



## Annual report 2017-18

Care processes and outcomes

# National Paediatric Diabetes Audit 2017/18

Care Processes and Outcomes

Report produced by the  
National Paediatric Diabetes Audit  
Royal College of Paediatrics and Child Health



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Front Cover artwork by Anitra Mae Jorge, winner of the NPDA art competition to design a cover for the NPDA annual report. Entrants were asked to design an image based on the theme of 'a good diabetes clinic visit'.



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# Foreword

I am very pleased to introduce the 2019 national report of the National Paediatric Diabetes Audit. As a paediatrician working in one of the paediatric diabetes units providing data to the audit, I am particularly pleased to write this foreword to the eighth audit report to be published by the Royal College of Paediatrics and Child Health, and the 15th published since the audit's inception. The report provides an analysis of data submitted by healthcare professionals caring for children and young people with diabetes in England and Wales over 2017/18. The report includes information on prevalence of diabetes, diabetes-related outcomes and complications, compliance with health care checks recommended by the National Institute for Health and Care Excellence, and recommendations for improvements in care.

Previous NPDA reports have shown consistent year on year improvements in completion rates of health checks recommended for children and young people with diabetes, and improvement in diabetes management evidenced by falling national average HbA1c. This 2017/18 report continues the encouraging trend for higher year on year completion of health checks, which is hugely important. It appears that data quality also continues to improve, which is a sign of a well-functioning audit. However, this year, there has been no reduction in national average HbA1c. The reasons for this are not clear – but this finding must provide renewed impetus for paediatric diabetes teams to engage in all opportunities available to them to facilitate improvement in diabetes management and outcomes. This should include participation in the Children and Young People's Diabetes Network and the National Children and Young People's Diabetes Quality Programme.

Long-term trends show an increase in insulin pump use, which is welcome. However there have been concerning increases in inequality in use of pumps over time, and also evidence of inequality in use of newer technologies such as continuous glucose monitoring sensors. This must change. Our goal must be for improvement in diabetes control and quality of life for all children – and inequality in access to treatments will worsen outcomes for all.

The increase in number of children and young people with Type 2 diabetes being cared for in paediatric diabetes units also requires national attention and action. Type 2 diabetes in adolescence is a severe progressive form of diabetes, that frequently presents with complications, responds poorly to treatment, and results in rapid progression of microvascular and macrovascular complications. In this context, teams must respond to the lower rates of health check completion amongst children and young children with Type 2 diabetes compared to Type 1 diabetes evidenced in this report by joining up with local health and social care services to improve engagement and uptake of services.

I would like to thank all those involved in writing the report and developing its recommendations, including the NPDA Project Board, Methodology and Dataset Group, the audit team, and Clinical Lead, Dr Justin Warner. I would like to thank the paediatric diabetes teams across England and Wales for their support to the audit and for their efforts to make improvements in their local services, resulting in the national improvements we've seen over the past several years. Children and young people with diabetes deserve nothing less.



**Professor Russell Viner, President of the Royal College of Paediatrics and Child Health**

# 1. Executive summary

## 1.1 Background to the audit

Diabetes is a condition where the amount of glucose in the blood is too high because the body cannot use it properly. High blood glucose levels over time may cause complications associated with diabetes including damage to small and large blood vessels and nerves. If not managed, this can result in blindness, kidney failure, heart disease, stroke, and amputations. However, with good diabetes care and blood glucose control, the risks of complications are markedly reduced, enabling children and young people with diabetes to live a healthy, happy and longer life.

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. The audit is commissioned by the Health Quality Improvement Partnership (HQIP), funded by NHS England and the Welsh Government, and is managed by the Royal College of Paediatrics and Child Health. This is the 15th annual report of the audit.

## 1.2 Audit aims

The audit's aims are to:

- Monitor the incidence and prevalence of diabetes amongst children and young people receiving care from a PDU in England and Wales
- Establish whether recommended health checks are being received by children and young people with diabetes
- Enable benchmarking of performance against standards of care specified by the National Institute for Health and Care Excellence (NICE) guidance at PDU, regional and national level
- Determine the prevalence and incidence of diabetes-related complications amongst children and young people with diabetes

## 1.3 Audit scope

The 2017/18 NPDA included all 173 PDUs in England and Wales, and captured information on 29,748 children and young people up to the age of 24 years under the care of a consultant paediatrician.

## 1.4 What the audit measures

The audit collects data submitted by PDUs detailing patient demographics, completion of health checks recommended for children and young people with diabetes, and their outcomes.

The health checks audited were those recommended by NICE in their guidance for the diagnosis and management of children and young people with Type 1 and Type 2 diabetes ([NG18, NICE, 2015](#)).

Prevalence and incidence of diabetes, associated complications, and completion of health checks (care processes) are broken down by age group, gender, type of diabetes, deprivation (using Indices

of Multiple Deprivation based on patient postcode), region and country. The audit's [online reporting tool](#) also provides breakdown by CCG (England) and Health Board (Wales). Since gender, ethnicity, age and deprivation are known to impact upon the level of diabetes control typically achieved by patients as reflected in mean HbA1c levels, case-mix adjusted mean HbA1c levels are presented so that PDU performance can be fairly represented and benchmarked taking these factors into account.

## 1.5 Report structure

This is the third year that the audit has reported health check completion rates and outcomes achieved for children and young people with Type 1 and Type 2 diabetes separately. This executive summary contains key findings and recommendations from the audit which are presented in more detail in later chapters. For the second time, a section on admissions has been added to the Outcomes of Care chapter.

## 1.6 Overall National HbA1c results

- The national mean in 2017/18 was 67.1 mmol/mol and the median was 64 mmol/mol.
- This is the first audit year in six years without a reduction in national HbA1c.



## 1.7 Key findings: Type 1 diabetes

### 1.7.1 Incidence, prevalence, and patient characteristics

- There were more boys than girls with Type 1 diabetes included within the audit.
- There were 2,809 children and young people aged 0 - 15 years old newly diagnosed with Type 1 diabetes in 2016/17, giving an incidence of 25.1 per 100,000 general population.
- Incidence of Type 1 diabetes was higher amongst boys (26.0 per 100,000) compared to girls (24.2 per 100,000).
- 22.3% of children with Type 1 diabetes lived in the most deprived areas of England and Wales compared to an expected 20%.



### 1.7.2 Completion of health checks and provision of diabetes management advice

- There has been a year on year increase in the completion of recommended health checks with over 85% being received by children and young people with Type 1 diabetes in 2017/18.
- Nearly 50% of children and young people with Type 1 diabetes received all seven key health checks nationally but there was wide variation between PDUs, with the percentage ranging from 0% to nearly 100%.
- The majority (86.6%) of children and young people with Type 1 diabetes were assessed for need of psychological support at least once within the audit year.
- Just over half (54.6%) of children and young people with Type 1 diabetes who completed a full year of care had four or more HbA1c measurements recorded.





- Four out of five children and young people newly diagnosed with Type 1 diabetes were screened for coeliac (80.2%) and thyroid disease (83.8%) within 90 days of diagnosis.
- Two-thirds (67.6%) of children and young people newly diagnosed with Type 1 diabetes received Level 3 carbohydrate counting training within 14 days of diagnosis.
- The majority of children and young people with Type 1 diabetes received recommended health care advice for living with diabetes including flu vaccine recommendation (75.9%), provision of 'sick day rules advice' (77.4%) and training in the use of blood ketone testing strips (82.7%).
- Just over four out of five (85.3%) children and young people with Type 1 diabetes were offered an additional dietetic appointment, and 50.3% attended.

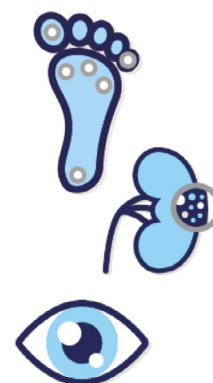
### 1.7.3 Blood glucose diabetes control targets (HbA1c)

- The national unadjusted mean HbA1c for children and young people with Type 1 diabetes increased by 0.02 mmol/mol to 67.5 mmol/mol in 2017/18 compared to 2016/17 and the median was unchanged at 64.0 mmol/mol.
- Several factors continue to be associated with higher HbA1c levels in children and young people with Type 1 diabetes. These factors include; being older, female, living in the more deprived areas of England and Wales, having non-White ethnicity, or longer duration of diabetes.
- Considerable variation in HbA1c target outcomes amongst children and young people with Type 1 diabetes persists between PDUs even after case-mix adjustment.



### 1.7.4 Microvascular complications

- Albuminuria was found in 10.2% of young people aged 12 years and above with Type 1 diabetes.
- The prevalence of albuminuria in Type 1 diabetes was higher amongst those living in the most deprived areas.
- Abnormal retinopathy screening was found in 12.8% of young people aged 12 and above with Type 1 diabetes. The prevalence of retinopathy fell between 2016/17 and 2017/18 from 14.8% to 12.8%.
- The risk of retinopathy increased with age and was highest amongst adolescent females. It was slightly higher amongst those living in more deprived areas and the risk was lower in all deprivation quintiles compared to 2016/17.



### 1.7.5 Macrovascular complications

- High blood pressure (hypertension) was found in 26.7% of young people aged 12 years and older with Type 1 diabetes.
- Just over a fifth (21.7%) of young people aged 12 years and older with Type 1 diabetes had a total blood cholesterol level exceeding the target of 5 mmol/l.
- 17.4% of children aged 0 to 11 years with Type 1 diabetes were overweight, and 17.2% were obese; of those aged 12 years and above, 18.4% were overweight and 23.3% obese. These figures exceeded the background prevalence for overweight and obesity seen in England and Wales.





## 1.7.6 Outcomes of psychological assessment

- Nearly a third of (28.2%) children and young people with Type 1 diabetes with a recorded outcome of psychological support were assessed as requiring additional psychological or CAMHS support outside of MDT clinics.
- Amongst children and young people with Type 1 diabetes, there was a higher proportion of adolescent girls recorded as requiring additional psychological support compared to adolescent boys.
- The percentage of children and young people with Type 1 diabetes assessed as requiring additional psychological support was highest amongst those who were either newly or recently diagnosed, amongst those living in the most deprived areas, and amongst those within the Black ethnic category.
- Children and young people with Type 1 diabetes were more likely to be recorded as requiring additional psychological support if they had an HbA1c above the target of 58 mmol/mol.



## 1.7.7 Hospital admissions

- The number of units submitting admissions data increased from 158 to 167 with only 6 PDUs failing to submit admissions data in 2017/18.
- Significant variation in reported admission rates between regions suggests incompleteness of data submission amongst units who did submit admissions data.
- Data quality and completeness needs to improve further before PDU submitted admission data can be considered representative of admission trends in England and Wales.



## 1.7.8 Treatment regimen

- Usage of insulin pumps to deliver insulin therapy in Type 1 diabetes has increased across all age groups in every audit period since 2014/15.
- Increased usage of pump therapy was associated with female gender, younger age, living in least deprived areas and White Ethnicity.
- The gap between pump usage amongst children and young people with Type 1 diabetes living in the most and least deprived areas has widened with time, from 18.4% versus 26.3% (a difference of 7.9 percentage points) in 2014/15, to 29.0% versus 41.1%, in 2017/18, respectively (a difference of 12 percentage points).



## 1.7.9 Continuous blood glucose monitoring

- Increased usage of CGM with alarms was associated with younger age, living in the least deprived areas and White ethnicity.
- Children and young people with Type 1 diabetes using CGM with alarms were more likely to be using insulin pump therapy than insulin injections.
- Insulin pump and CGM usage amongst children and young people with Type 1 diabetes was associated with better HbA1c outcomes. A causal relationship cannot be inferred given that lower HbA1c is associated with younger age and living in the least deprived areas and there is higher representation of children and young people with these characteristics within the cohorts of pump and CGM users.



### 1.7.10 Thyroid and coeliac disease

- 5.6% of children and young people in England and Wales with Type 1 diabetes had an indication of coeliac disease, and 3.0% were receiving treatment for thyroid disease.
- Prevalence of both co-morbid autoimmune disorders was higher amongst girls compared to boys.



## 1.8 Key findings: Type 2 diabetes

### 1.8.1 Incidence, prevalence, and patient characteristics

- 745 children and young people under the age of 25 with Type 2 diabetes in England and Wales were receiving care from a PDU in 2017/18, an increase of 30 since 16/17. Of these, 147 were diagnosed in the audit year.
- There were proportionally more girls, those of non-White ethnicity, and those living in the most deprived areas amongst the cohort with Type 2 diabetes.



### 1.8.2 Completion of health checks

- Completion rates for health checks were lower for children and young people with Type 2 diabetes compared to those with Type 1.
- Only a quarter (25.7%) of those with Type 2 diabetes aged 12 and above received all key health checks, a completion rate half that of those with Type 1.
- Over three-quarters (77.9%) of children and young people with Type 2 diabetes received a psychological assessment, compared to 86.6% of children and young people with Type 1 diabetes.



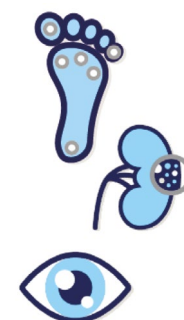
### 1.8.3 Blood glucose diabetes control targets (HbA1c)

- The unadjusted mean and median HbA1c of children and young people with Type 2 diabetes in England and Wales receiving care in a PDU in 2017/18 were 61.3 and 53.0 mmol/mol, respectively, with the latter reflecting a 1 mmol/mol increase since 2016/17.
- There was variation in mean HbA1c in those with Type 2 diabetes by ethnic group, with Black children and young people having a higher HbA1c level compared to those of other ethnic backgrounds.



### 1.8.4 Microvascular complications

- Albuminuria was found in 22.1% of children and young people with Type 2 diabetes; twice the rate observed in those with Type 1 diabetes.
- Abnormal eye screening results were found in 5.6% of young people with Type 2 diabetes; less than half the rate recorded amongst young people with Type 1 diabetes.



## 1.8.5 Macrovascular complications and risk factors

- 84.6% of children and young people with Type 2 diabetes were obese, 44.9% had high blood pressure, and 33.8% exceeded the higher target for total blood cholesterol ( $\geq 5$  mmol/l).



## 1.8.6 Outcomes of psychological assessment

- There were 126 (30.2%) children and young people with Type 2 diabetes assessed as requiring additional psychological or CAMHS support outside of MDT clinics.



## 1.8.7 Treatment regimen

- Treatment regimen data were either missing or reported as 'unknown' for almost one-quarter (22.4%) of children and young people with Type 2 diabetes.

# 1.9 Summary of recommendations

## 1.9.1 Prevalence and incidence

1. Healthcare professionals caring for children with diabetes and commissioners of paediatric diabetes services need to be aware of their case mix in terms of gender, ethnicity and deprivation, and provide and fund care according to local healthcare needs.
2. PDUs should ensure the collection and submission of accurate ethnicity data. The "not stated" and "not known" category appears to be over represented in the dataset and should only be used in line with Health and Social Care Dataset Change Notice (DSCN).



## 1.9.2 Completion of health checks

### Multidisciplinary paediatric diabetes teams should:

3. Ensure children and young people with diabetes are receiving the key essential health checks specific to their diabetes type, identify barriers to this annual provision, and develop quality improvement initiatives to mitigate these.
4. Be aware that completion rates of health checks tend to be higher amongst children and young people with Type 1 diabetes compared to those with Type 2 diabetes and steps should be taken to improve engagement with children and young people with Type 2 diabetes to ensure that these checks are carried out annually.
5. Ensure all children and young people with diabetes receive four or more HbA1c measurements per annum and these are utilised as part of diabetes management.
6. Ensure that screening for thyroid and coeliac disease, and Level 3 carbohydrate counting training takes place at diagnosis of Type 1 diabetes.
7. Signpost current smokers to smoking cessation services and caution non-smokers against smoking as they have a higher risk of cardiovascular disease. These discussions should be included in their on-going structured education programme.
8. Screen for psychological co-morbidities in children and young people with diabetes such as eating disorders, anxiety, and depression so that treatment strategies can be employed to improve emotional wellbeing.



