of ethnic minorities (excluding white minorities) among • adolescents and young adults with type 1 diabetes is lower than that found in the general population.
- A greater proportion of adolescents and young adults with type 1 diabetes lived in the most deprived areas compared to that found in the general population.

Table 2: Adolescents and young adults with type 1 diabetes, by ethnicity*, England, 2017-21

Type 1 Diabetes Table 1: Adolescents Sex and young adults Number with type 1 diabetes, Total 57,060 by sex*, England, Male 31.520 2017-21 Female 25.540

Table 3: Adolescents and young adults with type 1 diabetes, by social deprivation*,****, England, 2017-21

%

55.2

44.8

	Type 1 Diabetes			England***		Ţ	England*****		
Ethnicity	Number	%	% of known**	%	Deprivation	Number	%	% of known*****	%
Total	57,060	-	-	-	Total	57,060	-	-	-
White	46,850	82.1	86.1	80.5	Most deprived	11,595	20.3	22.4	20.7
Asian	3,155	5.5	5.8	10.8	2nd most deprived	10,670	18.7	20.6	20.0
Black	2,100	3.7	3.9	4.0	3rd most deprived	10,340	18.1	20.0	19.3
Mixed	1,205	2.1	2.2	3.2	2nd least deprived	9,515	16.7	18.4	18.2
Other	1,095	1.9	2.0	1.4	Least deprived	9,700	17.0	18.7	21.8
Unknown / Not stated	2,655	4.7	-	-	Unknown	5,235	9.2	-	-

* Totals may not sum due to data suppression. See 'Additional Information' for more details. ** People whose ethnicity is 'Unknown / Not stated' excluded from calculation. *** Data from 2011 Census for people aged between 15 and 29 11 years old (England only). Ethnicity data for people aged between 15 and 25 years old not available. **** Based on latest known social deprivation guintile when aged between 15 and 25 years old at start of audit year. ***** People whose social deprivation quintile is 'Unknown' excluded from calculation. ***** Based on linking ONS 2020 mid-year population estimates for people aged between 15 and 25 years old in England to Index of Multiple Deprivation.

Body Mass Index

Table 4: Adolescents and young adults with type1 diabetes, by BMI status*,***,***, England, 2017-21

	All 1			
BMI status	Total	Number	%	% of known****
Underweight		1,705	3.6	3.7
Healthy weight		23,660	50.3	51.7
Overweight	47,080	12,195	25.9	26.7
Obese		8,175	17.4	17.9
Unknown		1,345	2.9	-

- Half (50.3%) of adolescents and young adults with type 1 diabetes were of a healthy weight according to their BMI.
- However, from the age of 18 years old the percentage of adolescents and young adults with type 1 diabetes who were living with overweight or obesity increased with age.
- Conversely the percentage of those who were of a healthy weight decreased with age.

Figure 1: Adolescents and young adults with type 1 diabetes, by BMI status and age at BMI measurement****, England, 2017-21



Please note that methods for assigning BMI categorises differ between children (up to 18 years old) and adults. In adults, categories are assigned on BMI ranges. For children, their BMI is compared to reference values for children of the same sex and similar age that took part in national surveys. Therefore differences in BMI results between children and adults may be due to differences in methodology and should be treated with caution.

* Based on latest BMI when aged between 15 and 25 years old at date of BMI measurement. Only people with a BMI date are included in this analysis. ** It is not possible to include a national breakdown for comparison from the latest Health Survey for England (2019) as this source only reported a BMI breakdown for people aged 16-24 years old and the BMI categories for this age group were derived using adult methodology only. *** Totals may not sum due to data suppression. See 'Additional Information' for more details. **** People whose BMI is 'Unknown' when aged between 15 and 25 years excluded from calculation.

AYA 2017-21: Type 1 Diabetes

How many adolescents and young adults receive the care processes that are recommended to manage their type 1 diabetes?





Care Processes – NICE (annual)

All people with diabetes aged 12 years and over should receive all of the 9 NICE recommended care processes and attend a structured education programme shortly after diagnosis. Due to differences in data collection and reporting between the NDA and the NPDA, the age ranges where care processes are treated as 'should have occurred' were consolidated and are shown against each care process below.

