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Characteristics and care of young people with type 2 diabetes included in the national diabetes audit datasets for England

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Abstract

Introduction: We report contemporary age-related prevalence, characteristics and care of children and young people with type 2 diabetes in England.

Methods: Individuals with a recorded diagnosis of type 2 diabetes between January 2019 and March 2020 were identified from a whole population register. Age, sex, ethnicity, deprivation quintile, weight, HbA_{1c} and receipt of the nine National Institute for Health & Care Excellence (NICE) recommended annual care processes were extracted from electronic clinical records and analysed by pre-specified age bands.

Results: In total, 122,780 (4.6%) of 2,642,435 individuals in England with type 2 diabetes were aged under 40 years, comprising; 650 (0.5%) under 16 years, 910 (0.7%) aged 16–18 years, 8245 (6.7%) aged 19–25 and 112,975 (92%) aged 26–39 years. Compared to people with type 2 diabetes aged above 40 years, young people were significantly more likely to be from minority ethnic groups: 51% under 16 years, 41% 16–18 years, 38% 19–25 years, 38% 26–39 years, 27% 40–59 years and 15% 60–79 years were of Black or Asian ethnicity. In addition, those aged under 40 years were more likely to be obese, women, to live in the most-deprived socioeconomic areas and less likely to receive the NICE recommended annual care processes or achieve target HbA_{1c}.

Interpretation: The substantial number of people under 40 years of age with type 2 diabetes, are more likely to have characteristics associated with inequalities and are less likely to achieve HbA_{1c} targets and receive recommended care processes. These findings highlight the need to consider novel approaches to service provision for this high-risk group.

KEYWORDS

epidemiology, ethnic minority, obesity, type 2 diabetes

1 | INTRODUCTION

Type 2 diabetes has classically been considered a condition affecting middle-aged or older individuals. In recent years, increasing numbers of individuals presenting in younger age groups have become apparent.

Early onset of type 2 diabetes carries significant risks of mortality[1,2] with an estimated median 7 years of life lost in those with a diagnosis between 21 and 40 years compared to those without diabetes.[3] Affected individuals have a more aggressive diabetes phenotype than older-onset presentations[4,5] with a more rapid deterioration in glycaemic control that requires insulin treatment earlier,[6] a worse cardiometabolic risk factor profile[6–8] and higher proportions affected with diabetes-related microvascular and macrovascular complications.[7,9–12] In the most comprehensive analysis to date, 60% of children diagnosed with type 2 diabetes had at least one microvascular complication after a mean duration of 13 years.[13]

Early onset type 2 diabetes has been extensively studied in north American paediatric incident cohorts,[14,15] but the characteristics of those with type 2 diabetes in early-adulthood have been less comprehensively studied with analysis of either single ethnicity datasets,[6] absence of age-stratification of early-onset cases[6,16,17] or, in the United Kingdom, analysis of local cohorts[18] and general practice datasets with less than population-wide coverage.[16,17]

In the present analysis, we addressed these limitations by studying a population-level registry of all people with type 2 diabetes in England to determine (1) the proportions of people with type 2 diabetes aged under 40 years stratified by paediatric, adolescent and early-adulthood age bands, (2) the characteristics (ethnicity, index of multiple deprivation and BMI) of people aged under 40 years with type 2 diabetes compared to those aged over 40 years and (3) the proportions of people with type 2 diabetes receiving the National Institute for Health & Care Excellence (NICE) recommended annual care processes and meeting HbA_{1c} targets, by age.[19,20]

What's new?

- The characteristics of people with early-onset type 2 diabetes in England have been studied in small clinic-based cohorts.
- This population-level study identified 122,780 (4.6%) people with type 2 diabetes aged under 40 years. Most were obese, 42% were from minority ethnic groups, there was a highly significant association with deprivation and in those under 25 years, women exceeded men. Fewer in these younger age groups received all diabetes care processes and glycaemia was less well controlled than in older people with type 2 diabetes
- Our findings highlight the need for research into improved service organisation and treatment for young people with type 2 diabetes.