**Commissioners and regional diabetes networks should:**

9. Ensure PDUs have the resources to collect and store accurate data and provide consistent healthcare checks in accordance with NICE standards.

### 1.9.3 Blood glucose diabetes control targets (HbA1c)

**Multidisciplinary paediatric diabetes teams should:**

10. Aim for all children to achieve the HbA1c target set by NICE (individualised for the child) from diagnosis with emphasis on self-management education and psychological support.
11. Actively work towards improving the blood glucose levels of children and young people that are currently out of target range, paying attention to the care needs of those with persistently high HbA1c levels, and adapt communications and structured education provision to be able to meet the different needs of patient groups with characteristics associated with suboptimal glucose management.
12. View ethnic differences and variation associated with deprivation in HbA1c outcomes as challenges to be proactively engaged with and overcome rather than acceptable reasons for sub-optimal diabetes control.



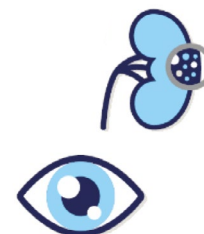
**Commissioners should:**

13. Support Quality Improvement strategies aimed at improving diabetes management.
14. Equip providers of paediatric diabetes care with the resources required to promote and deliver education and self-management strategies to improve HbA1c outcomes.
15. Be aware of the socioeconomic and patient demographic factors associated with poorer diabetes management and ensure services catering to higher percentages of children and young people from vulnerable subgroups are resourced sufficiently to meet their needs, and ensure community groups and schools are sufficiently aware and trained to support young people with diabetes.

### 1.9.4 Diabetes complications and risk factors

**Multidisciplinary paediatric diabetes teams should:**

16. Prioritise improving diabetes management to reduce the lifetime risk of developing complications.
17. Be aware of the significantly higher prevalence of albuminuria and hypertension amongst children and young people with Type 2 diabetes compared to those with Type 1.



**Commissioners should:**

18. Ensure that PDUs are resourced so that children and young people with diabetes have access to individually tailored dietetic and psychological support to promote a healthy diet and active lifestyle.

## 1.9.5 Psychological outcomes

### Multidisciplinary paediatric diabetes teams should:

19. Be aware of the complex psychological needs of children and young people with diabetes.
20. Work with commissioners, local health boards and others involved in commissioning services to ensure that care pathways are in place that enable all children and young people with diabetes to be reviewed in a timely way by an expert psychologist and/or CAMHS when necessary.
21. Recognise the impact of diagnosis and ensure that psychological support is integrated into routine care at diagnosis.
22. Consider whether the higher rates of need of psychological support amongst adolescent girls reflects higher psychological distress compared to adolescent boys, or under-diagnosis of psychological distress amongst the latter group.



### The National Children and Young People's Diabetes Network should:

23. Develop regional and/or national agreement on the best way to utilise expert psychologists in the clinical setting.
24. Promote the integral role of the psychologist within paediatric diabetes services.

## 1.9.6 Hospital admissions

25. All PDUs participating in the NPDA should submit a complete dataset, enabling benchmarking and associated QI activity around admission avoidance.
26. Please refer to the NPDA Hospital Admissions Report ([RCPCH, 2017](#)) for recommendations for avoidance of diabetes-related admissions.



## 1.9.7 Treatment regimen

### Multidisciplinary paediatric diabetes teams should:

27. Improve the completeness of the recording and submission of treatment regimen and CGM usage data for children and young people with both Type 1 and Type 2 diabetes.
28. Be aware of deprivation gradients associated with choice of insulin regimen and CGM usage.

### Regional Networks/Commissioners should:

29. Ensure that PDUs have appropriate IT facilities to record treatment regimens in children and young people with diabetes.
30. Facilitate the use of treatment regimens tailored to suit the individual needs of the patient that aid the best possible diabetes control which are in line with local prescribing policy and in keeping with NICE (2015) guidance, and acknowledge and address barriers to doing so.



## **1.10 Conclusion**

This 2017/18 NPDA report shows a welcome increase in the provision of most key health checks recommended for children and young people with diabetes since the previous audit year, but also that national average HbA1c results have not improved for the first time in six years. However, PDUs and the National Children and Young People's Diabetes Network have shown commitment to working together to improve the care and outcomes of children and young people with diabetes and to reducing the variation in both described within the report, using the national network structures and the National Children and Young People's Diabetes Quality Programme to support lasting and meaningful improvement.



## 2. Introduction

The NPDA is delivered by the Royal College of Paediatrics and Child Health (RCPCH) and has been reporting for 15 years. Data is submitted by healthcare professionals in all Paediatric Diabetes Units (PDUs) in England and Wales about the care received by the children and young people with diabetes using their service. The effectiveness of diabetes care is measured against NICE guidelines and includes treatment targets, health checks, patient education, psychological wellbeing, and assessment of diabetes related complications including acute hospital admissions, all of which are vital to monitoring and improving the long-term health and wellbeing of children and young people with diabetes.

All 173 PDUs in England and Wales participated in the 2017/18 audit, capturing information on 29,748 children and young people with diabetes up to the age of 24 years remaining in paediatric care. The vast majority (95.1%) of the children and young people in the audit had Type 1 diabetes.

The NPDA is designed to measure and motivate change at local, regional and national levels across England and Wales. It also has a role in assuring patient safety, as data from the audit are used to inform hospital inspections by the Care Quality Commission (CQC) in England. The audit encourages everyone with an interest in improving the lives of children and young people with diabetes to work together including healthcare managers, commissioners, children, young people, and their families as well as all members of the multi-disciplinary team.

In the last 3 years, NPDA outcome data have also been benchmarked against certain other European, American and Australasian countries, providing insights into areas where international comparisons can drive improvements (McKnight et al., 2015; Maahs et al., 2015; Sherr et al., 2016).

Past NPDA reports have recognised wide variation in the quality of care and outcomes achieved by PDUs in England and Wales. The audit provides an essential baseline for measuring PDU, regional, commissioning group and national performance, and enables benchmarking of year on year progress. These results support efforts within PDUs, regions and at a national level to understand variability, and by doing so focus efforts to improve care within centres performing less well, which will ultimately contribute to overall national improvement.

### 2.1 Commissioning

The NPDA is commissioned by the Healthcare Quality Improvement Partnership (HQIP). 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.

### 2.2 Background

Diabetes mellitus occurs when blood glucose levels are elevated because the body is unable to metabolise it. The UK has the largest prevalence of children and young people with Type 1 diabetes in Europe (Lacobucci, 2013). Complications associated with suboptimal diabetes management include damage to small and large blood vessels and nerves which over time can result in blindness, kidney failure, heart disease, stroke, and amputations. With good diabetes care and blood glucose management, the risks of complications are reduced, enabling children and young people to enjoy a healthy and longer life.

Diabetes care is complex and requires collaboration between healthcare professionals, children and young people and their families, carers and friends. Good quality care requires adequate resources and training of the workforce (Campbell & Waldron, 2013) to support the medical, emotional and psychological needs of children, young people and their families. In addition, families need ongoing and appropriate age-related structured patient education on self-management to provide knowledge, skills and competencies to manage their diabetes on a daily basis (Waldron & Campbell, 2014). Ensuring that patients and families are provided with a thorough understanding of the targets associated with good diabetes management and the need for regular health checks to prevent complications is an essential part of high-quality care (NICE, 2015).

## 2.3 NPDA outputs and collaborations

The NPDA produces the following reports, all of which can be viewed and downloaded from [www.rcpch.ac.uk/npda](http://www.rcpch.ac.uk/npda).

- The Care Processes and Outcomes Report produced annually compares results across England (by region) and Wales.
- A lay summary of the above specifically designed for patients and families will be made available online and in print shortly following the release of the main report.
- Individualised unit, region and CCG/Local Health Board level reports provide details of performance at each level. These are published online shortly following publication of the Care Processes and Outcomes Report. The online reporting tool enables comparison between specific units or regions, and contains outlier information.
- The NPDA Hospital Admissions and Complications Report measures rates of admission to hospital for complications such as diabetic ketoacidosis (DKA) or hypoglycaemia. The most recent report (RCPCH, 2017) combined admissions data submitted by PDUs with data extracted from the Hospital Episode Statistics in England (HES) and the Patient Episode Database for Wales (PEDW) to identify trends in admissions between 2012/13 – 2014/15.
- Patient Related Experience Measure (PREM) reports provide each unit with feedback from questionnaires completed by parents and patients who use their service. The most recent online PREM surveys were piloted in 2018, and will be rolled out nationally in early 2019.
- The NPDA collaborates with the National Diabetes Audit (NDA) for adults to produce a National Diabetes Transition Audit, tracking the care of young people with diabetes during the transition from paediatric diabetes services to adult diabetes services. The most recent report was published in 2017 (NHS Digital, 2017).
- The NPDA collaborates with national and international researchers to benchmark UK diabetes outcomes and co-morbidities.
- Data from the NPDA are used to provide data to justify PDUs in England receiving the Best Practice Tariff (Randell, 2012).

## 2.4 Scope of the 2017/18 NPDA report

The NPDA analyses data provided by healthcare professionals working in PDUs that are defined as clinics, hospital wards, hospital departments and any other hospital unit diagnosing and treating children and young people with diabetes mellitus in England and Wales. This 2017/18 report covers the health checks (care processes) and outcomes for children and young people with diabetes who have attended PDUs during the period from 1st April 2017 through to 31st March 2018. Whilst it is important to acknowledge improvements in diabetes care made during this period, this audit also aims to highlight deficiencies in care and make specific recommendations to commissioners of health services, regional diabetes networks, and PDUs to address the quality of recording of data relating to patient care and outcomes and the clear inequalities in outcomes across England and Wales.

## 2.5 Key audit questions

The report aims to address a series of questions relating to paediatric diabetes care, which include:

- What proportion of children and young people with diabetes are reported to be receiving key age-specific processes of diabetes care, as recommended by NICE?
- How many achieve outcome measures within specified treatment targets?
- Are children and young people with diabetes demonstrating evidence of small vessel disease (microvascular) and/or abnormal risk factors associated with large vessel disease (macrovascular) prior to transition into adult services?

## 2.6 Data completeness

Over the eight years that the RCPCH has been responsible for delivering the NPDA, there has been a steady improvement in both the quality and completeness of data submitted. However, there remains considerable variation across PDUs with respect to their ability to resource adequate IT systems to collect and submit accurate and complete data during the audit year. NPDA results are utilised by commissioners to measure performance and PDUs have been urged to improve the completeness of their record-keeping and data completeness to ensure it reflects their practice.

The 2017/18 audit is the third audit year in which a comprehensive data completeness report was available upon upload of audit data, enabling detection of missing or incorrectly coded data. It was also the third year that the NPDA asked clinical leads at each unit to provide a signature to confirm the completeness and accuracy of their data submission. It is expected that these developments will have had an impact on the overall quality of data submitted to the NPDA.

For the second time, this report includes analysis of admissions data submitted by PDUs. These data had not been included in previous reports as the data were considered to be of questionable quality and completeness. This was confirmed by comparison of admissions identified in both the NPDA, HES and PEDW datasets as part of the analysis for the NPDA Hospital Admissions Report ([RCPCH, 2017](#)), which found that only 32.3% of all admissions were found in both the NPDA submitted data and either the HES or PEDW dataset.

All but 6 of the 173 PDUs submitted admissions data in 2017/18. It is therefore not possible to use these data to calculate representative figures for numbers of diabetes-related admissions in England and Wales, or to base any recommendations on these data. However, a small amount of admissions data have been presented in order to stimulate focus on its submission. The NPDA will continue to work with PDUs over the next audit cycle to identify and resolve barriers to the submission of complete and good quality admissions data.

## 3. Case studies

### 3.1 Improving care for children and young people with Type 2 diabetes in England and Wales: A National Network Approach

The NPDA has reported on health check completion rates and diabetes-related outcomes for children and young people with Type 2 diabetes since 2017. Results from the past three audit years have shown that this cohort tend to receive fewer recommended health checks than those with Type 1 diabetes, and they are at twice the risk of kidney disease. The vast majority of children and young people living with diabetes have Type 1, and only a handful of paediatric diabetes units (PDUs) have a caseload comprising 10% or more children and young people with Type 2. Whilst the numbers of children and young people with Type 2 diabetes being managed within PDUs are increasing, the short time since the condition has been observed in children and young people in England and Wales and the small numbers seen in most PDUs mean that it has been challenging for many individual paediatric diabetes teams to develop experience, expertise and confidence in the successful management of this patient cohort.

The National Children and Young People's Diabetes Network has therefore established a working group on Type 2 diabetes to support teams to achieve improvements in the care and outcomes of children and young people living with the condition.

Two multidisciplinary members of each regional network attended the first meeting of the group in September, with the aims of:

- Networking – finding out how young people with Type 2 diabetes are being managed regionally/nationally and identifying areas of good practice.
- Sharing resources and identifying those necessary for development.
- Identifying workstreams and nominating people/networks to them.
- Establishing a work plan.

Workstreams prioritised included:

- Dissemination of research and guidance around exercise and dietary management of Type 2 diabetes.
- Investigation of the feasibility of a national registry for children and young people with Type 2 diabetes.
- Review of research and licensing of medications used to manage Type 2 diabetes and their use in children.
- Development of clinic proformas to be used nationally.
- Use of community champions to better engage ethnic groups at greater risk of Type 2 diabetes.
- Development of staff competencies and knowledge of optimal management of children and young people with Type 2 diabetes.

- Supporting NHS England with the commissioning of new adolescent surgery centres and developing guidelines for bariatric surgery to be shared across the network.
- Review of international guidance and guidance produced by the West Midlands network.
- Encouraging participation in research amongst children and young people with Type 2 diabetes.

A further meeting took place in November at which progress against all delegated tasks was discussed and it was clear that much had already been achieved. A schedule of further meetings has been established. The National Network structure has facilitated clinicians from all regions of England and Wales to work collaboratively towards defining and implementing excellence in Type 2 diabetes care, and provided a framework for those in the Type 2 working group to volunteer their time and energies to these ends.

We look forward to seeing improvements in the engagement and management of children and young people with Type 2 diabetes resulting from the efforts of this group reflected in improved health check completion rates and better outcomes for these patients in future NPDA reports.

**Dr Billy White, Consultant Paediatrician, University College London Hospitals NHS Foundation Trust, Type 2 Diabetes Working Group Chair**

## 3.2 Improving care process completion and HbA1c outcomes, Newham hospital

Newham Hospital is one of three hospitals in Barts Health NHS Trust providing paediatric diabetes care. Since 2015, the nursing, dietetic and psychology teams have been working across all three sites, whereas the medical provision was still separate. The diabetes teams from each hospital held regular meetings to align practices and discuss outcomes and it was noted that there were disparities in median HbA1c and achievement of the key health checks (care processes) across the three hospitals.

Therefore, we decided to provide a medical outreach clinic from the Royal London Hospital to Newham Hospital from May 2017 onwards to increase communication and patient discussions between health care providers and align practice.

A considerable effort was made to be consistent in our message to patients regarding aspects of diabetes care and a positive 'can do' mentality and 'alright is not good enough' culture was stimulated.

An age-banded teenage/transition clinic was created providing a consistent team of health care practitioners for this challenging group of patients.