Table 5: 9 annual care processes for people with type 1 diabetes								
Responsibility of Diabetes Care providers								
1. HbA1c [All ages] (blood test for glucose control)	5. Urine Albumin/Creatinine Ratio [Aged 12+] (urine test for risk of kidney disease)							
2. Blood Pressure [Aged 12+] (measurement for cardiovascular risk)	6. Foot Risk Surveillance [Aged 12+] (examination for foot ulcer risk)							
3. Serum Cholesterol [All ages] (blood test for cardiovascular risk)	7. Body Mass Index [All Ages] (measurement for cardiovascular risk)							
4. Serum Creatinine [Aged 19+](blood test for kidney function)	8. Smoking History [Aged 19+] (question for cardiovascular risk)							
Responsibility of NHS Diabetes	Responsibility of NHS Diabetes Eye Screening (NHS England)							
9. Digital Retinal Screening [Aged 12+] (photographic eye test for early detection of eye disease)								

Please note cholesterol is not a mandated care process for adolescents and young adults. Thyroid checks are a mandatory care process for adolescent and young adults. However as the NDA does not collect this data this care process is not assessed in this report.

Due to retinal screening data only being available from 2019-20 and due to serum creatinine and smoking checks not being included in the NPDA, this report is restricted to 6 of the 9 care processes for England.

Care Processes

Figure 2: Care process completion rates^{*,**,***} in adolescents and young adults with type 1 diabetes, by age at audit year start^{****,****}, England, 2017-21



- For the majority of care processes, the highest completion rate occurred at ages 16 and 17 years and the lowest rates occurred at age 19 and 20.
- Completion rates tended to be consistent from 21 years old onwards.
- The completion rate of cholesterol care process increased with age.
 However this is most likely due to the measuring of cholesterol not being mandatory in paediatric services.

* Due to retinal screening data only being available from 2019-20 and due to serum creatinine and smoking checks not being included in the NPDA, this report is restricted to 6 of the 9 care processes for England.

** Under 12s: HbA1c, BMI and cholesterol care processes.

12-18 years: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes.

19 years and over: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot exam, smoking status and creatinine care processes. *** Cholesterol is not a mandated care process for adolescents and young adults.

**** For a table of the underlying percentages see Appendix. ***** For individual charts on HbA1c, Urine Albumin Creatinine Ratio (UACR) and blood pressure care process completion rates see Appendix.

Care Processes

Figure 3: All 6 care process completion rates*,**,*** in adolescents and young adults with type 1 diabetes, by age at audit year start, England, 2017-21



- The highest completion rates for all 6 care processes were found in adolescents and young adults with type 1 diabetes aged 15 to 17 years.
- This dropped at 18 years old and then again at 19 years old where the lowest completion rate was found.
- The completion rate steadily rose from the age of 20 years, but did not reach the percentages found in younger age groups.

* Due to retinal screening data only being available from 2019-20 and due to serum creatinine and smoking checks not being included in the NPDA, this report is restricted to 6 of the 9 care processes for England.

** Under 12s: HbA1c, BMI and cholesterol care processes.

12-18 years: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes.

19 years and over: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot exam, smoking status and creatinine care processes. *** Cholesterol is not a mandated care process for adolescents and young adults.

AYA 2017-21: Type 1 Diabetes

How many adolescents and young adults with type 1 diabetes achieve the NICE recommended treatment targets?





Figure 4: Median and mean HbA1c result (mmol/mol)* by age at HbA1c result**, England, 2017-21



- 84.9% of adolescents and young adults aged between 15 and 25 years with type 1 diabetes had a valid HbA1c level recorded.
- The lowest average HbA1c level was found in adolescents and young adults with type 1 diabetes aged 15 years (median = 65.0; mean = 69.0).
- The average HbA1c level then increased with age until its peak at 20 years old (median = 73.0; mean = 76.8).
- After 20 years old the average HbA1c level of adolescents and young adults with type 1 diabetes decreased with age (at 25 years old: median = 69.0; mean = 73.1).

Figure 5: Percentage of adolescents and young adults with type 1 diabetes achieving HbA1c ≤ 58 mmol/mol* by age at HbA1c result, England, 2017-21



Figure 6: Percentage of adolescents and young adults with type 1 diabetes and HbA1c > 86 mmol/mol* by age at HbA1c result, England, 2017-21



- Adolescents and young adults with type 1 diabetes aged 15 years showed the highest rates of achieving HbA1c less than or equal to 58 mmol/mol and the lowest rates of having HbA1c greater than 86 mmol/mol.
- These rates decreased and increased respectively with age and reached their lowest and highest rates at the age of 20 years. The rates improved after the age of 20 but did not reach similar rates found in the younger age groups.

Treatment target: UACR

Figure 7: Percentage of adolescents and young adults with type 1 diabetes with an abnormal Urine Albumin Creatinine Ratio (UACR) level*,**,*** by age at UACR result, England, 2017-21



Figure 8: Percentage of adolescents and young adults with type 1 diabetes and abnormal Urine Albumin Creatinine Ratio (UACR) levels^{*,***,****} by age at UACR result and diabetes duration^{*****}, England, 2017-21



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Around 60% of adolescents and young adults with type 1 diabetes (59.7%) had their UACR measured between the age of 15 and 25 years****.
 Of those 85.1% had a UACR level recorded.