2 | METHODS

We linked records of people in England aged under 80 years old from the National Diabetes Audit (NDA) dataset[21] (primary care and specialist care comprising greater than 97% of people with a recorded diagnosis of diabetes, full description of cohort available here[22]) and National Paediatric Diabetes Audit data[23] (NPDA, comprising data on children attending specialist paediatric diabetes clinics) to generate a population level cohort of people with diabetes aged under 40 years.

We included the following individuals (Figure S1):

1. All individuals recorded as having type 2 diabetes in the NPDA April 2019 to March 2020 and those aged 19–39 years recorded as type 2 diabetes in NDA from January 2019 to March 2020 (n = 115,390).
2. Those aged 0–18 years recorded as type 2 diabetes in the NDA from January 2019 to March 2020 who did not appear in the NDPA. We further selected from these, those with an HbA_{1c} greater than or equal to 48 mmol/mol (6.5%) (n = 370) and/or those prescribed oral hypoglycaemics with or without insulin or metformin alone (n = 190).
3. Finally, we selected those aged 0–39 in NDA, not in NPDA and recorded with type 1 or unknown diabetes who were not prescribed insulin alone or insulin plus metformin but who had an HbA_{1c} greater than or equal to 48 mmol/mol (6.5%) (n = 5395) or who were prescribed non-metformin oral hypoglycaemic drugs with or without insulin or metformin alone (n = 1430).

This made a final cohort of 122,780 individuals with type 2 diabetes aged under 40 years old. People aged 40–79 years recorded as having type 2 diabetes in NDA from January 2019 to March 2020 were also included in the cohort (n = 2,519,655).

To fulfil its statutory duties, NHS England and NHS Improvement require access to and linkage of various pseudonymised national datasets, in line with the requirements of the General Data Protection Regulation. The legal basis for the NDA data collection and linkage is a direction from NHS England to NHS Digital according to section 254 of the Health and Social Care Act for England 2012. Data are not extracted if the person has withdrawn their permission to use their record for

secondary analyses, which is estimated to apply to 2·6% of records.

Records were grouped by age into children under 16 years, adolescents aged 16–18 years, young adults aged 19–25 years and adults aged 26–39 years. We also analysed older age groups split into those aged 40–59 years and 60–79 years. Sex was recorded as male or female. Ethnicity was grouped as white, Asian, Black, mixed and other based on data recorded in routine health records, submitted to the NDA and NPDA. Socioeconomic deprivation was defined by the English Index of Multiple Deprivation (IMD) 2019 associated with the Lower Layer Super Output Area derived from the individuals home postcode and grouped into quintiles (from 1 = most deprived to 5 = least deprived).[24] BMI was categorised by age and ethnicity as follows; for those under 19 years from all ethnicities, WHO z-scores centiles were used: underweight below 2nd centile, healthy weight 2nd–85th centile, overweight 85th–95th centile and obese above 95th centile. White adults were classified as: underweight BMI less than 18.5, healthy weight 18.5 to less than 25, overweight 25 to less than 30 and obese greater than or equal to 30 kg/m^2. For people from other ethnic groups,[25] adults were classified as: underweight below 18.5, healthy weight 18.5 to less than 23, overweight 23 to 27.5 and obese greater than or equal to 27.5 kg/m^2. For each variable (sex, ethnicity, IMD and BMI) records with missing data were included as an additional category.

Consistent with NICE guidelines,[19,20] we assessed receipt of diabetes care processes as follows: under 12 years old, HbA_{1c}, BMI, cholesterol, blood pressure and urine albumin care processes; 12–18 years: HbA_{1c}, BMI, cholesterol, blood pressure, urine albumin, retinal screening and foot exam care processes; 19 years and over: HbA_{1c}, BMI, cholesterol, blood pressure, urine albumin, retinal screening, foot check, smoking status and creatinine care processes. Finally, we assessed proportions achieving the treatment target of HbA_{1c} <58 mmol/mol (7.5%) using the latest recorded HbA_{1c} in the audit period.