A successful 'High HbA1c' clinic was rolled out further in Newham; this is a clinic where patients with high HbA1c's are seen more frequently and praised for every small step forward.

In monthly MDT meetings, reports on HbA1c and its distribution were discussed and achievement of the seven key care processes in our patients was monitored. These reports were provided by a database manager working across all three sites with input from a database administrator for each site separately.

Over the last year the median HbA1c has gradually improved from 8.3% to 7.5%, and there has been a trend towards lower HbA1c across our whole patient group. Achievement of the seven key care processes has also improved dramatically, with the overall completion rate increasing from 57.5% to 85.7% between 2016/17 and 2017/18.

**Dr Ruben Willemsen and Dr Evelien Gevers, Newham Hospital, Barts Health NHS Trust**



## 4. Characteristics, prevalence and incidence

### 4.1 Audit cohort

A total of 29,752 children and young people with diabetes were included in the 2017/18 audit, an increase of 599 compared to the 2016/17 audit.

**Table 1:** Number of children and young people with diabetes included in the audit by age and type of diabetes, 2017/18

	0-4 years	5-9 years	10-14 years	15-19 years+	20-24 years+	Total (% of cohort)
Type 1 Insulin-dependent diabetes mellitus	1,588	6,303	11,432	8,962	15	28,300 (95.1)
Type 2 Non-insulin-dependent diabetes mellitus	*	16	260	465	*	745 (2.5)
Cystic fibrosis-related diabetes	*	16	106	78	0	202 (0.7)
Monogenic types of diabetes	19	27	51	56	0	153 (0.5)
Other specified diabetes mellitus	22	37	86	71	0	216 (0.7)
Not specified diabetes mellitus	11	22	47	49	*	130 (0.4)
Missing type of diabetes	*	0	*	*	0	6 (0.0)

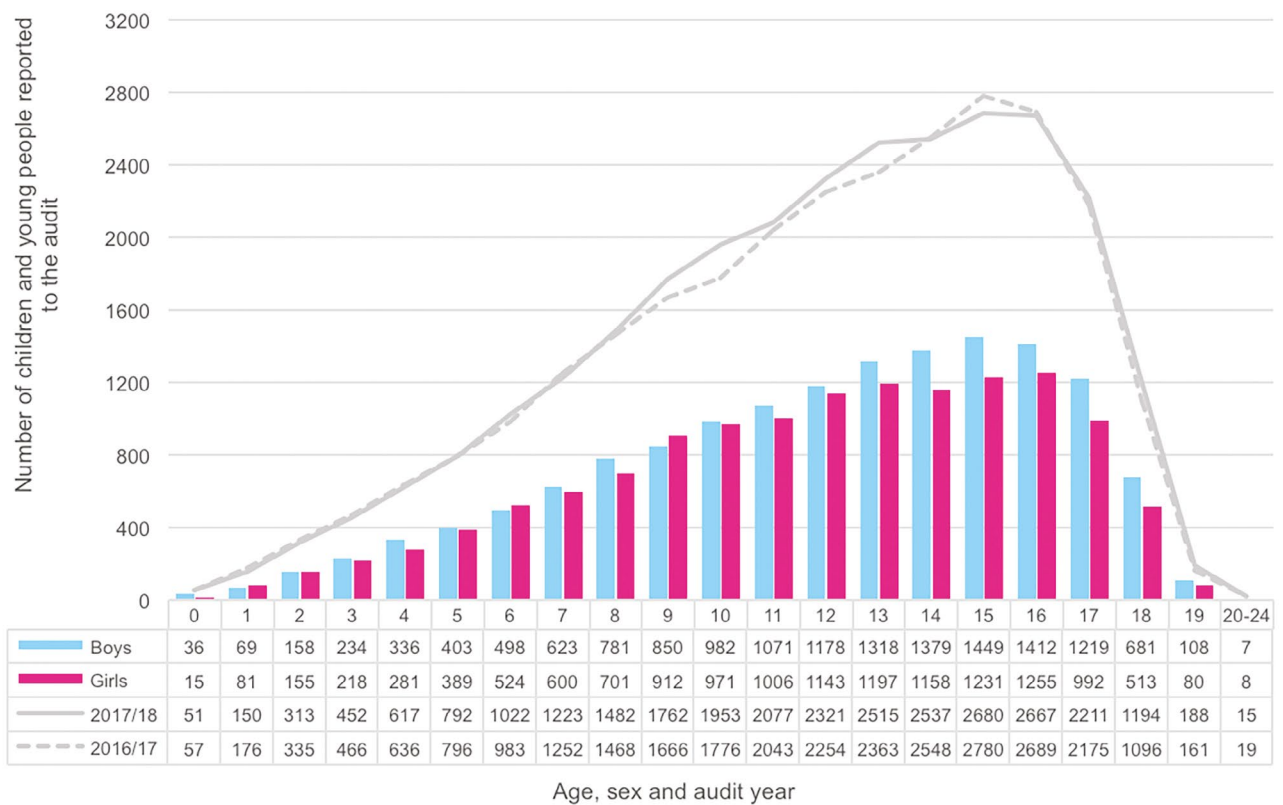
\* indicates a number less than 5 which has been suppressed

+ The NPDA recognises that transition to adult diabetes services usually starts in a patient's late teenage years. The numbers presented in these columns represents the number still receiving care from a PDU and may not necessarily represent the total number of young people with diabetes in these age groups in England and Wales.

## 4.2 Characteristics of children and young people with Type 1 diabetes

### 4.2.1 Age and sex

Figure 1 shows the number of children and young people with Type 1 diabetes reported to the audit by age in whole years at the beginning of the audit period.



**Figure 1:** Numbers of children and young people with Type 1 diabetes included in the NPDA by age and gender, 2017/18

### 4.2.2 Location

Table 2 describes the number of children and young people with Type 1 diabetes by country, regional network and age category. Children and young people are allocated to a region and country based on the last paediatric diabetes unit (PDU) that they attended.

**Table 2:** Number of children and young people with Type 1 diabetes by country, region and age group, 2017/18

	0-4 years	5-9 years	10-14 years	15-19 years+	20-24 years+	Total (% of cohort)
England and Wales	1,588	6,303	11,432	8,962	15	28,300 (100)
England	1,525	5,969	10,807	8,537	15	26,853 (94.9)
Wales	63	334	625	425	0	1,447 (5.1)
East of England	185	685	1,234	1,049	0	3,153 (11.1)
East Midlands	119	424	827	576	0	1,946 (6.9)
London and South East	382	1,496	2,557	2,013	8	6,456 (22.8)
North East and North Cumbria	98	340	622	532	0	1,592 (5.6)
North West	188	791	1,426	1,099	0	3,504 (12.4)
South Central	148	543	991	759	0	2,441 (8.6)
South West	123	460	938	689	*	2,211 (7.8)
Wales	63	334	625	425	0	1,447 (5.1)
West Midlands	139	647	1,106	974	*	2,869 (10.1)
Yorkshire and Humber	143	583	1,106	846	*	2,681 (9.5)

\* indicates a number less than 5 which has been suppressed

### 4.2.3 Ethnicity

Table 3 shows the number and percentage of children and young people with Type 1 diabetes by ethnic category. Percentage ethnicity distribution for children and young people with Type 1 diabetes are also shown excluding 'not stated' and 'unknown' categories to allow comparison with 2011 census data. There was no difference in the ethnicity of children with Type 1 diabetes compared to 2011 census background population.

**Table 3:** Ethnic group of children and young people with Type 1 diabetes England and Wales, 2017/18

	No. of children and young people with T1 diabetes	% of total sample	% of total with stated ethnicity*	% of total population**
White	22,160	78.3	84.9	86.0
Asian	1,536	5.4	5.9	7.5
Black	1,023	3.6	3.9	3.3
Mixed	734	2.6	2.8	2.2
Other	640	2.3	2.5	1.0
Not stated	1,902	6.7	-	-
Not known	281	1.0	-	-
Missing	21	0.1	-	-

\* Ethnicity percentages have been calculated without the 'not stated' and unallocated groups to allow comparison to 2011 census data

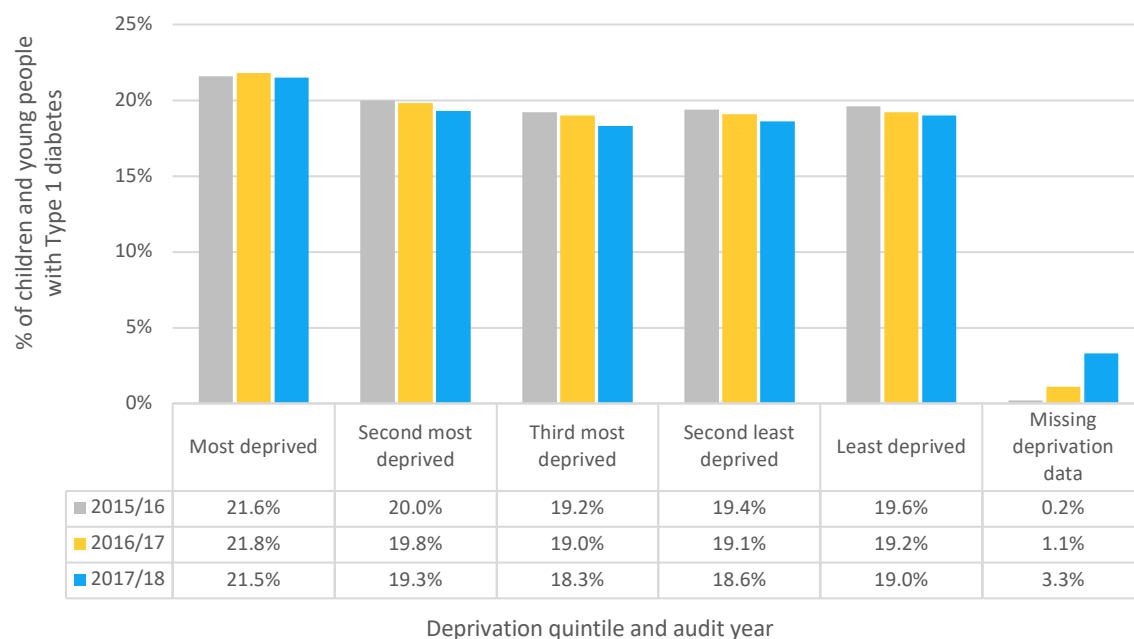
\*\* Percentage of total population in 2011 England and Wales Census

## 4.2.4 Deprivation

Table 4 shows the breakdown of children and young people with Type 1 diabetes by deprivation quintile, derived by matching postcodes to the English (IMD, 2016) and Welsh (WIMD, 2015) indices of multiple deprivation data. A small proportion (3.3%) could not be allocated to a deprivation quintile because their postcode was either missing or invalid, or their postcode that had no matching lower super output area (LSOA). The proportion of children and young people with Type 1 diabetes living in the most deprived quintile was slightly higher, and this has been a trend across audit years (Figure 2).

**Table 4:** Percentage and number of children and young people with Type 1 diabetes by deprivation quintile, 2017/18

	No. of children and young people with T1 diabetes	% of total sample	% of total (excl. missing)
Most deprived	6,093	21.5	22.3
Second most deprived	5,468	19.3	20.0
Third least deprived	5,177	18.3	18.9
Second least deprived	5,265	18.6	19.2
Least deprived	5,368	19.0	19.6
Missing	929	3.3	-

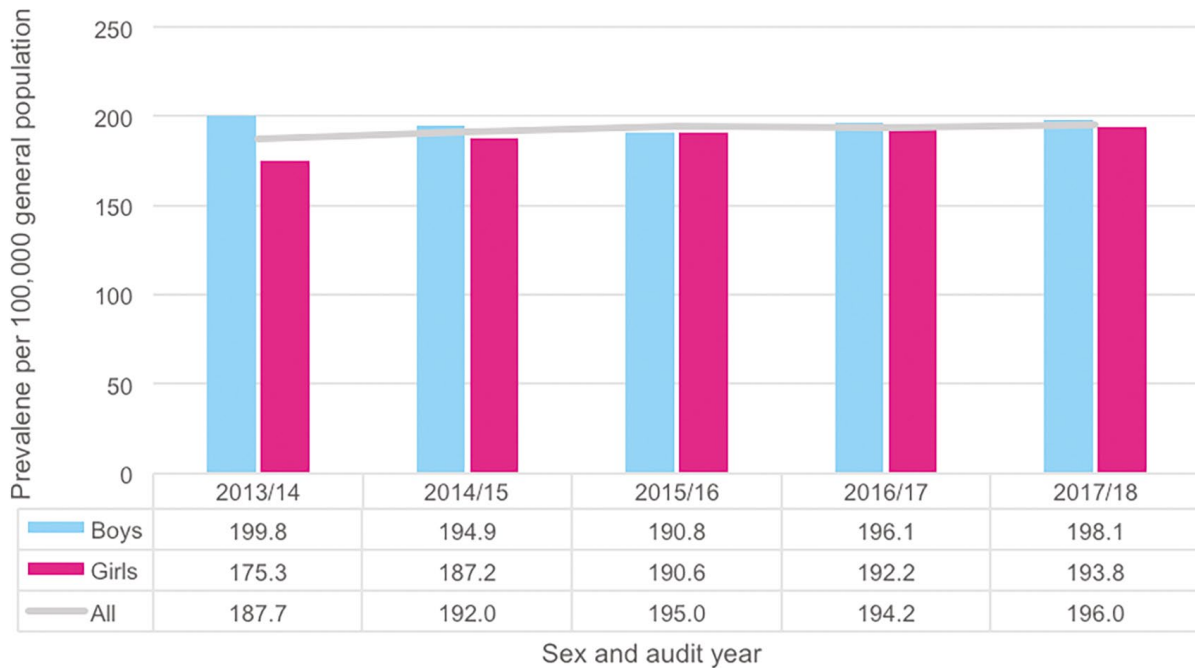


**Figure 2:** Percentage and number of children and young people with Type 1 diabetes by deprivation quintile, 2015/16 to 2017/18

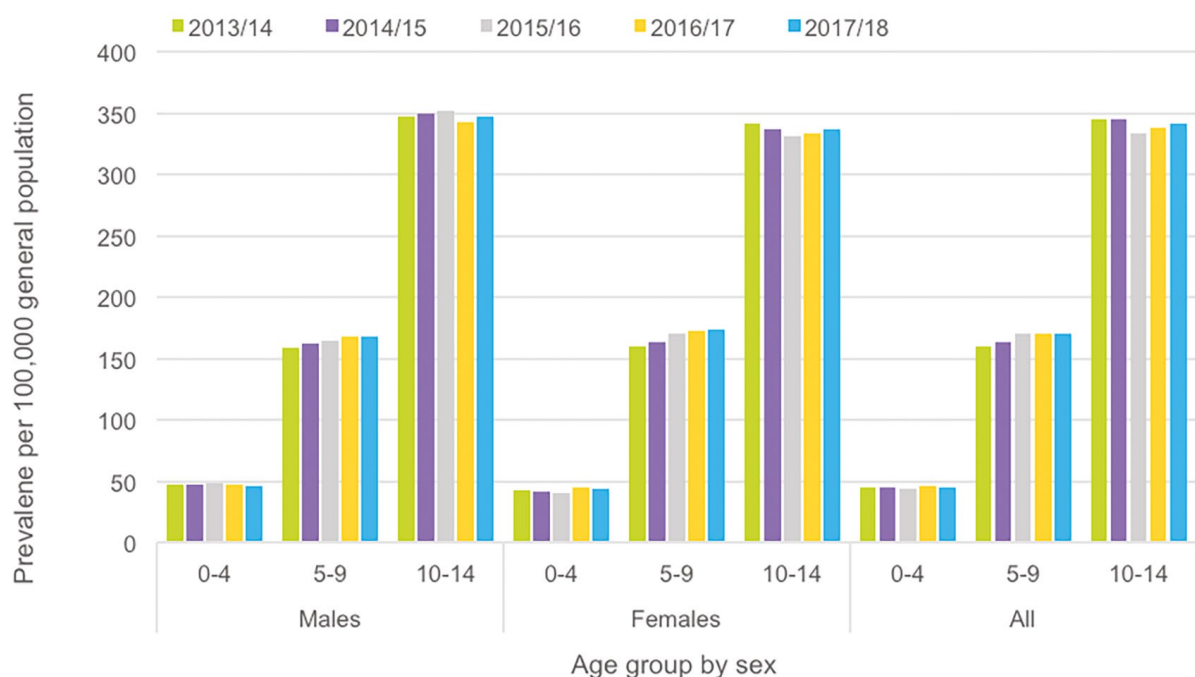
## 4.3 Prevalence and incidence of Type 1 diabetes

### 4.3.1 Prevalence

Prevalence is calculated for children and young people aged 15 and below given that transition to adult services typically occurs from this age onwards. Figure 3 and Figure 4 show the prevalence rates over the last five audit years. In 2017/18, the prevalence of Type 1 diabetes in children and young people aged 0 to 15 years old in England and Wales was 196.0 per 100,000 of the general population; it was slightly higher among boys (198.1 per 100,000) compared to girls (193.2 per 100,000).