- The percentage of adolescents and young adults with type 1 diabetes with abnormal UACR levels was lowest at 15 and 16 years old.
- This percentage increased with age, particularly so between the ages of 16 and 21 years. This may be due to longer diabetes duration.

* Abnormal levels are above 2.5mg/mmol in males and above 3.5mg/mmol in females. ** As a percentage of adolescents and young adults with type 1 diabetes with a UACR date and level at age in years. **** Based on latest UACR result at age in years. **** Based on having a recorded UACR date on or after their diagnosis date. ***** Percentages may not add up to 100% due to data suppression. See 'Additional Information' for more details.

AYA 2017-21: Type 1 Diabetes

Adolescents and young adults with type 1 diabetes who transferred from paediatric services to adult services





HbA1c at transfer from paediatric to adult services

Figure 9: Percentage of adolescents and young adults with type 1 diabetes achieving HbA1c ≤ 58 mmol/mol* by age at transfer**,*** from paediatric services to adult services, England, 2017-21 Figure 10: Percentage of adolescents and young adults with type 1 diabetes and HbA1c > 86 mmol/mol* by age at transfer**,*** from paediatric services to adult services, England, 2017-21



• Apart from age 15 (small number) the proportion with HbA1c ≤ 58mmol/mol was similar. The older the age at transfer from paediatric services to adult services the more likely the HbA1c at age of transfer was to be greater than 86 mmol/mol.

* Based on latest HbA1c result at age in years. ** A person transferred when they appeared in the NDA the audit year following transfer date. *** Data on people over 20 years old at age of transfer not reported due to small numbers.

AYA 2017-21: Type 1 Diabetes

Diabetic ketoacidosis (DKA) Hospital Inpatient Admissions





DKA Hospital Inpatient Admissions

Figure 11: Percentage of adolescents and young adults with type 1 diabetes and with at least 1 hospital admission with a diagnosis of diabetic ketoacidosis (DKA)* by age at audit year start, England, 2017-21**

Percentage 14 12 10 9.1 8.9 8.5 8.2 8.0 7.5 8 6.9 6.5 6.4 6.1 6 5.2 4 2 0 15 16 17 18 19 20 21 22 23 24 25 Age at audit year start

Figure 12: Percentage of adolescents and young adults with type 1 diabetes and with at least 1 hospital admission with a diagnosis of diabetic ketoacidosis (DKA)* by age at audit year start and number of admissions***, England, 2017-21**



• The percentage of adolescents and young adults with type 1 diabetes who had a least 1 hospital admission with a diagnosis of DKA* increased with age between the ages of 15 and 18 years, from 5.2% and peaking at 9.1%. After 18 years old this percentage steadily decreased with age.

• The majority of those who had at least 1 admission with a DKA diagnosis had only 1 admission. Although multiple admissions also peaked at age 18 years.

* Where an episode of DKA occurred at any time during the hospital admission. Admissions that start in the same year of diabetes diagnosis are excluded. ** From the onset of the coronavirus pandemic, people with pre-existing type 1 diabetes, particularly those aged up to 39 years, were found less likely to present with DKA (<u>Misra et al. The Lancet Diabetes & Endocrinology, 2021 Oct; 9(10): 671-680</u>). *** Percentages in figure 12 may not sum up to percentages in figure 11 due to data suppression. See 'Additional Information' for more details.

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AYA 2017-21: Type 1 Diabetes

Adolescents and Young Adults with type 1 diabetes on Insulin Pump





Insulin pump

Figure 13: Percentage of adolescents and young adults with type 1 diabetes on an insulin pump* by age at audit year start, England, 2017-21



- A quarter of adolescents and young adults (24.5%) with type 1 diabetes were on an insulin pump at some point during the AYA period.
- 81.9% of adolescents and young adults who were on an insulin pump in paediatric services were later also on an insulin pump in adult services**.

Table 6: Number and percentage of adolescents and young adults with type 1 diabetes on an insulin pump in NPDA and then on an insulin pump later in NDA**,***, England, 2017-21

Diabatas sorviçãos	Type 1 Diabetes			
Diabeles services	Number	%		
Total on insulin pump in NPDA	4,415	-		
On insulin pump in NDA	3,615	81.9		
Not on insulin pump in NDA	800	18.1		

Insulin pump: HbA1c ≤ 58 mmol/mol

Figure 14: Percentage of adolescents and young adults with type 1 diabetes achieving HbA1c ≤ 58 mmol/mol* by age at audit year start and insulin pump usage**, England, 2017-21



- A greater proportion of adolescents and young adults with type 1 diabetes on insulin pumps achieved a HbA1c level of less than or equal to 58 mmol/mol compared to those not on an insulin pump.
- This finding is consistent across all ages between 15 and 25 years.