2.1 | Statistical methods

Characteristics by sex, ethnicity, deprivation, BMI category and duration of diabetes were presented stratified by age group with associations tested using a two-way chi-square test. The median (and interquartile range) was calculated for HbA_{1c} and Kruskal–Wallis tests performed to assess differences across age categories.

We used population estimates for England and Wales (2019) for age and ethnicity from the Office for National Statistics (ONS)[26] to calculate expected cross-sectional prevalence for Asian and Black ethnic group populations based on white prevalence, to account for differences in population structure in Asian and Black individuals by age.

Missing data were included for all statistical tests except for those related to receipt of care processes, differences in weight categories by ethnicity and achievement of HbA_{1c} targets.

Statistical significance was set at <0.05 and all analyses were done in SAS Enterprise Guide version 8.3.

3 | RESULTS

During the study period, we identified a total of 122,780 individuals with type 2 diabetes aged under 40 years in England, comprising: 650 (0.5%) children under 16 years, 910 (0.7%) adolescents aged between 16 and 18 years, 8245 (6.7%) young adults aged between 19 and 25 years and 112,975 (92%) adults aged between 26 and 39 years. In total, those aged under 40 years of age with type 2 diabetes, accounted for 4.6% of all people aged below 80 years with type 2 diabetes coded in the NDA dataset (Table 1).

3.1 | Sex

Up until the age of 25 years, women predominated, accounting for over 60% of type 2 diabetes cases, both under the age of 18 years and between 19 and 25 years. Between the ages of 26–39 years, cases in men and women were equal (women 49%). In contrast, for those aged between 40 and 59 years, men predominated with only 41% of cases in women and similarly, 43% of those aged 60–79 years were in women ($p < 0.001$).

3.2 | Ethnicity

Among all those aged under 40 years, 11,145 had no ethnicity coded (9.1%). There were age-related differences in the distribution of people with type 2 diabetes by ethnic group ($p < 0.001$) (Table 1). Among those aged under 40 years, 49% were white, 31% were of Asian ethnicity, 7% were of Black ethnicity, 2% were of mixed ethnicity and 2% were from another ethnic group. For those aged 40 years and over, 66% were white, 15% were of Asian ethnicity, 5% were of Black ethnicity, 1% were of mixed ethnicity and 2% were from another ethnic group.

The age distributions of the Asian and Black populations across England and Wales were younger than for white ethnicity (Table S1). Applying the estimated prevalence from white individuals aged under 40 years old

TABLE 1 Key characteristics of people living with type 2 diabetes in England stratified by current age, in those aged under 80 years