**Figure 3:** Prevalence of Type 1 diabetes per 100,000 general population among children aged 0-15 by sex and audit year, 2013/14 to 2017/18



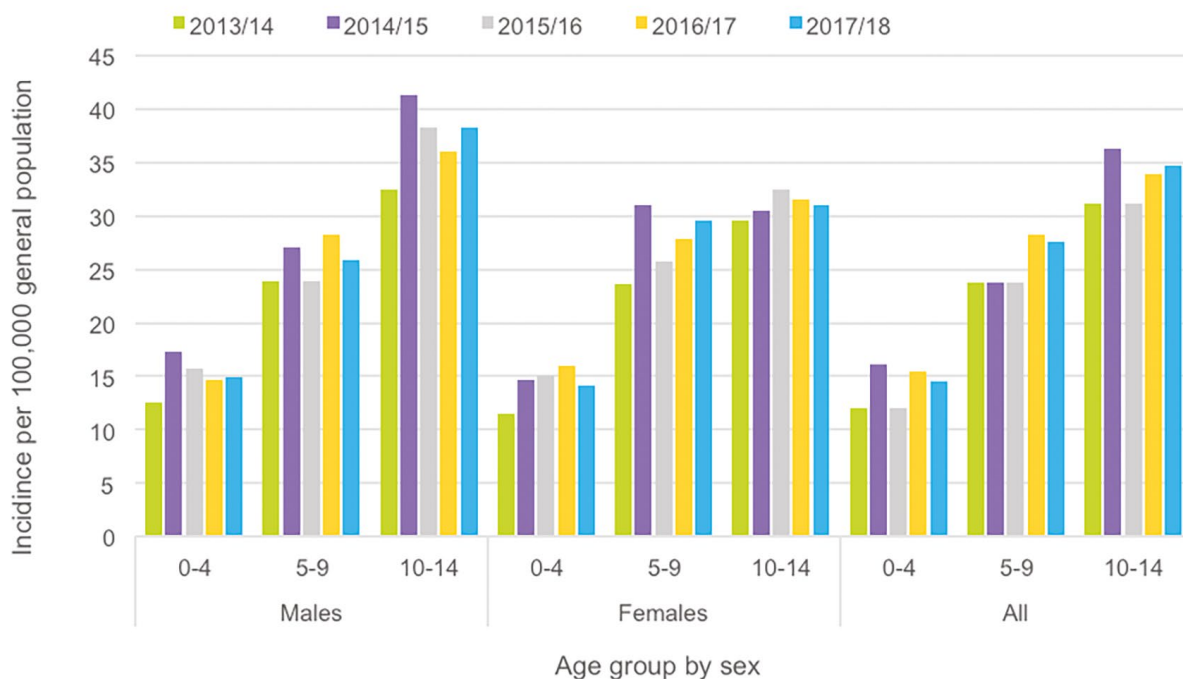
**Figure 4:** Prevalence of Type 1 diabetes per 100,000 general population by age group and sex, 2013/14 to 2017/18

### 4.3.2 Incidence

In 2017/18, there were 2,809 children and young people aged 0 to 15 years old newly diagnosed with Type 1 diabetes in England and Wales, giving an incidence of 25.1 per 100,000 general population within this age group. The incidence was similar to the 2016/17 rate of 25.4 per 100,000 general population (Figure 5). Figure 6 shows that the incidence rates for different age groups have varied since 2013/14.



**Figure 5:** Incidence of Type 1 diabetes per 100,000 general population among children aged 0-15 by sex, 2013/14 to 2017/18



**Figure 6:** Incidence of Type 1 diabetes per 100,000 general population by age group and sex, 2013/14 to 2017/18

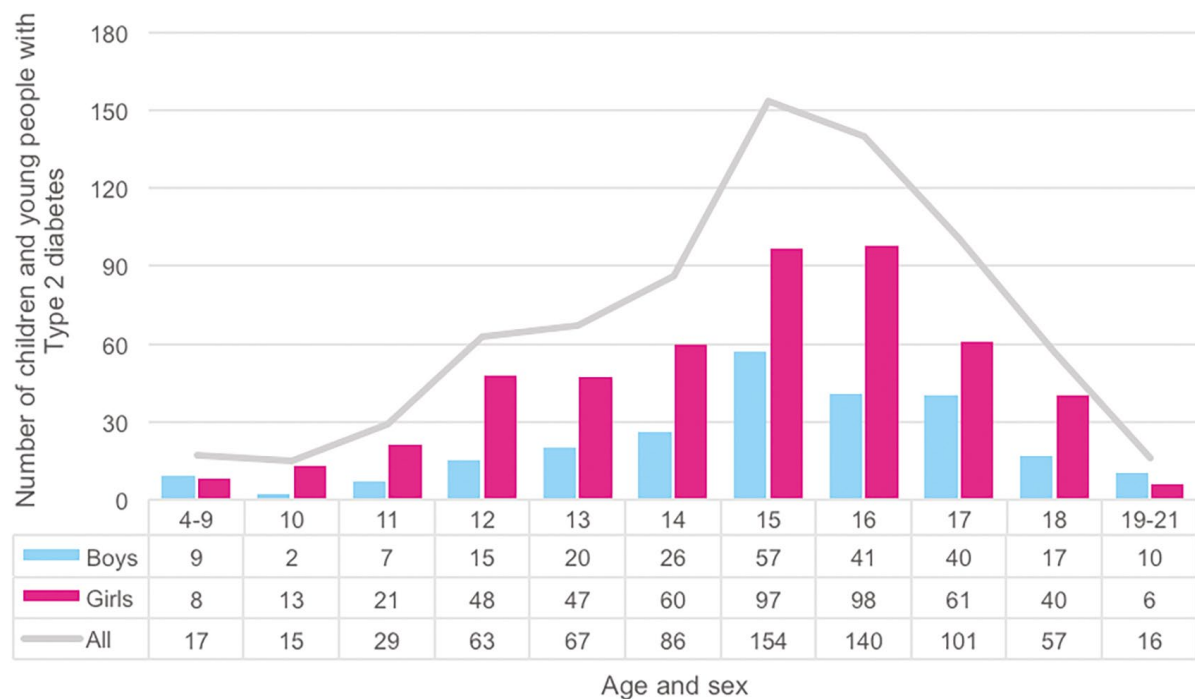


## 4.4 Characteristics of children and young people with Type 2 diabetes

In 2017/18, there were 745 children and young people with Type 2 diabetes reported to the audit who were being cared for in a PDU in England and Wales; of whom 147 were newly diagnosed within the audit year. Prevalence and/or incidence rates of Type 2 diabetes cannot be accurately calculated from NPDA data as an unknown number of children and young people are treated for Type 2 diabetes in primary care and will therefore not be included in the audit. All that can be concluded is that there are year on year increases in the number of children and young people with Type 2 diabetes being managed within PDUs. This year, the number of children and young people reported to the audit increased by 30 compared to the number reported in 2016/17.

### 4.4.1 Age and gender

Figure 7 shows the numbers of children and young people with Type 2 diabetes being cared for in a PDU decreasing from the age of 15, suggesting that young people are either transitioning to adult services or are being managed within primary care in greater numbers from diagnosis from this age.



**Figure 7:** Numbers of children and young people with Type 2 diabetes included in the NPDA by age and gender, 2017/18

### 4.4.2 Location

Table 5 describes the number of children and young people included in the audit with Type 2 diabetes by country and region, based on PDU location.

**Table 5:** Number of children and young people included in the audit with Type 2 diabetes by country and region, 2017/18

	No. of children and young people with T2 diabetes	% of total
England and Wales	745	100
England	720	96.6
Wales	25	3.4
East of England	38	5.1
East Midlands	43	5.8
London and South East	242	32.5
North East and North Cumbria	24	3.2
North West	87	11.7
South Central	49	6.6
South West	43	5.8
West Midlands	122	16.4
Yorkshire and Humber	72	9.7

### 4.4.3 Ethnicity

Table 6 presents a breakdown of children and young people with Type 2 diabetes included in the audit by ethnic category. The percentage of the general population in each ethnic category according to the most recent census is presented to enable comparison of prevalence of Type 2 diabetes within each. The results show that whilst most children and young people with Type 2 diabetes were White, children and young people of non-White ethnicity had a disproportionately higher prevalence of Type 2 diabetes.

**Table 6:** Ethnic group of children and young people with Type 2 diabetes England and Wales, 2017/18

	No. of children and young people with T2 diabetes	% of total sample	% of total with stated ethnicity*	% of total population**
White	253	34.0	38.8	86.0
Asian	243	32.6	37.3	7.5
Black	85	11.4	13.0	3.3
Mixed	36	4.8	5.5	2.2
Other	35	4.7	5.4	1.0
Not stated	77	10.3	-	-
Not known	15	2.0	-	-
Missing	1	0.1	-	-

\* Ethnicity percentages have been calculated without the 'not stated' and unallocated groups to allow comparison to 2011 census data

\*\* Percentage of total population in 2011 England and Wales Census

### 4.4.4 Deprivation

Table 7 shows that there were a disproportionate number of children and young people with Type 2 diabetes living in the most deprived areas compared to the least deprived.

**Table 7:** Numbers and percentages of children and young people with Type 2 diabetes by deprivation quintile, 2017/18

	No. of children and young people with T2 diabetes	% of total sample	% of total sample (excl. missing)
Most deprived	340	45.6	47.5
Second most deprived	171	23.0	23.9
Third least deprived	106	14.2	14.8
Second least deprived	57	7.7	8.0
Least deprived	42	5.6	5.9
Missing	29	3.9	-

## 4.5 Key findings

- A total of 29,752 children and young people with diabetes were included in the 2017/18 audit, an increase of 599 since the 2016/17 audit.
- There were more boys with Type 1 diabetes included within the audit compared to girls.
- Prevalence and incidence rates of Type 1 diabetes amongst children aged 0 to 15 have remained stable since 2013/14.
- There was no difference in the ethnicity of those with Type 1 diabetes compared to the general population.
- 22.3% of children with Type 1 diabetes lived in the most deprived areas of England and Wales compared to an expected 20%.
- 745 children and young people under the age of 25 with Type 2 diabetes in England and Wales were reported to the audit, of whom 147 were diagnosed in the audit year.
- There were proportionally more girls, those of non-White ethnicity, and those living in the most deprived areas amongst the cohort with Type 2 diabetes.

## 4.6 Recommendations

- Healthcare professionals caring for children with diabetes and commissioners of paediatric diabetes services need to be aware of their case mix in terms of gender, ethnicity and deprivation, and provide and fund care according to local healthcare needs.
- PDUs should ensure the collection and submission of accurate ethnicity data. The “not stated” and “not known” category appears to be over-represented in the dataset and should only be used in line with Health and Social Care Dataset Change Notice (DSCN).

## 5. Completion of health checks (care processes)

### 5.1 Completion of health checks for children and young people with Type 1 diabetes

#### 5.1.1 Completion of key health checks

There are several healthcare checks recommended by NICE for children and young people with Type 1 diabetes (NG18, NICE 2015; NG19, 2015) that should be performed at least once annually.

The NPDA has considered seven of these to be essential annual checks:

1. Glycated Haemoglobin A1c (HbA1c) (blood test for diabetes control)
2. Body Mass Index (BMI) (measure of cardiovascular risk)
3. Blood pressure (measure of cardiovascular risk)
4. Urinary albumin (urine test for kidney function)
5. Thyroid screen (blood test for hyper/hypothyroidism)
6. Eye screening (photographic test for eye risk)
7. Foot examination (foot examination for ulcer risk)

Guidelines specify a starting age of 12 years for commencing all checks except for HbA1c and measurement of height and weight, which should be recorded in all ages of children and young people with Type 1 diabetes, and thyroid screening, which should be performed at diagnosis and annually thereafter.

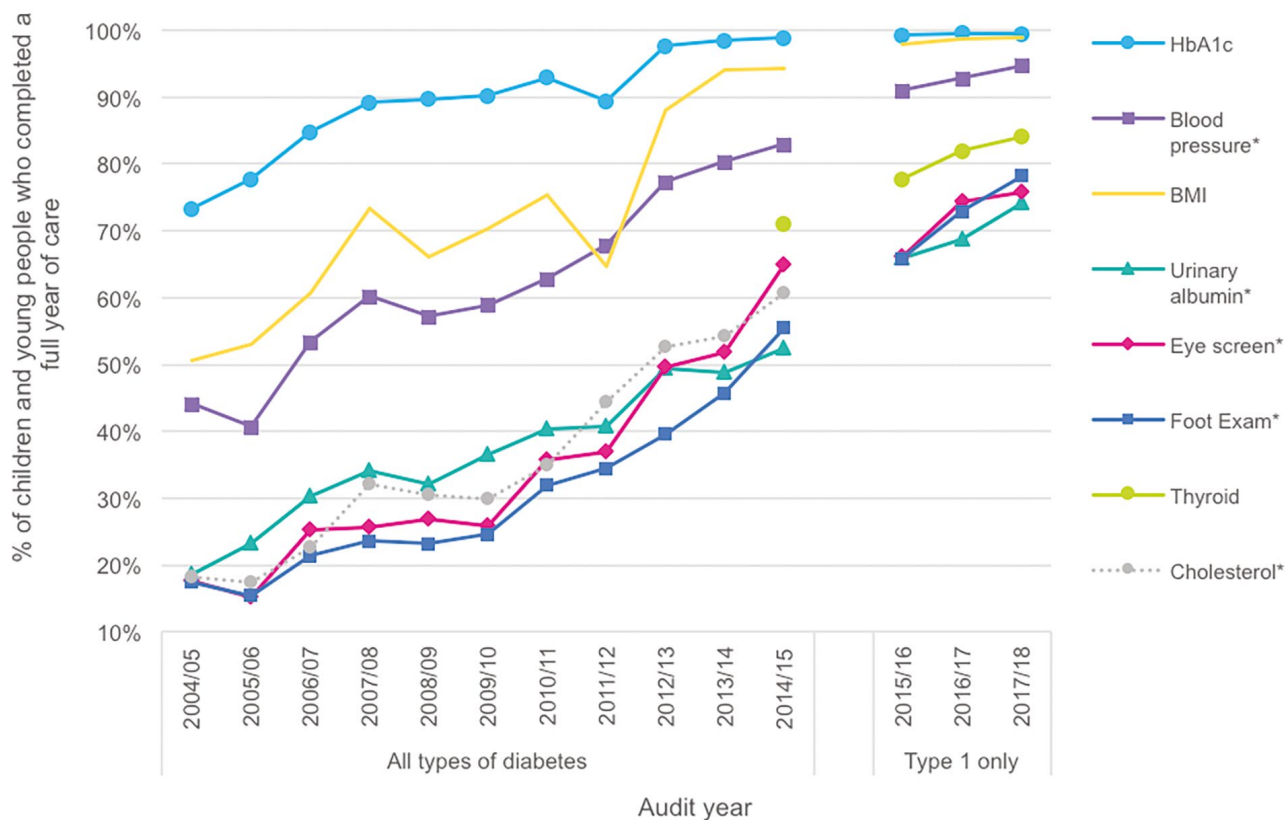
In 2017/18, there were 23,130 children and young people with Type 1 diabetes included in the audit who completed a full year of care (i.e. who did not transition to adult services and were not diagnosed within the audit year), of which 13,363 were aged 12 and above.