Insulin pump: HbA1c > 86 mmol/mol

Figure 15: Percentage of adolescents and young adults with type 1 diabetes with HbA1c > 86 mmol/mol* by age at audit year and insulin pump usage**, England, 2017-21



- Adolescents and young adults with type 1 diabetes were less likely to have high levels of HbA1c (i.e. greater than 86 mmol/mol) if they were on an insulin pump.
- This finding is consistent across all ages between 15 and 25 years.
- However the difference between those on insulin pumps and those not on pumps is more pronounced in younger and older ages.

Insulin pump: HbA1c

Figure 16: Median HbA1c result (mmol/mol)* by age at audit year start and insulin pump usage**,***, England, 2017-21

HbA1c value HbA1c value (mmol/mol) (mmol/mol) 90 90 77.8 74.0 80 80 73.2 73.9 70.0 68.0 70 70 70.9 67.0 60 60 65.3 66.2 63.0 62.0 50 50 -On insulin pump -On insulin pump 40 40 -----Not on insulin pump ----Not on insulin pump 30 30 20 20 10 10 0 0 15 16 17 18 19 20 21 22 23 24 25 15 16 17 18 19 20 21 22 23 24 25 Age at audit year start Age at audit year start

England, 2017-21

Figure 17: Mean HbA1c result (mmol/mol)* by age at

audit year start and insulin pump usage**,***,

• Insulin pump treatment is associated with a lower median and mean HbA1c result.

Insulin pump: DKA

Figure 18: Percentage of adolescents and young adults with type 1 diabetes and with at least 1 hospital admission with a diagnosis of diabetic ketoacidosis (DKA)* by age at audit year start, insulin pump usage** and number of admissions**, England, 2017-21



Adolescents and young adults with type 1 diabetes were less likely to have single or multiple hospital inpatient admissions with a DKA diagnosis* if they were on an insulin pump.

•

• This is particularly so in younger years.

AYA 2017-21: Type 1 Diabetes

Additional information





Definitions

Diabetes

Diabetes is a condition where the amount of glucose in the blood is too high because the pancreas doesn't produce enough insulin. Insulin is a hormone produced by the pancreas that allows glucose to be used as a body fuel and other nutrients to be used as building blocks. There are 2 main types of diabetes: type 1 diabetes (no insulin); type 2 diabetes (insufficient insulin).

Specialist Service

This is a service (often hospital based but sometimes delivered in a community setting) which includes diabetes specialists working in multidisciplinary teams. These teams usually comprise physicians (diabetologists), diabetes specialist nurses and dieticians; it may also include clinical psychologists.

Insulin pump

Insulin pump or Continuous Insulin Infusion therapy uses rapid acting insulin delivered subcutaneously under the control of a 'Pump'. Background rates are programmed and mealtime boluses are added manually.

Adolescents and young adults

For the purposes of this report adolescents are people aged 15 to 18 years old. Young adults are people aged 19 to 25 years old (inclusive).

Care Processes (NICE recommends all of these at least once a year)

Blood Pressure is a measurement of the force driving the blood through the arteries. Blood pressure readings contain 2 figures, e.g.130/80. The 1st is known as the systolic pressure which is produced when the heart contracts. The 2nd is the diastolic pressure which is when the heart relaxes to refill with blood.

BMI measurement - Body Mass Index (BMI) is calculated from weight and height. Methods differ between children (up to 18 years old) and adults. In adults, categories are assigned on BMI ranges. For children, their BMI is compared to reference values for children of the same sex and similar age that took part in national surveys. Assignments for both groups are:

Category	Children (Centile)	Adults – (BMI value)
Underweight	≤ 2nd centile	< 18.5
Healthy Weight	> 2nd and < 85th centile	18.5 to 24.9
Overweight	≥ 85th and < 95th centile	25 to 29.9
Obese	≥ 95th centile	≥ 30

Serum creatinine - this is a blood test used to measure kidney function.

Urinary albumin - this urine test detects the earliest stages of kidney disease.

Cholesterol - this blood test measures a type of fat that can damage blood vessels. This is not a mandated care process for adolescents and young adults.

Foot check/exam - this examination checks the blood supply and sensation (feeling) in the feet. Loss of either is a risk for foot disease.

Smoking Status - this records whether the person is a smoker. Smoking increases the diabetic risk for heart attacks and stroke.

HbA1c - this is a blood test for average blood glucose levels during the previous 2 to 3 months.