	<16 years		16–18 years		19–25 years		26–39 years		40–59 years		60–79 years		*p*-value
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%	
Total	650		910		8245		112,975		945,080		1,574,575		
Sex													
Men	230	35	345	38	3195	39	57,400	51	559,375	59	899,485	57	
Women	415	64	565	62	5045	61	55,575	49	385,705	41	675,095	43	<0.001
Missing	5	0.8	—	—	5	0.1	—	—	—	—	5	0	
Ethnicity													
White	230	35	385	42	4445	54	54,770	48	547,520	58	1,108,415	70	
Asian	245	38	280	31	1865	23	35,555	31	192,805	20	180,355	11	
Black	85	13	95	10	590	7.2	7860	7.0	68,760	7.3	56,710	3.6	
Mixed	35	5.4	35	3.8	210	2.5	2385	2.1	15,135	1.6	12,930	0.8	<0.001
Other	20	3.1	20	2.2	170	2.1	2360	2.1	19,680	2.1	23,095	1.5	
Missing	40	6.2	95	10	965	12	10,045	8.9	101,185	11	193,075	12	
Deprivation													
IMD 1(most deprived)	270	42	345	38	2890	35	38,985	35	273,990	29	344,110	22	
IMD 2	180	28	220	24	2015	24	29,040	26	229,240	24	336,905	21	
IMD 3	105	16	150	16	1365	17	21,230	19	185,665	20	327,995	21	
IMD 4	45	6.9	90	9.9	960	12	13,495	12	142,535	15	304,950	19	<0.001
IMD 5 (least deprived)	30	4.6	75	8.2	700	8.5	9215	8.2	110,590	12	252,860	16	
Missing	20	3.1	30	3.3	315	3.8	1015	0.9	3065	0.3	7765	0.5	
Body mass index													
Underweight	5	0.8	10	1.1	65	0.8	345	0.3	1810	0.2	6250	0.4	
Healthy weight	45	6.9	70	7.7	555	6.7	5715	5.1	48,940	5.2	151,265	9.6	
Overweight	45	6.9	90	9.9	925	11	18,430	16	197,610	21	433,840	28	<0.001
Obese	505	78	595	65	4735	57	65,045	58	524,085	55	736,485	47	
Missing	50	7.7	145	16	1965	24	23,445	21	172,640	18	246,740	16	
Duration													
<2 years	410	63	415	46	3010	37	35,040	31	176,080	19	165,595	11	
2 to <10 years	230	35	465	51	4470	54	63,820	56	502,655	53	645,825	41	<0.001
10 years plus	10	1.5	25	2.7	740	9.0	13,975	12	266,130	28	762,810	48	
Missing	—	—	5	0.5	25	0.3	140	0.1	215	0	345	0	

Note: In line with National Diabetes Audit information governance rules, all counts are rounded to the nearest 5. This means that the sum of counts in the table do not always match the totals provided.*p*-values represent statistical significance using Chi Square tests of the distribution across age bands and all the categories of each variable.

to Asian and Black populations of the same age resulted in an expected number of 9440 cases in Asian and 3975 cases in Black individuals. These expected cases were far exceeded by the observed cases presented in this analysis (37,945 in Asian ethnic groups and 8630 in Black ethnic groups).

3.3 | Social deprivation

People from the most deprived quintile accounted for significantly higher proportions of younger individuals compared to older individuals; 42% of those aged under 16 years, 38% of adolescents aged 16–18 years, 35% of 19- to 25-year-olds and 35% aged 26–39 years were from the most deprived quintile ($p < 0.001$). In contrast, 29% of those aged 40–59 years and 22% of those aged 60–79 years were from the most deprived quintile ($p < 0.001$).

3.4 | BMI

The proportions of those living with obesity decreased with increasing age; 78% of children under 16 years, 65% of adolescents aged 16–18 years, 57% of 19-25-year-olds and 58% of 26–39-year-olds were living with obesity ($p < 0.001$). In contrast, 55% of 40- to 59-year-olds and 47% of 60–79 years olds were living with obesity. Taking those under 40 years together, 58% were living with obesity compared to 50% of those aged 40–79 years ($p < 0.001$).

Analysis of BMI by ethnic group (Figure 1) revealed high proportions of obesity across all ethnicities in those aged under 19 years; 72% of Asian individuals, 70% of Black individuals and 70% of white individuals aged under 19 years with type 2 diabetes were living with obesity $p < 0.0001$. The proportions living with obesity reduced in the 19- to 39-year-old age band across all ethnic groups. The proportions living with obesity in those aged 40–79 years was 43% in Asian individuals, 57% in Black individuals and 50% in white individuals.

3.5 | Care processes and treatment targets

The proportion of individuals meeting all NICE, age related, recommended care processes increased significantly with higher age (Table 2). The overall percentage meeting an HbA_{1c} target of below 58 mmol/mol (7.5%) was highest in older adults and significantly lower in those age 16–18 and 19–26 years ($p < 0.001$).