Table 8 shows the percentage of children and young people recorded as receiving essential healthcare checks in the audit year, from 2015/16 to 2017/18.

**Table 8:** Percentage of children and young people with Type 1 diabetes who completed a full year of care recorded as receiving health checks, 2015/16 to 2017/18

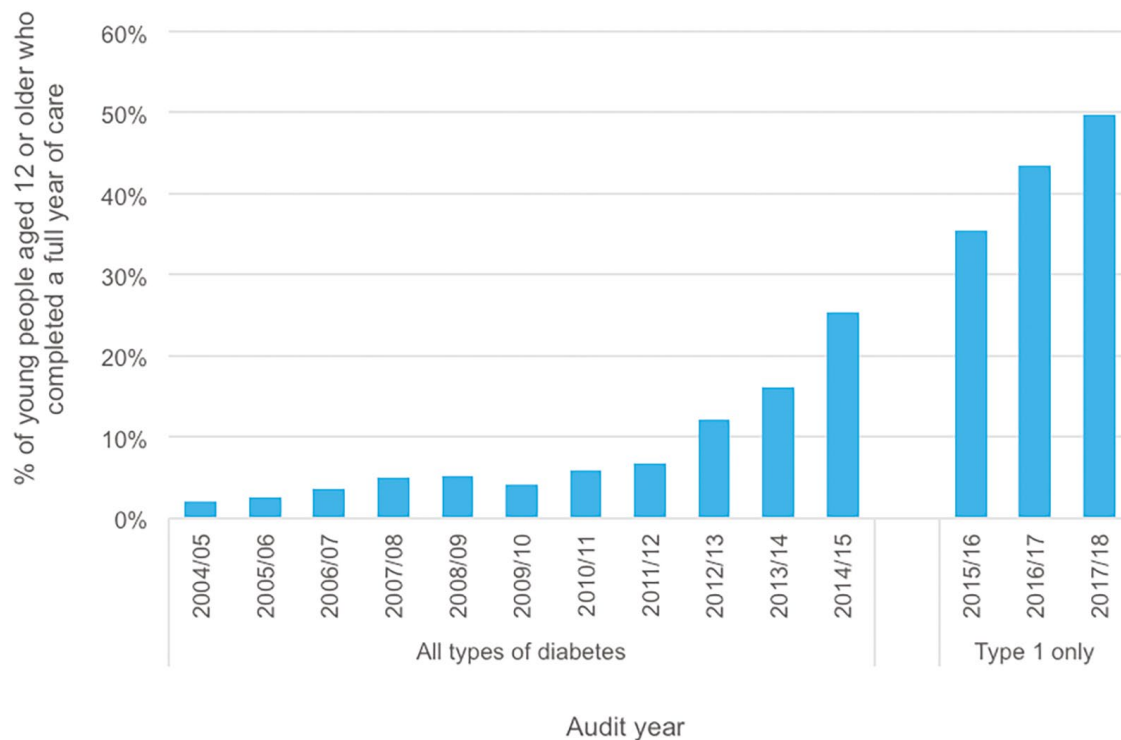
Age	Health check completion	Audit year		
		2015/16	2016/17	2017/18
All ages	No. of children and young people with T1 diabetes (n)	22,567	22,933	23,130
	HbA1c (%)	99.2	99.5	99.4
	BMI (%)	97.9	98.7	98.9
	Thyroid (%)	77.7	81.8	84.0
Aged 12 and above	No. of young people with T1 diabetes (n)	13,313	13,437	13,363
	Blood pressure (%)	90.8	92.7	94.6
	Urinary albumin (%)	66.0	68.7	74.3
	Eye screen (%)	66.2	74.4	75.9
	Foot Exam (%)	65.8	72.8	78.2
	<b>All seven health checks (%)</b>	<b>35.5</b>	<b>43.5</b>	<b>49.8</b>

Since 2004/05, there has been consistent improvement in the percentages of children and young people recorded as receiving essential health checks; both in terms of the proportion completing each individual health check (Figure 8) and the proportion completing all seven (Figure 9). It is important to note that it is not possible to make direct comparisons across completion rates reported for all years because health check data has been reported separately for children and young people with Type 1 and Type 2 diabetes since 2015/16. However, given that the majority of children and young people reported to the audit have Type 1 diabetes, the improvements in completion rates shown can be taken to reflect real improvements in health check completion and/or completeness of data submitted to the NPDA.



\* relates to % of young people aged 12 and above

**Figure 8:** Percentage of children and young people who completed a full year of care recorded as receiving individual health checks, 2004/05 to 2017/18



**Figure 9:** Percentage of young people aged 12 or above who completed a full year of care recorded as receiving all seven key health checks, 2004/05 to 2017/18

## 5.1.2 Variation in key health check completion

### 5.1.2.1 Variation in completion rates nationally and regionally

Tables 9 and 10 provide a breakdown of the healthcare checks recorded as received by children and young people with Type 1 diabetes with a complete year of care in 2017/18 by region, country and overall in England and Wales. Table 9 contains data on the health checks received by all children and young people and Table 10 contains data on the health checks received by young people aged 12 and above.

**Table 9:** Percentage of children and young people of all ages with Type 1 diabetes who completed a full year of care recorded as having received health checks by country and region, 2017/18

	No. of children and young people with Type 1 diabetes	Percentage completing health checks		
		Hba1c	BMI	Thyroid
England and Wales	23,130	99.4	98.9	84.0
England	21,980	99.4	98.9	83.7
Wales	1,150	98.7	98.4	88.8
East of England	2,619	99.2	99.0	78.8
East Midlands	1,587	99.4	98.6	88.7
London and South East	5,330	98.9	98.7	78.0
North East and North Cumbria	1,302	99.5	99.2	88.2
North West	2,837	99.5	99.2	89.6
South Central	1,939	99.9	99.6	89.2
South West	1,792	99.7	98.5	86.8
West Midlands	2,341	99.6	99.2	83.4
Yorkshire and Humber	2,233	99.6	98.7	82.7

**Table 10:** Percentage of young people aged 12 and above with Type 1 diabetes who completed a full year of care recorded as having received health checks by country and region, 2017/18

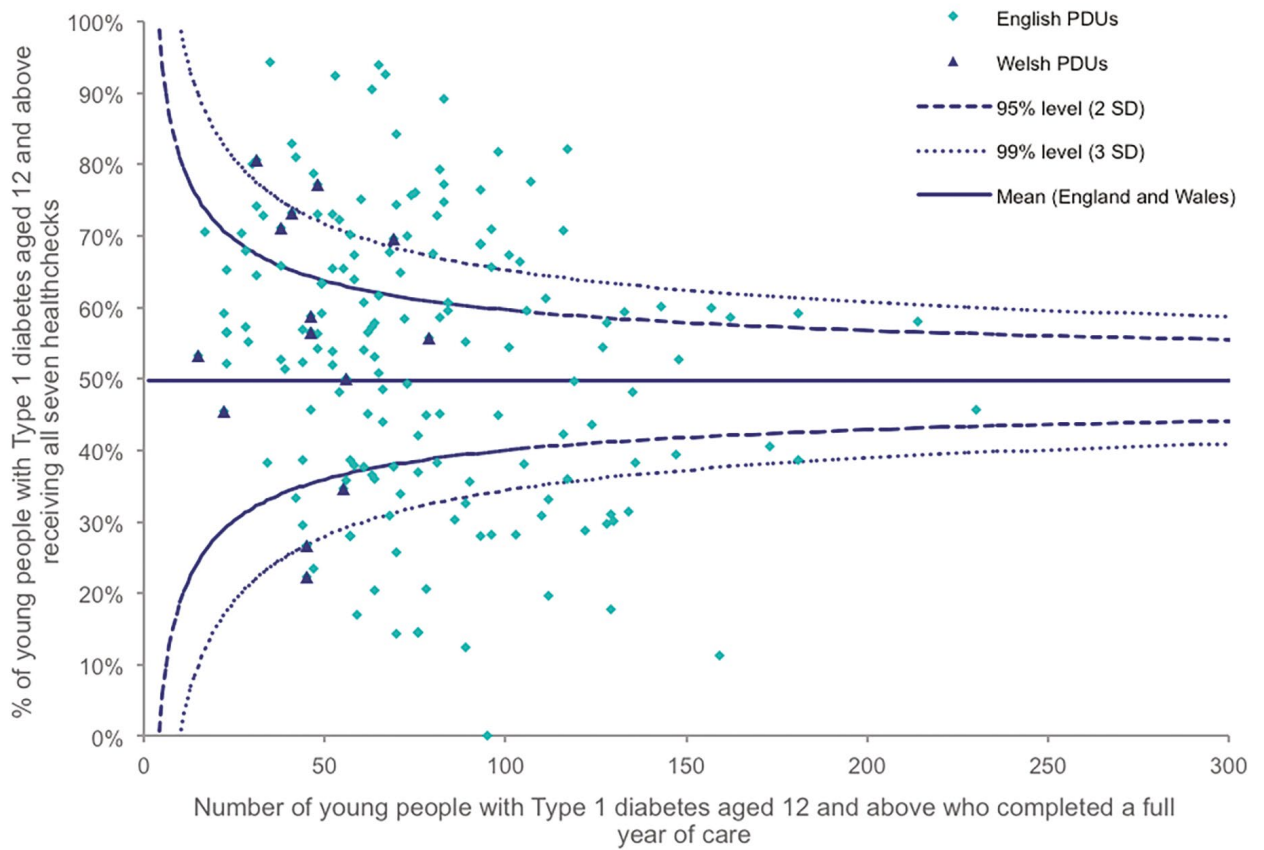
	No. of young people aged 12 and above with Type 1 diabetes	Percentage completing health checks				
		Foot exam	Blood pressure	Urinary albumin	Eye screen	All seven key health checks
England and Wales	13,363	78.2	94.6	74.3	75.9	49.8
England	12,727	77.7	94.7	73.8	76.0	49.5
Wales	636	88.1	93.4	83.3	74.1	55.2
East of England	1,550	76.3	96.0	70.3	77.5	44.1
East Midlands	920	88.3	89.8	74.7	74.5	52.9
London and South East	3,046	71.2	95.0	69.3	70.4	45.5
North East and North Cumbria	768	72.4	93.4	82.7	80.9	52.9
North West	1,593	85.9	95.0	80.0	77.7	55.9
South Central	1,101	79.1	93.1	84.7	79.9	56.3
South West	1,045	76.8	93.1	69.4	78.7	47.0
West Midlands	1,395	80.4	96.3	68.8	75.0	48.1
Yorkshire and Humber	1,309	76.9	96.9	74.9	78.6	51.0

### 5.1.2.2 Variation in completion rates across PDUs

Figure 10 shows the variation by unit in the percentage of young people aged 12 years and older who were recorded to have received all seven key healthcare checks. The horizontal navy line shows the mean completion rate for England and Wales, and the dotted lines indicate units whose results are within two standard deviations (dashes) or three standard deviations (dots) of the mean. There remains considerable variation in percentage of young people receiving all seven health checks across PDUs.<sup>1</sup> PDUs below the bottom dotted line (>3SD) are considered 'alarm' outliers as a significantly smaller percentage of their patients received all the key checks compared to other PDUs in England and Wales.

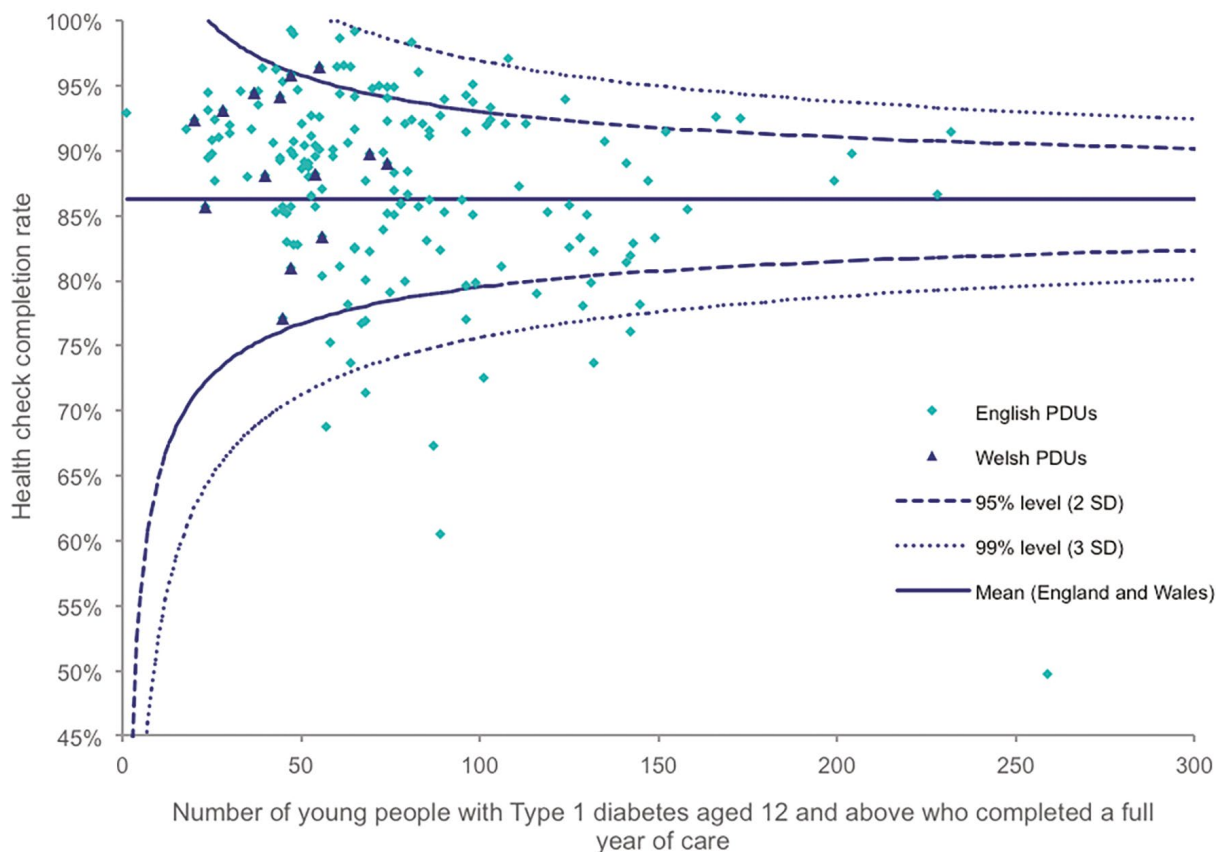
<sup>1</sup> Individual PDU level reports will be published at [www.rcpch.ac.uk/npda](http://www.rcpch.ac.uk/npda) to detail unit level performance.