Urine Albumin-to-Creatinine Ratio (UACR)

UACR is a ratio between 2 measured substances urine albumin and urine creatinine. Unlike a urine dipstick test for albumin, UACR is unaffected by variation in urine concentration.

Treatment Targets (NICE defines target levels to reduce risks of complications for people with diabetes)

HbA1c - the closer this is to normal (less than 42mmol/mol) the lower is the risk of all long term complications of diabetes.

Cholesterol - reducing cholesterol levels lowers the risk of heart attacks and strokes.

Blood Pressure - high levels are a risk for heart attacks and strokes; they also drive progression of eye and kidney disease.

Diabetic ketoacidosis (DKA)

It is a potentially life-threatening complication of predominantly type 1 diabetes that occurs when insulin levels become very low. As a result of the lack of insulin the body is unable to store or use blood sugar (glucose) which rises uncontrollably. Fat is broken down to use as an alternative energy source but in an uncontrolled fashion. This causes a build-up of potentially harmful, acidic, ketones. The high glucose and ketone levels lead to excessive urination, vomiting, dehydration, low blood pressure and collapse/coma. Without treatment DKA is fatal.

Notes and Additional Information



Time period covered:

- The NPDA years covered are 2017-18 to 2019-20 which covers the period 01 April 2017 to 31 March 2020.
- The NDA years covered are 2017-18 to 2020-21 which covers the period 01 January 2017 to 31 March 2021. 2020-21 data is included to provide data on people in the 2019-20 NPDA who then transferred to adult services.

Suppression:

- Disclosure control has been applied to mitigate the risk of patient identification. Zeros are reported, and all numbers are rounded to the nearest 5, unless the number is 1 to 7, in which case it is rounded to '5'. This allows for more granular data to be made available.
- Rounded numbers are used to calculate percentages such as care process completion and treatment target achievement. Consequently totals may not sum.
- At Clinical Commissioning Group (CCG)/Local Health Board (LHB) level and above the use of rounded numbers makes virtually no difference to the resultant percentages. However, where numbers are small, percentages are volatile and should already be treated with caution.

Prepared in collaboration with:









The National Diabetes Audit (NDA) is commissioned by the **Healthcare Quality Improvement Partnership** (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.

www.hqip.org.uk/national-programmes

NHS Digital is the trading name for the Health and Social Care Information Centre (HSCIC). NHS Digital managed the publication of the annual report.

The Royal College of Paediatrics and Child Health (RCPCH) is the membership body for paediatricians in the UK and around the world. Founded in 1996 and now with about 19,000 members in the UK and internationally, it plays a major role in postgraduate medical education, professional standards, research and policy.

Diabetes UK is the charity leading the fight against the most devastating and fastest growing health crisis of our time, creating a world where diabetes can do no harm.

National Diabetes Audit, 2017-21 Adolescent and Young Adult Type 1 Diabetes

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AYA 2017-21: Type 1 Diabetes

Appendix



Care Processes

Table 7: Care process completion rates *,**,*** in adolescents and young adults with type 1 diabetes, by age at audit year start, England, 2017-21

Age at audit start	HbA1c	UACR	Blood pressure	Cholesterol***	BMI	Foot exam
15	82.6	57.0	83.5	55.4	88.5	59.2
16	85.4	55.9	86.8	59.9	88.6	63.0
17	85.9	52.3	86.9	64.3	86.7	65.4
18	82.3	44.2	84.3	65.2	82.2	61.8
19	78.0	38.8	81.6	65.4	75.9	59.5
20	78.0	39.2	81.6	66.7	75.6	59.8
21	78.4	39.1	82.2	68.2	75.8	60.5
22	79.3	39.7	82.5	69.3	76.3	61.9
23	79.9	39.7	82.2	69.8	75.8	61.9
24	79.7	39.9	82.2	70.5	75.5	62.8
25	80.7	39.7	82.8	71.3	76.4	62.9

• For the majority of care processes, the highest completion rate occurred at ages 16 and 17 years and the lowest rates occurred at ages 19 and 20 years.

* Due to retinal screening data only being available from 2019-20 and due to serum creatinine and smoking checks not being included in the NPDA, this report is restricted to 6 of the 9 care processes for England. ** Under 12s: HbA1c, BMI and cholesterol care processes.

12-18 years: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes.

19 years and over: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot exam, smoking status and creatinine care processes. *** Cholesterol is not a mandated care process for adolescents and young adults.

Care Processes

Figure 19: HbA1c care process completion rates* in adolescents and young adults with type 1 diabetes, by age at audit year start, England, 2017-21



- 7.9% of adolescents and young adults with type 1 diabetes did not have a HbA1c care process check when aged between 15 and 25 years**.
- HbA1c care process completion rates were highest in younger years and peaked when aged 17 years.
- HbA1c care process completion rates were lowest at 19 and 20 years.