In all age bands, a longer duration of diabetes was associated with higher median HbA_{1c} ($p < 0.001$) (Table 3).

4 | DISCUSSION

In this first ever population-level analysis of children, adolescents and young adults in England with type 2 diabetes, we found 122,780 individuals living with type 2 diabetes and aged under 40 years. Children under 19 years account for only 1.3% of people under 40 years with type 2 diabetes but the number of people with type 2 diabetes rises progressively with each age-band studied from age 19 to

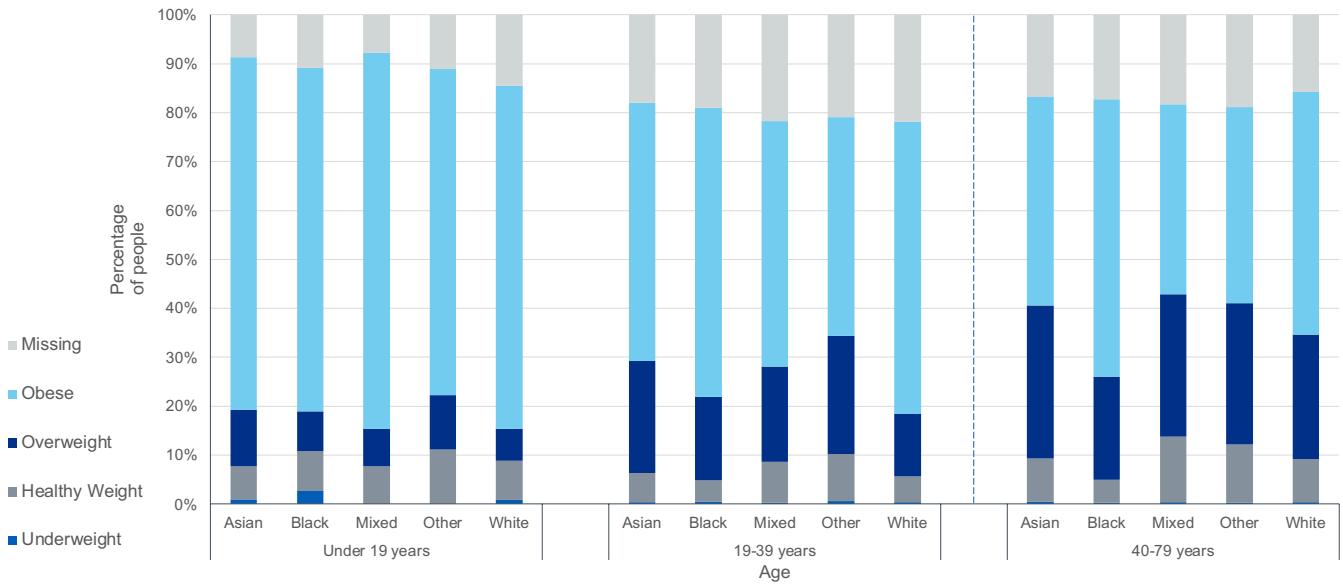

FIGURE 1 Bar chart depicting percentage of individuals in each weight category stratified by current age (in those aged under 80 years) and ethnicity in people living with type 2 diabetes in England.

TABLE 2 Care processes received and HbA_{1c} targets achieved in people living with type 2 diabetes in England stratified by current age for those aged under 80 years