**Figure 10:** Percentage of young people aged 12 years and above with Type 1 diabetes who completed a full year of care recorded as receiving all seven health checks by unit, 2017/18

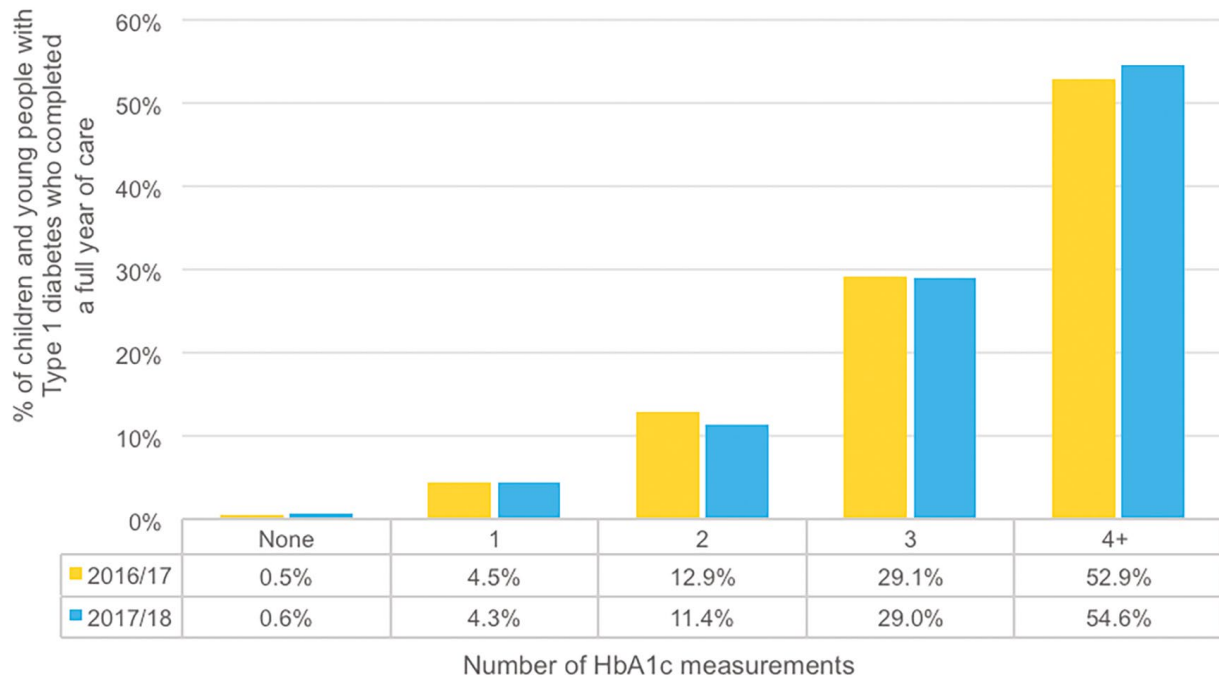
Figure 11 plots PDU health check completion rates against the total number of young people with Type 1 diabetes aged 12 and above who completed a full year of care in each unit. The health check completion rate is calculated by dividing the sum of the number of health checks received by young people with Type 1 diabetes aged 12 and above who completed a full year of care by the sum of the total expected number of health checks. The total expected number of health checks is equal to the number of young people, with Type 1 diabetes aged 12 and above who completed a full year of care, multiplied by 7 (i.e. the number of health checks that they should have received within the audit year). PDUs below the bottom dotted line (>3SD) are considered 'alarm' outliers as they were providing significantly fewer key health checks than other PDUs in England and Wales.



**Figure 11:** Health check completion rate of young people aged 12 years and above with Type 1 diabetes who completed a full year of care by unit, 2017/18

### 5.1.3 Number of HbA1c measurements received

NICE (NG18) recommends that four HbA1c measurements are offered to children and young people with Type 1 diabetes unless there is concern about suboptimal blood glucose control, in which case more frequent testing may be appropriate. Figure 12 shows the percentage of children and young people with Type 1 diabetes receiving a full year of care by number of HbA1c measurements received in the audit year. It shows that 54.6% had four or more measurements recorded in 2017/18.



**Figure 12:** Percentage of children and young people with Type 1 diabetes who completed a full year of care by number of HbA1c measurements recorded per child or young person, 2016/17 to 2017/18

Table 11 shows the percentage of children and young people with Type 1 diabetes receiving a full year of care by number of HbA1c measurements in each country and region.

**Table 11:** Percentage of children and young people with Type 1 diabetes who completed a full year of care by number of HbA1cs measurements recorded 2017/18, by country and region

	None (%)	One (%)	Two (%)	Three (%)	Four or more (%)
England and Wales	0.6	4.3	11.4	29.0	54.6
England	0.6	4.3	11.1	28.4	55.6
Wales	1.3	4.7	18.1	39.4	36.5
East of England	0.8	4.4	12.0	31.0	51.8
East Midlands	0.6	2.8	9.5	25.8	61.4
London and South East	1.1	6.8	12.1	29.3	50.7
North East and North Cumbria	0.5	1.8	7.1	17.4	73.3
North West	0.5	4.4	11.4	31.5	52.3
South Central	*	1.4	5.4	21.4	71.7
South West	0.3	3.0	11.1	30.5	55.1
West Midlands	0.4	5.2	15.0	30.5	48.9
Yorkshire and Humber	0.4	3.5	11.4	29.9	54.8

## 5.1.4 Dietary and nutritional support

NICE (NG18) recommends offering children and young people with diabetes dietetic support to help optimise body weight and blood glucose control, and NHS England's Best Practice Tariff criteria for paediatric diabetes care (Randell, 2012) include the offering of an additional dietetic appointment.

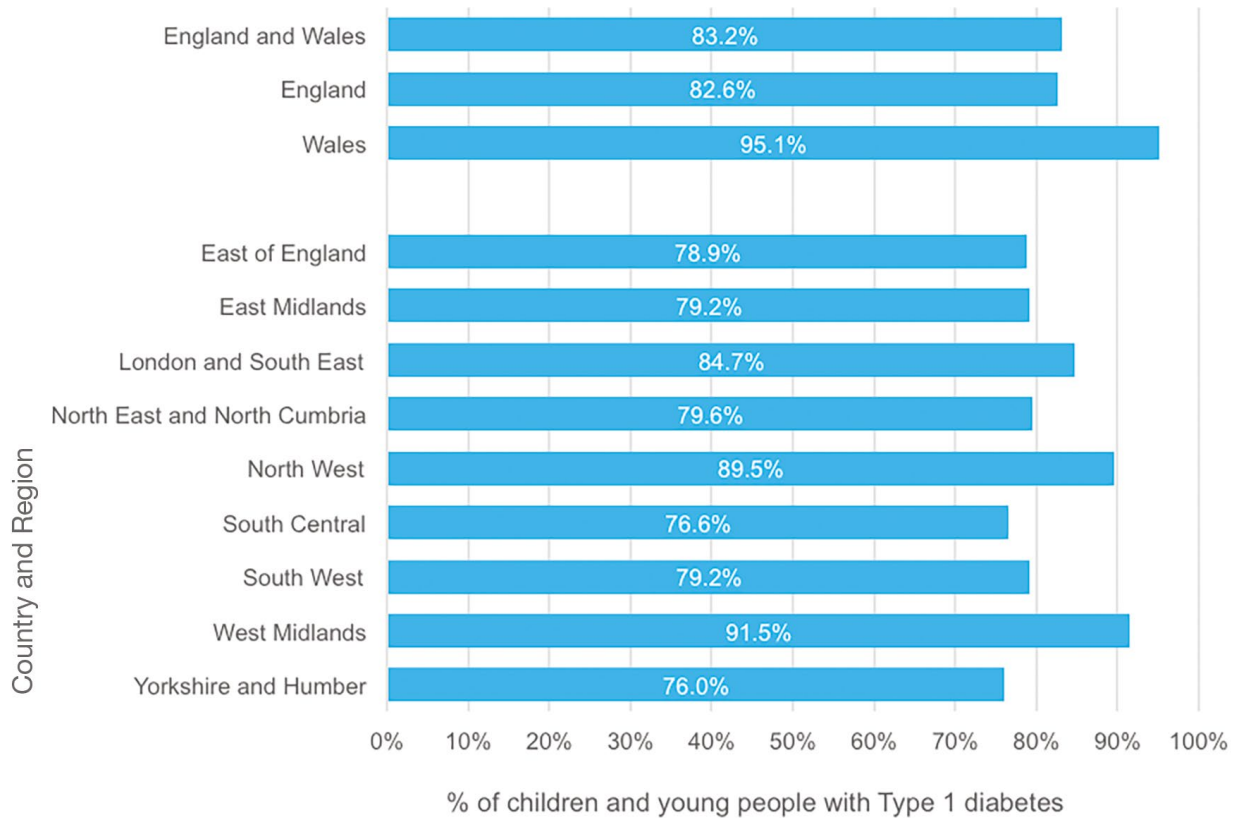
Table 12 shows the percentage of children and young people with Type 1 diabetes with a complete year of care who were offered an additional appointment, attended the offered appointment, and the rate of acceptance of the offer and attending an additional dietetic appointment within the audit year. Lower take up rates of offered dietetic appointments should be interpreted with caution as they could reflect poorer engagement or greater satisfaction with dietetic input received as part of routine clinic appointments.

**Table 12:** Percentage of children and young people with Type 1 diabetes who completed a full year of care who were offered and/or attended an additional dietetic appointment by country and region, 2017/18

	Appointment offered (%)	Appointment attended (%)	Appointment take up rate (%)
England and Wales	85.3	50.3	59.0
England	86.5	50.7	58.6
Wales	61.5	43.1	70.2
East of England	87.1	57.2	65.7
East Midlands	92.3	42.6	46.1
London and South East	86.0	56.7	66.0
North East and North Cumbria	91.5	43.5	47.5
North West	78.6	51.7	65.8
South Central	92.0	46.1	50.1
South West	87.4	53.6	61.3
West Midlands	83.8	50.6	60.4
Yorkshire and Humber	87.8	39.1	44.6

## 5.1.5 Smoking

Figure 13 shows the percentage of young people aged 12 and above with Type 1 diabetes completing a full year of care with a smoking status recorded. Table 13 shows the percentage of all young people aged 12 and above with Type 1 diabetes with a recorded smoking result in the audit period classified as 'current smoker' and the percentage of 'current smokers' who were recorded as being offered a referral to smoking cessation services. Approximately one in 30 young people were recorded as smoking within the audit year and of those, 40.0% were offered a referral to smoking cessation services.



**Figure 13:** Percentage of young people aged 12 and above with Type 1 diabetes who completed a full year of care recorded as having their smoking status checked

**Table 13:** Percentage of young people aged 12 and above with Type 1 diabetes recorded as a 'current smoker' who were referred to smoking cessation services by region and country, 2017/18

	No. of young people aged 12 and above with T1 diabetes (n)	Proportion recorded as 'current smoker' (%)	Referred to smoking cessation services (%)
England and Wales	16,368	3.1	40.0
England	15,544	3.1	40.8
Wales	824	2.9	25.0
East of England	1,821	4.2	39.0
East Midlands	1,142	2.1	54.2
London and South East	3,654	2.8	51.0
North East and North Cumbria	948	3.4	56.3
North West	1,986	3.1	37.7
South Central	1,410	3.9	20.0
South West	1,305	3.8	42.0
West Midlands	1,706	1.6	48.1
Yorkshire and Humber	1,572	2.9	26.1

## 5.1.6 Completion of all other annual health checks

The NPDA also collects data on four additional health checks for children and young people with Type 1 diabetes as recommended by NICE 2015 (NG18):

1. Psychological assessment (assessment for need of psychological support)
2. Offering of immunisation against influenza
3. Advice about managing diabetes ('sick-day rules')
4. Using (or trained to use) blood ketone testing strips and a meter

Results are shown in Table 14 for all children and young people with a complete year of care.

**Table 14:** Percentage of children and young people with Type 1 diabetes who completed a full year of care recorded as receiving health checks by region and country, 2017/18

	Psychological support (%)	Flu vaccine (%)	'Sick day rules' (%)	Blood ketone testing (%)
England and Wales	86.6	75.9	77.4	82.7
England	88.1	75.3	76.9	82.4
Wales	58.7	88.3	86.8	88.3
East of England	80.8	61.9	71.2	63.5
East Midlands	94.6	75.6	87.7	95.8
London and South East	90.0	80.3	77.8	84.5
North East and North Cumbria	95.8	78.4	81.4	93.1
North West	82.1	77.2	75.4	79.7
South Central	86.6	74.3	70.1	78.4
South West	89.2	74.7	72.9	79.2
West Midlands	90.2	82.6	80.4	83.7
Yorkshire and Humber	88.5	68.2	78.7	92.0

## 5.1.7 Care at diagnosis

### 5.1.7.1 Screening for autoimmune conditions

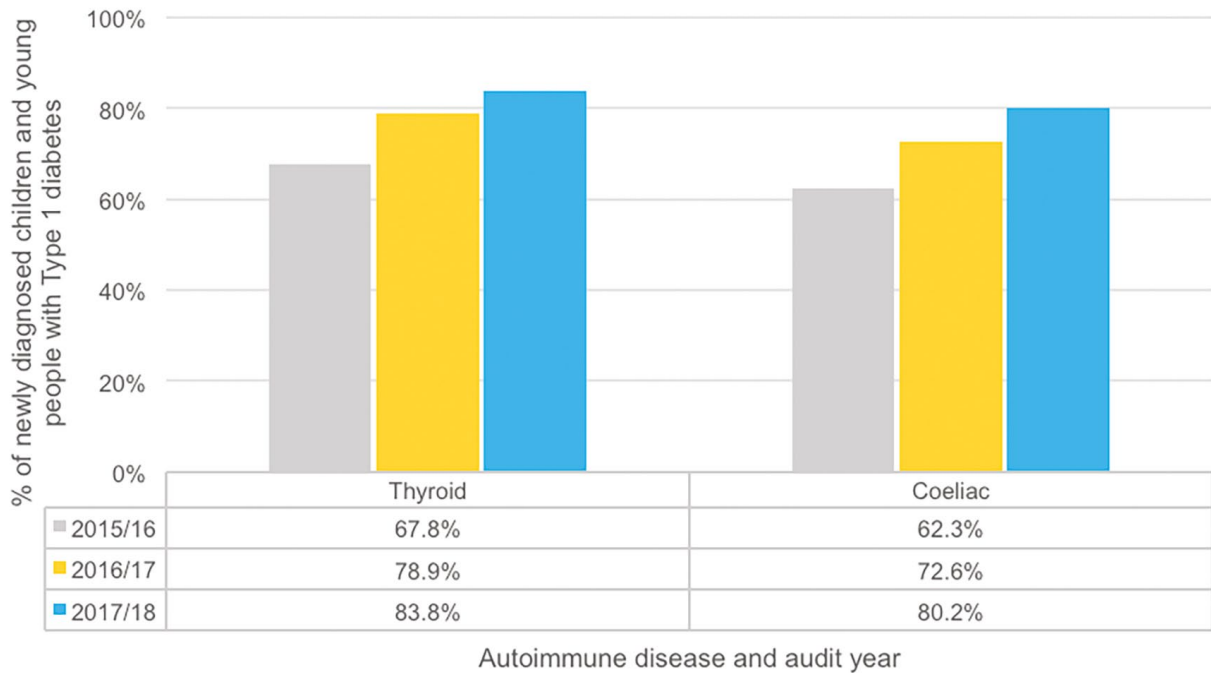
Children and young people with Type 1 diabetes are at greater risk of having other autoimmune conditions. NG18 (NICE, 2015) and NG20 (NICE, 2015) recommend screening for thyroid and coeliac disease at diagnosis.