* Under 12s: HbA1c, BMI and cholesterol care processes.

12-18 years: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes.

19 years and over: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot exam, smoking status and creatinine care processes. ** Based on age at audit year start.

Care Processes: Cardiovascular risk factors

Figure 20: Urine Albumin Creatinine Ratio (UACR) completion rates* in adolescents and young adults with type 1 diabetes, by age at audit year start, England, 2017-21



Figure 21: Blood pressure completion rates* in adolescents and young adults with type 1 diabetes, by age at audit year start, England, 2017-21



- UACR care process completion rates were highest at 15 and 16 years, decreased between the ages of 16 and 19 years, and remained steady in those aged 19 years old and older.
- Blood pressure care process completion rates peaked for 16 and 17 year olds, before decreasing slightly and then remaining consistent for those
 aged 19 years and older.

12-18 years: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes.

^{*} Under 12s: HbA1c, BMI and cholesterol care processes.

¹⁹ years and over: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot exam, smoking status and creatinine care processes.

Care Processes

Figure 22: Care process completion rates^{*,**,***} in adolescents and young adults^{****} with type 1 diabetes, by audit year, England, 2017-21



• Care process completion rates were steady between 2017-18 and 2019-20, but dropped greatly in 2020-21. This is likely due to the impact the coronavirus pandemic had on diabetes services.

* Due to retinal screening data only being available from 2019-20 and due to serum creatinine and smoking checks not being included in the NPDA, this report is restricted to 6 of the 9 care processes for England.

19 years and over: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot exam, smoking status and creatinine care processes. *** Cholesterol is not a mandated care process for adolescents and young adults **** Aged 15 to 25 years old at audit year start.

^{**} Under 12s: HbA1c, BMI and cholesterol care processes.

¹²⁻¹⁸ years: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes.

Care Processes

Table 8: Care process completion rates^{*,**,***} in adolescents and young adults^{****} with type 1 diabetes, by audit year, England, 2017-21

Audit year	HbA1c	UACR	Blood pressure	Cholesterol***	BMI	Foot exam
2017-18	85.8	47.6	89.3	72.4	84.0	69.7
2018-19	86.8	47.7	90.0	73.7	84.9	70.9
2019-20	83.3	48.5	88.5	69.2	83.7	67.5
2020-21	66.9	29.8	64.9	50.8	64.1	38.8

• Care process completion rates were steady between 2017-18 and 2019-20, but dropped greatly in 2020-21. This is likely due to the impact the coronavirus pandemic had on diabetes services.

19 years and over: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot exam, smoking status and creatinine care processes. *** Cholesterol is not a mandated care process for adolescents and young adults **** Aged 15 to 25 years old at audit year start.

^{*} Due to retinal screening data only being available from 2019-20 and due to serum creatinine and smoking checks not being included in the NPDA, this report is restricted to 6 of the 9 care processes for England.

^{**} Under 12s: HbA1c, BMI and cholesterol care processes.

¹²⁻¹⁸ years: HbA1c, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes.

Age at HbA1c result	Number of people	Mean HbA1c	Median HbA1c	Interquartile range	Range**	Standard deviation
15	9,090	69.0	65.0	56.0 - 78.0	153.0	20.1
16	9,865	71.5	66.0	56.0 - 81.0	170.8	22.2
17	10,975	73.0	68.0	57.0 - 84.0	159.8	22.8
18	11,270	75.2	70.0	58.0 - 88.0	156.6	23.5
19	10,955	76.3	71.0	59.0 - 89.0	163.8	23.7
20	11,155	76.8	73.0	60.0 - 90.0	168.0	23.2
21	11,555	76.1	72.0	60.0 - 89.0	161.4	22.8
22	12,130	75.4	71.0	59.0 - 87.7	171.6	22.5
23	12,570	74.3	70.0	58.0 - 87.0	165.0	21.9
24	12,910	73.7	70.0	58.0 - 86.0	168.8	21.7
25	13,250	73.1	69.0	57.4 - 85.0	160.0	21.7

Table 9: HbA1c results (mmol/mol)* by age at HbA1c result, England, 2017-21

• The lowest average HbA1c level was found in adolescents and young adults with type 1 diabetes aged 15 years.

• The average HbA1c level then increased with age until its peak at 20 years.

Figure 23: Median HbA1c result (mmol/mol)* by age at HbA1c result and whether known to paediatric services**,****, England, 2017-21



Figure 24: Mean HbA1c result (mmol/mol)* by age

at HbA1c result and whether known to paediatric

services**,***, England, 2017-21

 Mean and median HbA1c were slightly lower in older adolescents and young adults with type 1 diabetes known to paediatrics services compared to those not known to paediatric services (at 20 years old: Median difference = 3.0 mmol/mol; Mean difference = 2.7 mmol/mol).