	<16 years	16–18 years	19–25 years	26–39 years	40–59 years	60–79 years	*p*-value[b]
Total	650	910	8245	112,975	945,080	1,574,575	
Care processes received[a] *n* (%)	165 (25)	245 (27)	1880 (23)	38,000 (34)	439,975 (47)	921,780 (59)	<0.001
HbA_{1c}							
Cases with available data n (%)	550 (82)	825 (91)	6885 (84)	99,895 (88)	869,005 (92)	1,492,235 (95)	<0.001
HbA_{1c} <58 mmol/mol or <7.5% *n* (%)	355 (65)	415 (50)	3550 (52)	54,470 (55)	496,260 (57)	1,021,160 (68)	<0.001
Median (IQR) mmol/mol	51 (41–71)	58 (47–80)	58 (47–81)	56 (48–75)	56 (48–70)	52 (47–62)	<0.001
Median (IQR) %	6.8 (5.9–8.6)	7.5 (6.5–9.6)	7.5 (6.5–9.6)	7.3 (6.5–9.0)	7.3 (6.5–8.6)	6.9 (6.5–7.8)	<0.001

[a]Care processes received were different across age groups. Under 12 years old: HbA_{1c}, BMI, cholesterol, blood pressure and urine microalbumin care processes; 12–18 years: HbA_{1c}, BMI, cholesterol, blood pressure, urine microalbumin, retinal screening and foot exam care processes; 19 years and over: HbA_{1c}, BMI, cholesterol, blood pressure, urine microalbumin, retinal screening, foot check, smoking status and creatinine care processes.
[b]*p*-values represent statistical significance using Chi Square tests of the distribution across age bands and each categorical variable or for continuous variables, Kruskal–Wallis tests. IQR, inter-quartile range.

39 years. Compared to people with type 2 diabetes aged over 40 years, those aged below 40 years were considerably more likely to be from a minority ethnic group, to be in an obese weight category and to live in an area with high rates of social deprivation. This analysis shows that these ethnicity, weight and deprivation differences are inversely related to age even just in those up to 40 years, with the proportions living with obesity or from the most deprived quintiles decreasing as age increases. We also show that cases in women predominate only up until the age of 25 years after which men become and remain the more affected sex throughout adulthood.

Our analysis reveals that in contrast to 'later-onset' type 2 diabetes, where Asian people have the lowest proportion in the obese category, in children aged under 19 years there are equally high proportions in the obese category across all ethnic groups. It is important to consider that interpretation of proportions in obese and overweight categories is complicated by the different BMI thresholds applied for obesity between children and adults. We show that compared to older individuals living with type 2 diabetes, those aged below 40 years are less likely to receive the NICE recommended care processes or achieve target HbA_{1c}.

The numbers of young adults (under 40 years) with type 2 diabetes in England now exceeds those living with type 1 diabetes (albeit most with type 2 diabetes are in the 26–39 age group). In the recently published NDA data, 84,595 adults living with type 1 diabetes were aged 19–40 years, whereas in this analysis we found 121,220 adults with type 2 diabetes.[27]

Our findings are consistent with emerging data from other countries and datasets, although the current analysis represents, to our knowledge, the largest analysis to date in a whole multi-ethnic population. A Swedish study showed high rates of obesity in those diagnosed <40 years[6,28] attenuating with increasing age and analysis of GP registries in England have also shown over-representation of ethnic minority groups in those aged under 40 years[17] with high rates of obesity at diagnosis.[8] Our observations outline the already high caseload of those aged <40 years and identify some key age related characteristics of those affected—a preponderance of people from ethnic minority groups, higher proportions of women (with implications for pre-gestational diabetes affecting pregnancy), high proportions of those living with obesity that attenuate with increasing age within the early-onset group and high proportions of people living in areas of high social deprivation.

It remains unclear whether the reported adverse outcomes associated with early-onset type 2 diabetes are related to personal characteristics, to its longer lifetime impact or to the provision of care received or accessed. Routine ongoing diabetes management is the element most amenable to

TABLE 3 Median HbA_{1c} in people living with type 2 diabetes in England stratified by current age (in those aged under 80 years) and duration of diabetes