Table 15 shows the percentage of children and young people diagnosed more than 90 days before the end of the audit year (n=2,179) who received screening for coeliac and thyroid disease within 90 days of diagnosis by country and region.

**Table 15:** Percentage of children and young people with Type 1 diabetes who received screening within 90 days of diagnosis by country and region, 2017/18

	No. diagnosed 90 days before the end of the audit (n)	Thyroid disease screen (%)	Coeliac disease screen (%)
England and Wales	2,179	83.8	80.2
England	2,063	83.9	80.0
Wales	116	82.8	82.8
East of England	269	74.0	79.9
East Midlands	135	77.8	73.3
London and South East	485	87.8	83.7
North East and North Cumbria	115	83.5	85.2
North West	286	76.6	74.8
South Central	193	92.7	88.6
South West	161	86.3	74.5
West Midlands	222	88.3	84.7
Yorkshire and Humber	197	86.8	71.1

Figure 14 shows the percentage of children and young people diagnosed more than 90 days before the end of the audit year (n=2,179), who received screening for coeliac and thyroid disease within 90 days of diagnosis. There has been an improvement in the rates of completion of both health checks at diagnosis from 2015/16 to 2017/18.

**Figure 14:** Percentage of newly diagnosed children and young people with Type 1 diabetes who received screening within 90 days of diagnosis, 2015/16 to 2017/18

### 5.1.7.2 Level 3 carbohydrate counting

NG18 (NICE) also recommends offering level 3 carbohydrate-counting education to children and young people with Type 1 diabetes from diagnosis.

Table 16 shows variation in the percentage of children and young people diagnosed more than 14 days before the end of the audit year (n=2,858) who received level 3 carbohydrate-counting education within 14 days of diagnosis by region.

**Table 16:** Percentage of children and young people with Type 1 diabetes recorded as receiving carbohydrate-counting education within 14 days of diagnosis by country and region, 2017/18

	No. diagnosed 14 days before the end of the audit (n)	Carb counting (%)
England and Wales	2,858	67.6
England	2,706	68.3
Wales	152	54.6
East of England	337	49.3
East Midlands	185	69.2
London and South East	645	66.4
North East and North Cumbria	148	73.0
North West	375	62.7
South Central	250	77.2
South West	208	73.6
West Midlands	297	83.2
Yorkshire and Humber	261	73.2

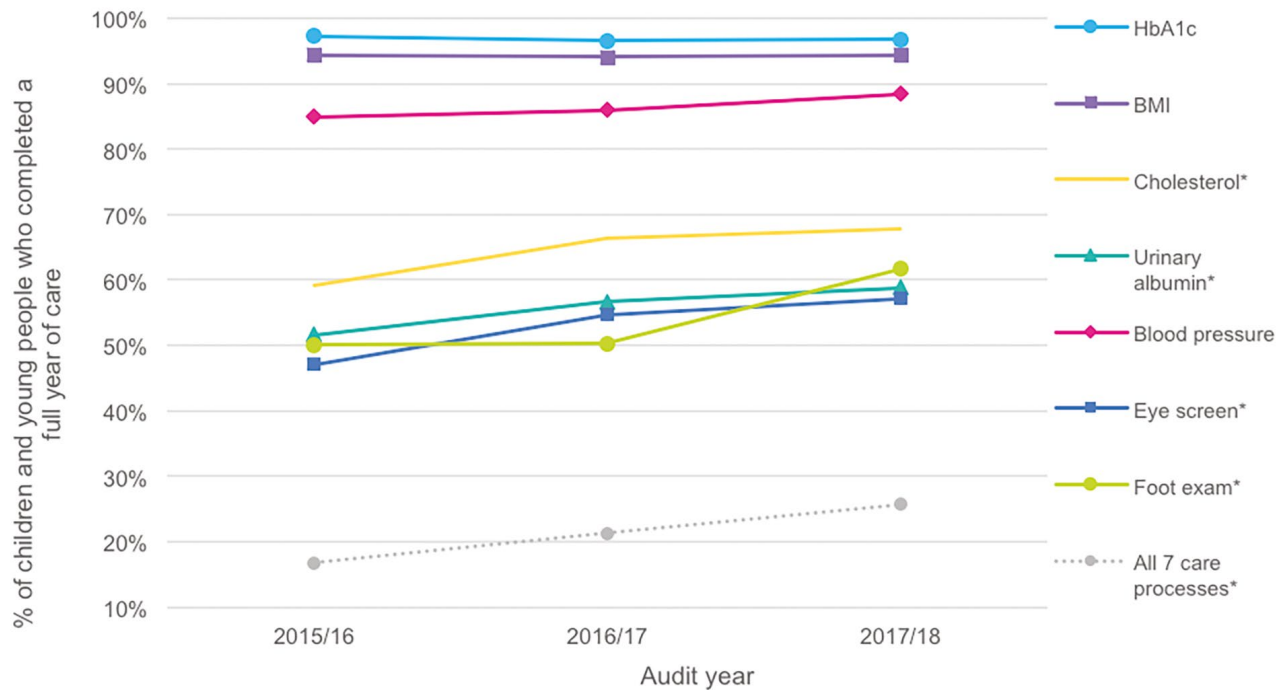
## 5.2 Healthcare checks for children and young people with Type 2 diabetes

The healthcare checks for children and young people with Type 2 diabetes recommended in NG18 and NG19 (NICE, 2015) differ slightly from those for Type 1 diabetes. The NPDA includes cholesterol screening as being one of the seven essential annual checks rather than thyroid screening. All should be performed annually from diagnosis, except for foot examination and eye screening, which are indicated from age 12. In 2017/18, there were 470 children and young people who completed a full year of care recorded as having Type 2 diabetes, of which 436 were aged 12 years and above.



## 5.2.1 Completion of key health checks

Figure 15 shows the percentage of children and young people with Type 2 diabetes who completed a full year of care recorded as receiving each of the seven recommended health checks from 2015/16 to 2017/18.



\* % refers to young people aged 12 or older with a complete year of care

**Figure 15:** Percentage of children and young people with Type 2 diabetes who completed a full year of care recorded as receiving key health checks, 2015/16 to 2017/18

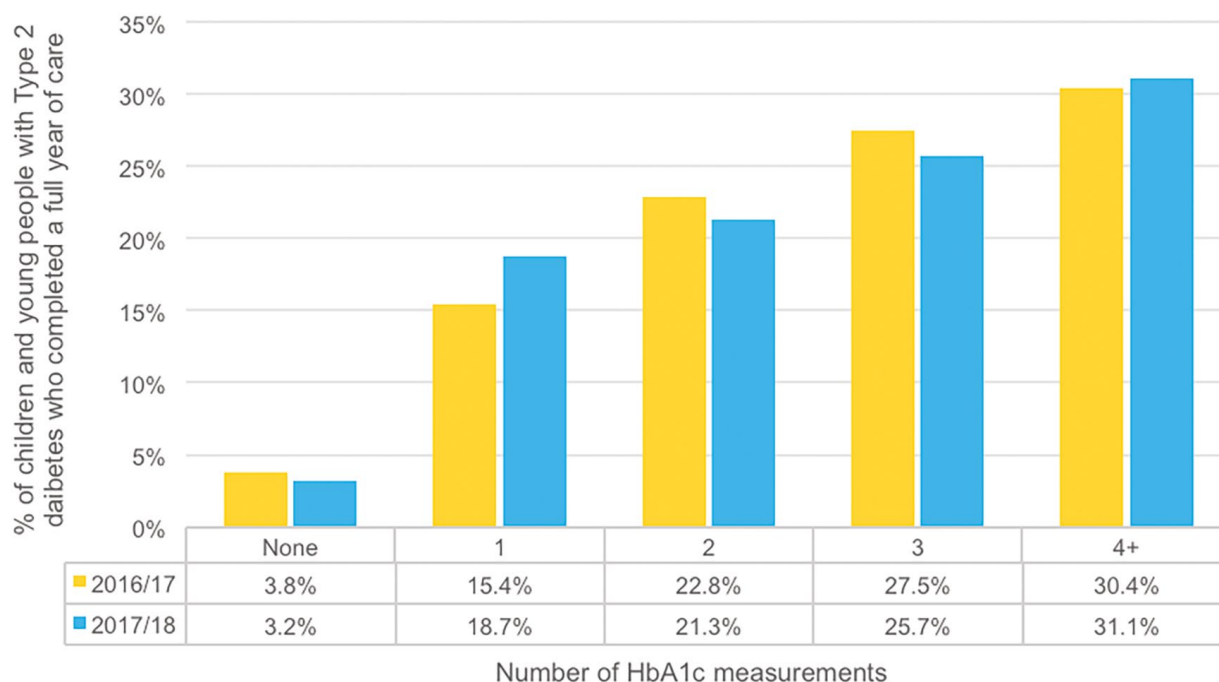
Table 17 shows the percentage of children and young people recorded as receiving essential healthcare checks in the audit year, from 2015/16 to 2017/18.

**Table 17:** Percentage of children and young people with Type 2 diabetes who completed a full year of care recorded as receiving recommended health checks, 2015/16 to 2017/18

Age	Health check	Audit year		
		2015/16	2016/17	2017/18
All ages	No. of children and young people (n)	412	473	470
	HbA1c (%)	97.3	96.6	96.8
	BMI (%)	94.4	94.1	94.5
	Cholesterol (%)	59.2	66.4	67.9
Aged 12 and above	No. of young people (n)	390	436	436
	Urinary albumin (%)	51.7	56.7	58.9
	Blood pressure (%)	85.0	86.0	88.5
	Eye screen (%)	47.2	54.8	57.3
	Foot Exam (%)	50.0	50.2	61.7
	All seven health checks (%)	16.7	21.3	25.7

## 5.2.2 Number of HbA1c measurements

Figure 16 shows that 31.1% of children and young people with Type 2 diabetes, recorded as completing a full year of care, received four or more HbA1c measurements.



**Figure 16:** Number of HbA1c measurements recorded for children and young people with Type 2 diabetes receiving a full year of care, 2017/18

## 5.2.3 Completion of all other health checks

Table 18 shows the percentage of children and young people with Type 2 diabetes completing a full year of care recorded as being offered and attending an additional dietetic appointment.

**Table 18:** Percentage of children and young people with Type 2 diabetes who completed a full year of care recorded as being offered and attending an additional dietetic appointment, 2017/18

	England and Wales
Appointment offered (%)	70.0
Appointment attended (%)	48.7
Appointment take up rate (%)	43.9

Table 19 shows the percentage of young people aged 12 and above with Type 2 diabetes who completed a full year of care recorded as receiving a smoking status health checks. It also includes the percentage of all young people aged 12 and above with Type 2 diabetes with a recorded smoking result in the audit period classified as 'current smoker' and the percentage of those who were recorded as being offered a referral to smoking cessation services.

**Table 19:** Percentage of young people aged 12 and above with Type 2 diabetes who completed a full year of care recorded as receiving a smoking health check and the percentage of current smokers referred to smoking cessation services, 2017/18

		England and Wales
Percentage of young people with a complete year of care with a recorded smoking status (%)		83.3
Young people aged 12 or older with a recorded smoking status	Total (n)	684
	'Current smoker' (%)	2.6
	Referred to smoking cessation services (%)	50.0

The NPDA also collects data on three additional health checks for children and young people with Type 2 diabetes:

1. Psychological assessment (assessment for need of psychological support)
2. Offering of immunisation against influenza
3. Advice about managing diabetes

Results are shown in Table 20 for all children and young people with a complete year of care.

**Table 20:** Percentage of young people with Type 2 diabetes who completed a full year of care recorded as receiving health checks by region and country, 2017/18

	England and Wales
Assessment for Psychological support (%)	77.9
Flu vaccine recommendation (%)	49.4
'Sick day rules' (%)	41.7

## 5.3 Key findings

- There has been a year on year increase in the completion of recommended health checks with over 85% being completed in children and young people with Type 1 diabetes in 2017/18.
- Nearly 50% of children and young people with Type 1 diabetes received all seven key health checks nationally but there was wide variation between PDUs, with the percentage ranging from 0% to nearly 100%.
- The majority (86.6%) of children and young people with Type 1 diabetes received were assessed for need of psychological support.
- Just over half (54.6%) of children and young people with Type 1 diabetes who completed a full year of care had four or more HbA1c measurements recorded.
- Four out of five children and young people newly diagnosed with Type 1 diabetes were screened for coeliac (80.2%) and thyroid disease (83.8%) within 90 days of diagnosis.
- Two-thirds (67.6%) of children and young people newly diagnosed with Type 1 diabetes received Level 3 carbohydrate counting training within 14 days of diagnosis.
- The majority of children and young people with Type 1 diabetes received recommended health care advice for living with diabetes including flu vaccine recommendation (75.9%), provision of 'sick day rules advice' (77.4%) and training in the use of blood ketone testing strips (82.7%).
- Just over four out of five (85.3%) of children and young people with Type 1 diabetes were offered an additional dietetic appointment, and 50.3% attended.
- Completion rates for health checks were lower for children and young people with Type 2 diabetes compared to those with Type 1.
- Only a quarter (25.7%) of those with Type 2 diabetes aged 12 and above received all key health checks, a completion rate half that of those with Type 1.
- Over three-quarters (77.9%) of children and young people with Type 2 diabetes received a psychological assessment.

## 5.4 Recommendations

### **Multidisciplinary paediatric diabetes teams should:**

- Ensure children and young people with diabetes are receiving the key essential health checks specific to their diabetes type and identify barriers to this annual provision and develop quality improvement initiatives to mitigate these.
- Be aware that completion rates of health checks tend to be higher amongst children and young people with Type 1 diabetes compared to those with Type 2 diabetes, and attempt to improve engagement with children and young people with Type 2 diabetes to ensure that these checks are carried out annually.
- Ensure all children and young people with diabetes receive four or more HbA1c measurements per annum and these are utilised as part of diabetes management.
- Ensure that screening for thyroid and coeliac disease, and Level 3 carbohydrate counting training takes place at diagnosis of Type 1 diabetes.

- Signpost current smokers to smoking cessation services and caution non-smokers against smoking as they have a higher risk of cardiovascular disease. These discussions should be included in their on-going structured education programme.
- Screen for psychological co-morbidities in children and young people with diabetes such as eating disorders, anxiety, and depression so that treatment strategies can be employed to improve emotional wellbeing.

**Commissioners and regional diabetes networks should:**

- Ensure PDUs have the resources to collect and store accurate data and provide consistent healthcare checks in accordance with NICE standards.
- Network leads and managers should review results from each of their PDUs and encourage and support quality improvement collaborative to drive improvement.

## 6. Outcomes

### 6.1 HbA1c

HbA1c is a marker of overall diabetes blood glucose levels over the preceding six to eight weeks and is associated with lifetime risk of microvascular complications. There is clear evidence from the DCCT trial (The Diabetes Control and Complications Trial Research Group, 1994) and the follow up EDIC trial (Nathan et al., 2005) that good diabetes management in childhood tracks into adulthood with a lower risk of developing vascular complications and early mortality in the future.

In 2015, NICE (NG18, 2015) introduced a stricter HbA1c target of 48mmol/mol or less to indicate excellent diabetes management for both Type 1 and 2 diabetes and requested that providers also report those achieving a level of 53 mmol/mol or below. To allow historical benchmarking, the NPDA also reports the numbers achieving the previous NICE (2004) target of 58 mmol/mol or below and an HbA1c level above 80mmol/mol representing considerable increased risk of both microvascular diabetic complications (eye disease and kidney disease) and cardiovascular disease.