* Based on latest HbA1c result at age in years. ** 'Known to paediatric services' defined by having a HbA1c date recorded in NPDA at age in years. *** Data on people over 20 years old not reported due to small number of those known to paediatric services. **** For a summary of the statistics see next 2 slides.

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Table 10: HbA1c results (mmol/mol)* adolescents and young adults with type 1 diabetes known to paediatric services** by age at HbA1c result***, England, 2017-21

Age at HbA1c result	Number of people	Mean HbA1c	Median HbA1c	Interquartile range	Range****	Standard deviation
15	7,180	68.6	65.0	56.0 - 77.0	151.1	19.4
16	7,310	70.8	66.0	56.0 - 80.0	146.0	21.4
17	6,860	72.4	67.0	57.0 - 83.0	148.6	22.2
18	5,305	74.0	69.0	58.0 - 85.0	156.0	22.2
19	1,445	73.8	70.0	58.0 - 85.0	158.5	21.8
20	130	74.2	70.0	58.0 - 87.0	103.0	21.5

• The average HbA1c level of older adolescents and young adults with type 1 diabetes known to paediatrics services was slightly lower compared to those not known to paediatric services.

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Table 11: HbA1c results (mmol/mol)* adolescents and young adults with type 1 diabetes not known to paediatric services** by age at HbA1c result, England, 2017-21

Age at HbA1c result	Number of people	Mean HbA1c	Median HbA1c	Interquartile range	Range***	Standard deviation
15	1,910	70.6	66.0	56.0 - 80.0	150.5	22.7
16	2,555	73.3	67.2	56.3 - 85.0	170.8	24.2
17	4,115	74.0	68.0	57.0 - 86.0	158.0	23.9
18	5,960	76.3	71.0	59.0 - 90.0	153.6	24.5
19	9,505	76.7	72.0	59.0 - 90.0	163.8	23.9
20	11,030	76.9	73.0	60.0 - 90.0	168.0	23.2
21	11,545	76.1	72.0	60.0 - 89.0	161.4	22.8
22	12,125	75.4	71.0	59.0 - 87.7	171.6	22.5
23	12,565	74.3	70.0	58.0 - 87.0	165.0	21.9
24	12,910	73.7	70.0	58.0 - 86.0	168.8	21.7
25	13,250	73.1	69.0	57.4 - 85.0	160.0	21.7

• The average HbA1c level of older adolescents and young adults with type 1 diabetes known to paediatrics services was slightly lower compared to those not known to paediatric services.

* Based on latest HbA1c result at age in years. ** 'Known to paediatric services' defined by having a HbA1c date recorded in NPDA at age in years. *** The range is the difference between the highest and the lowest HbA1c levels.

Figure 25: Percentage of adolescents and young adults with type 1 diabetes known and not known to paediatric services* achieving HbA1c ≤ 58 mmol/mol** by age at HbA1c result, England, 2017-21 Figure 26: Percentage of adolescents and young adults with type 1 diabetes achieving HbA1c ≤ 58 mmol/mol** by age at HbA1c result and whether known to paediatric services*,***, England, 2017-21



• Figure 25 shows that as adolescents and young adults with type 1 diabetes grew older they were less likely to be known to paediatric services.

• Figure 26 shows that those known to paediatric services were consistently more likely to achieve a HbA1c result less than or equal to 58 mmol/mol than those not known to such services. However, this difference is very slight in younger years.

* 'Known to paediatric services' defined by having a HbA1c date recorded in NPDA at age in years ** Based on latest HbA1c result at age in years. *** Data on people over 20 years old not reported due to small number of those known to paediatric services.

Figure 27: Percentage of adolescents and young adults with type 1 diabetes known and not known to paediatric services* and with HbA1c > 86 mmol/mol** by age at HbA1c result, England, 2017-21



Figure 28: Percentage of adolescents and young adults with type 1 diabetes and HbA1c > 86 mmol/mol** by age at HbA1c result and whether known to paediatric services*,***, England, 2017-21



• Figure 27 shows that as adolescents and young adults with type 1 diabetes grew older they were less likely to be known to paediatric services.

• Figure 28 shows that those not known to paediatric services were consistently more likely to have a HbA1c result greater than 86 mmol/mol than those known to paediatric services.

* 'Known to paediatric services' defined by having a HbA1c date recorded in NPDA at age in years. ** Based on latest HbA1c result at age in years. *** Data on people over 20 years old not reported due to small number of those known to paediatric services.