Age band years	Duration	n	Median HbA_{1c} mmol/mol/% (IQR)	*p*-value
Aged < 19	<2 years	715	52 (42-71)/6.9 (6.0-8.6)	
	2–9 years	635	58 (44-80)/7.5 (6.2-9.5)	<0.001
	>10 years	25	67 (58-95)/8.2 (7.5-10.8)	
Aged 19–39	<2 years	35,640	52 (47-66)/6.9 (6.5-8.2)	
	2–9 years	58,535	58 (48-76)/7.5 (6.5-9.1)	<0.001
	>10 years	12,475	67 (53-87)/8.3 (7.0-10.1)	
Aged 40–79	<2 years	328,195	49 (46-55)/6.6 (6.4-7.2)	
	2–9 years	1,067,665	52 (46-61)/6.9 (6.4-7.7)	<0.001
	>10 years	965,065	58 (50-70)/7.5 (6.7-8.6)	

Note: *p* values represent statistical significance using Kruskal–Wallis tests.

healthcare intervention with the low proportion of individuals receiving all care processes and achieving the HbA_{1c} treatment target, areas for potential improvement. A recent study of the national diabetes retinal screening service found that people with diabetes aged 18–34 years were least likely to attend for annual retinal screening and despite reductions in certifications for vision loss in every other age group, this reduction had not been observed in those 18–34.[29] Interestingly, compared to white individuals, Asian people were more likely to attend and Black people similarly more likely to attend but those of mixed ethnicity least likely and there was also 27% higher odds of non-attendance in those from the most deprived quintile. These analyses were not stratified by age and one may speculate there may be differences by type of diabetes.

Irrespective of the underlying drivers for poor outcomes, these results suggest there will be a need for novel approaches to care provision in those living with type 2 diabetes under the age of 40 years. These approaches must include a focus on strategies that engage people of working age, women of child-bearing age and indeed those that are tailored to people from deprived communities of any ethnic group and those from minority ethnic groups.[30]

5 | LIMITATIONS

Our analysis has some limitations. First, we relied on submitted diagnostic coding to identify cases of type 2 diabetes and acknowledge that in those aged below 40 years the potential for miscoding may be higher as other types of diabetes may be more frequently encountered and phenotypically difficult to segregate from early-onset type 2 diabetes. Second, due to the cross-sectional nature of our analysis, we did not undertake linkage of the combined NPDA/NDA dataset with Hospital Episode Statistics to verify ethnicity and this likely accounts for the level of missing ethnicity data obtained in this analysis. Third, the ONS estimates used in this analysis are likely to underestimate prevalence due to the combined denominator for England and Wales and the proportion of cases with missing ethnicity data. Finally, we restricted analyses of the receipt of care processes and achievement of HbA_{1c} targets to those with complete data and acknowledge that these outcomes are likely to be worse in those with missing data.

6 | CONCLUSION

This large contemporary population-based analysis has identified 122,780 individuals aged under 40 years living with type 2 diabetes in England. Children account for a relatively small percentage of this group. The total number is similar to the population of young people with Type 1 diabetes (aged under 40 years). In contrast to their young type 1 counterparts and to older people with type 2 diabetes, people with type 2 diabetes in this age-group are significantly more likely to be from minority ethnic groups, to be in obese weight categories, to be women up to the age of 25 years and to live in the most socio-economically deprived areas. Current models of diabetes care provision were developed and implemented when early-onset type 2 diabetes cases were infrequent. The burgeoning numbers demonstrated in this analysis both in adolescence and early adulthood, suggest that there is a pressing need for research into the best therapeutic approaches and to reconsider how services are best organised to support this group, which is both at high-risk and currently has poorer care outcomes.

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CONFLICTS OF INTEREST

All authors are or have been members of clinical advisory groups to the National Diabetes Audit. BY and JV are members of the NDA Research Advisory Group. JV is National Clinical Director for Diabetes and Obesity at NHS England & NHS Improvement.

DATA AVAILABILITY STATEMENT

Data from the NDA can be requested through the NHS Digital Data Access Request Service process at: https://digital.nhs.uk/services/data-access-request-service-dars/data-access-request-service-dars-process.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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