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HbA1c at transfer from paediatric to adult services

Figure 29: Median and mean HbA1c result (mmol/mol)* by age at completed transfer**,*** from paediatric services to adult services****, England, 2017-21



- 4,985 adolescents and young adults with type 1 diabetes transferred from paediatric services to adult services*.
- 4,945 transferred between the ages of 15 and 20 years***.
- Over 90% of all adolescents and young adults who transferred had an HbA1c result recorded when age of transfer was between 15 and 20 years*** (92.6%).
- The average HbA1c level at age of transfer was similar for all ages of transfer between 15 and 20 years.

* Based on latest HbA1c result at age of transfer. ** Person who is in NPDA with a recorded leaving date and the reason for leaving paediatric services being transfer to adult services. A person transferred when they appeared in the NDA the audit year following transfer date. *** Data on people over 20 years old at age of transfer not reported due to very low number of people who transferred when over the age of 20 years old. **** For a summary of the statistics see next slide.

HbA1c at transfer from paediatric to adult services

Table 12: HbA1c results (mmol/mol)* by age at completed transfer** from paediatric services to adult services***, England, 2017-21

Age at HbA1c result	Number of people	Mean HbA1c	Median HbA1c	Interquartile range	Range****	Standard deviation
15	25	72.5	65.0	54.0 - 85.0	78.7	21.8
16	455	73.3	69.0	58.0 - 83.0	111.0	22.3
17	800	73.4	68.0	58.0 - 84.0	134.0	21.9
18	2,070	73.7	69.0	58.2 - 84.5	156.6	21.3
19	1,155	75.0	71.0	59.0 - 87.0	136.6	21.8
20	75	75.3	71.7	58.0 - 87.3	119.0	22.7

• The average HbA1c level at age of transfer slightly increased with age when the age of transfer was between 15 and 20 years.

* Based on latest HbA1c result at age of transfer. ** Person who is in NPDA with a recorded leaving date and the reason for leaving paediatric services being transfer to adult services. A person transferred when they appeared in the NDA the audit year following transfer date. *** Data on people over 20 years old at age of transfer not reported due to very low number of people who transferred when over the age of 20 years old. **** The range is the difference between the highest and the lowest HbA1c levels.

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Insulin pump: HbA1c

Table 13: HbA1c results (mmol/mol)* of adolescents and young adults with type 1 diabetes on an insulin pump by age at audit year start, England, 2017-21

Age at HbA1c result	Number of people	Mean HbA1c	Median HbA1c	Interquartile range	Range**	Standard deviation
15	3,115	65.3	62.0	55.0 - 72.0	115.0	16.2
16	3,085	66.8	63.9	55.0 - 74.0	121.0	17.2
17	2,935	68.9	65.0	56.0 - 77.0	140.8	18.7
18	2,575	70.5	67.0	57.0 - 80.0	131.0	19.0
19	2,160	72.2	69.0	58.0 - 81.0	138.0	19.6
20	1,945	70.9	67.0	58.0 - 80.0	138.4	18.6
21	1,835	70.7	67.0	58.0 - 80.0	138.0	18.5
22	1,740	69.6	67.0	58.0 - 78.0	115.0	17.0
23	1,660	68.1	65.0	56.0 - 77.0	141.0	17.2
24	1,645	67.7	65.0	56.0 - 77.0	132.0	17.1
25	1,705	66.2	63.0	55.0 - 74.0	136.0	17.2

• Insulin pump treatment is associated with a lower median and mean HbA1c result.

Insulin pump: HbA1c

Table 14: HbA1c results (mmol/mol)* of adolescents and young adults with type 1 diabetes not on an insulin pump by age at audit year start, England, 2017-21

Age at HbA1c result	Number of people	Mean HbA1c	Median HbA1c	Interquartile range	Range**	Standard deviation
15	5,875	73.2	68.0	57.0 - 85.0	163.0	23.2
16	6,700	75.2	70.0	58.0 - 88.0	170.0	24.2
17	7,470	77.0	71.0	59.0 - 91.0	162.0	25.0
18	8,065	78.0	73.0	60.0 - 93.0	159.8	24.7
19	8,460	78.3	74.0	60.0 - 92.0	162.0	24.2
20	9,120	77.8	74.0	61.0 - 91.0	165.0	23.5
21	9,655	77.0	73.0	60.0 - 90.0	157.0	23.4
22	10,315	75.9	72.0	59.0 - 89.0	169.9	22.8
23	10,705	75.3	71.0	59.0 - 88.0	167.7	22.3
24	11,000	74.6	71.0	58.0 - 87.0	169.0	22.2
25	11,435	73.9	70.0	58.0 - 86.0	155.0	21.9

• Insulin pump treatment is associated with a lower median and mean HbA1c result.