HbA1c values were included in the outcome analysis if they were within an acceptable range (20-195mmol/mol), dated within the audit year, and recorded at least 90 days following diagnosis, since newly diagnosed individuals are unlikely to have established a level of control prior to this cut off and may therefore skew results. Where more than one valid HbA1c was recorded during the year per patient, the median value for each was used.

Average HbA1c and the proportion of children and young people meeting specific HbA1c targets vary depending on the type of diabetes. Children and young people with non-Type 1 diabetes tend to have a lower HbA1c than those with Type 1 diabetes. Some of the data presented below refer to children and young people with all types of diabetes whilst other sections detail the results of those with Type 1 or Type 2 diabetes separately. Numbers of children and young people with other types of diabetes were too low to enable meaningful analysis.

#### 6.1.1 HbA1c outcomes of children and young people with all types of diabetes

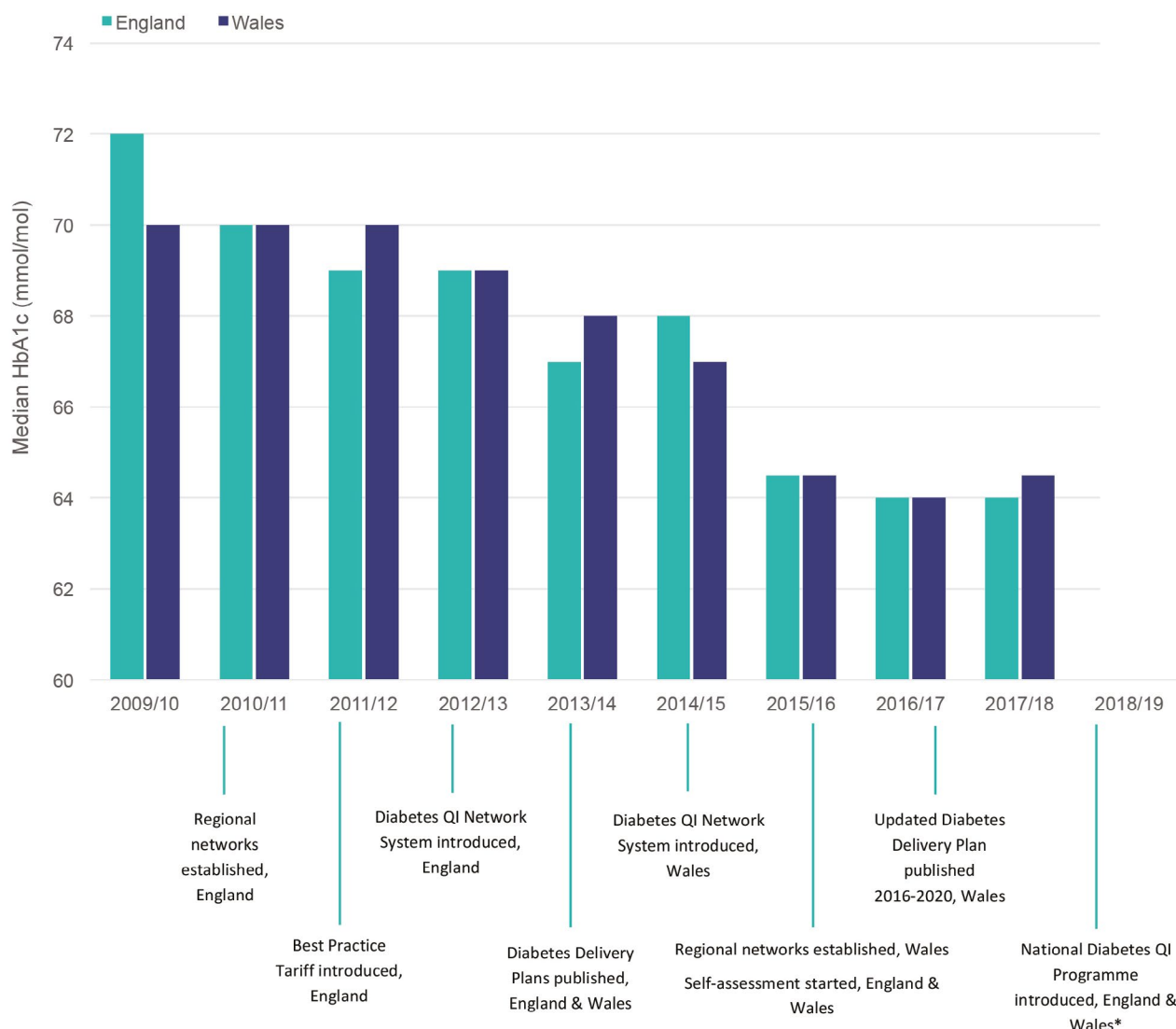
Table 21 provides a breakdown of the unadjusted mean and median HbA1c results achieved by each region and country, and the level of variation within them. The mean HbA1c of children and young people with all types of diabetes in England and Wales receiving care in a PDU in 2017/18 was 67.1 mmol/mol; this is an increase of 0.2 mmol/mol compared to that recorded in 2016/17. The median HbA1c was 64.0 mmol/mol and is unchanged compared to the previous year.

For the first time since 2009/10, there has not been a fall in overall HbA1c levels for England and Wales.

**Table 21:** HbA1c for all children and young people with all types of diabetes and one or more valid HbA1c measurements by country and regional network, 2017/18

Audit year	No. of children and young people with all types of diabetes	HbA1c in mmol/mol			
		Mean	Standard deviation	Median	Inter quartile range
England and Wales	27,953	67.1	17.6	64.0	18.0
England	26,568	67.0	17.6	64.0	18.0
Wales	1,385	67.6	17.7	64.5	18.5
East of England	3,049	66.8	17.7	63.4	18.0
East Midlands	1,882	63.2	15.1	61.0	16.0
London and South East	6,438	68.2	18.5	65.0	19.0
North East and North Cumbria	1,557	65.6	16.0	63.0	16.0
North West	3,496	68.7	18.4	65.5	19.0
South Central	2,412	65.0	16.6	62.0	16.0
South West	2,175	65.2	16.9	62.5	17.0
West Midlands	2,890	67.7	17.4	65.0	18.5
Yorkshire and Humber	2,669	68.5	17.2	65.0	18.0

Figure 17 shows the median HbA1c for children and young people with all types of diabetes, in England and Wales, from 2009/10 to 2017/18. The timeline below the graph highlights key quality improvement initiatives implemented in England and Wales over the same period.



**Figure 17:** Median HbA1c for children and young people with all types of diabetes in England and Wales 2009/10 to 2017/18 with associated NHS policy and/or paediatric diabetes delivery structural changes

\*This programme involving a Quality Improvement (QI) Collaborative, an annual Self-Assessment process and a Peer Review programme, was developed in partnership with the National Children and Young People’s Diabetes Network and aims to improve outcomes for children and young people with diabetes in England and Wales

## 6.1.2 HbA1c outcomes of children and young people with Type 1 diabetes

The data presented in this section refers to children and young people with Type 1 diabetes and captures the variation in HbA1c outcomes nationally and regionally as well as by patient characteristics.

### 6.1.2.1 National and regional unadjusted HbA1c results

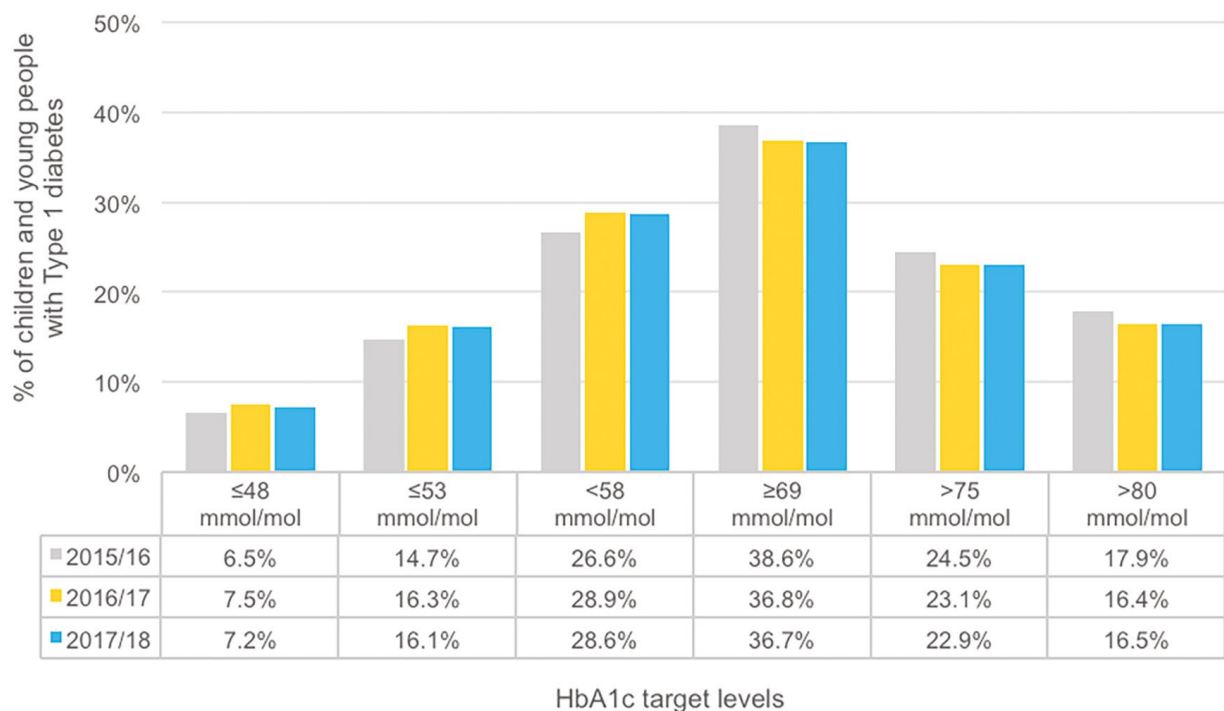
Table 22 shows the unadjusted mean and median HbA1c results for children and young people with Type 1 diabetes achieved by region and country. The unadjusted mean HbA1c was 67.5 mmol/mol; this is an increase of 0.2 mmol/mol compared to the mean recorded in 2016/17. The median HbA1c was 64.0 mmol/mol and is unchanged compared to 2016/17.

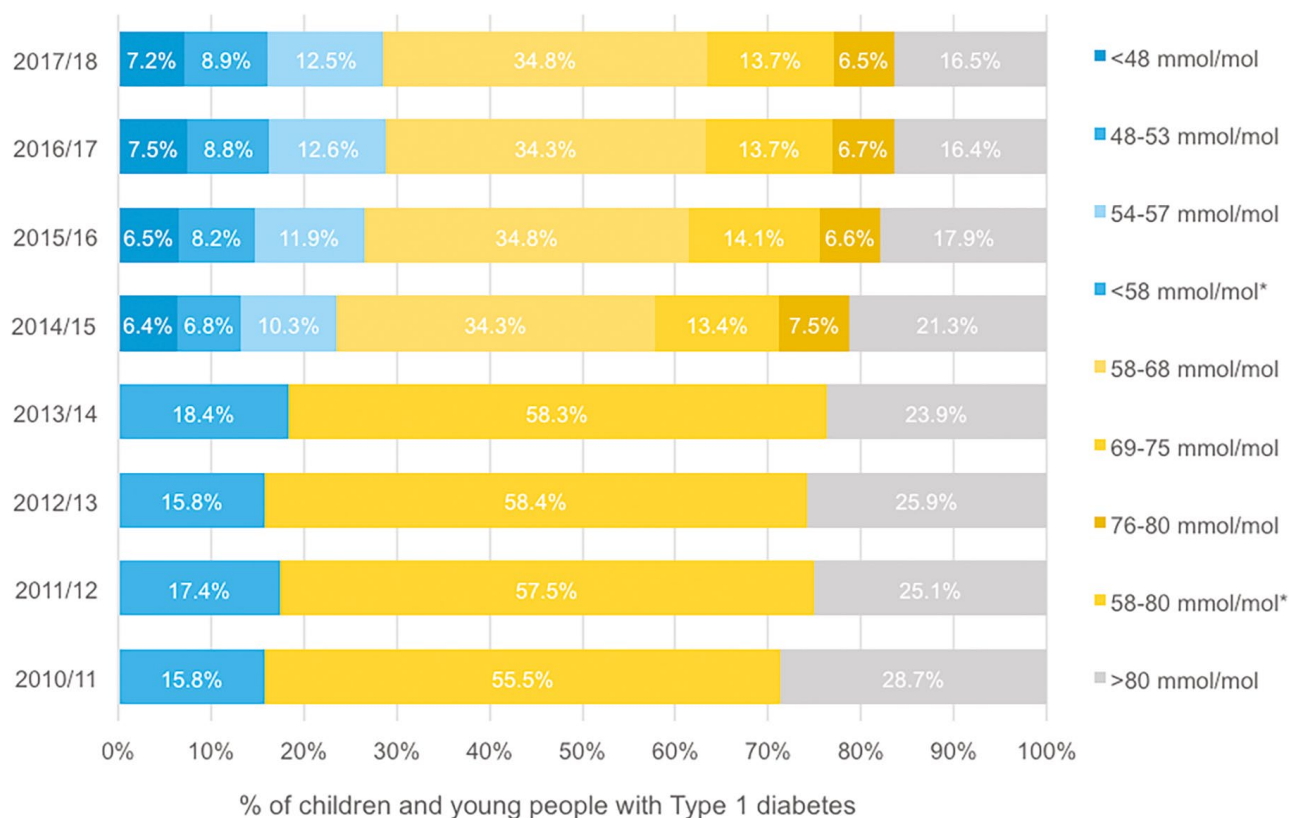


**Table 22:** HbA1c for all children and young people with Type 1 diabetes and one or more valid HbA1c measurements by country and regional network, 2017/18

	No. of children and young people with T1 diabetes	Mean mmol/mol	Standard deviation mmol/mol	Median mmol/mol	Inter-quartile range mmol/mol
England and Wales	26,739	67.5	17.2	64.0	17.5
England	25,391	67.5	17.2	64.0	17.5
Wales	1,348	67.9	17.6	65.0	18.0
East of England	2,982	67.1	17.5	63.5	18.0
East Midlands	1,807	63.7	14.8	61.0	16.0
London and South East	6,067	68.7	17.9	65.0	18.6
North East and North Cumbria	1,521	65.7	15.8	63.0	16.0
North West	3,325	69.3	17.9	66.0	18.0
South Central	2,329	65.2	16.3	62.0	16.0
South West	2,100	65.6	16.8	62.5	17.0
West Midlands	2,714	68.4	16.9	65.0	18.0
Yorkshire and Humber	2,546	68.8	17.0	65.0	17.5

Figure 18 and Figure 19 show the percentages of children and young people with Type 1 diabetes who achieved each of the NICE (2004, 2015) treatment targets from 2015/16 to 2017/18. Figure 18 also includes the percentages of children and young people with Type 1 diabetes who achieved the NICE (2004, 2015) treatment targets of below 58 mmol/mol, between 58 mmol/mol and 80 mmol/mol, and above 80 mmol/mol from 2010/11 to 2014/15.

**Figure 18:** Percentage of children and young people with Type 1 diabetes achieving HbA1c targets, 2015/16 to 2017/18



\* prior to 2014/15, the percentages achieving treatment targets of <58 mmol/mol, between 58-80 mmol/mol and >80 mmol/mol were reported only

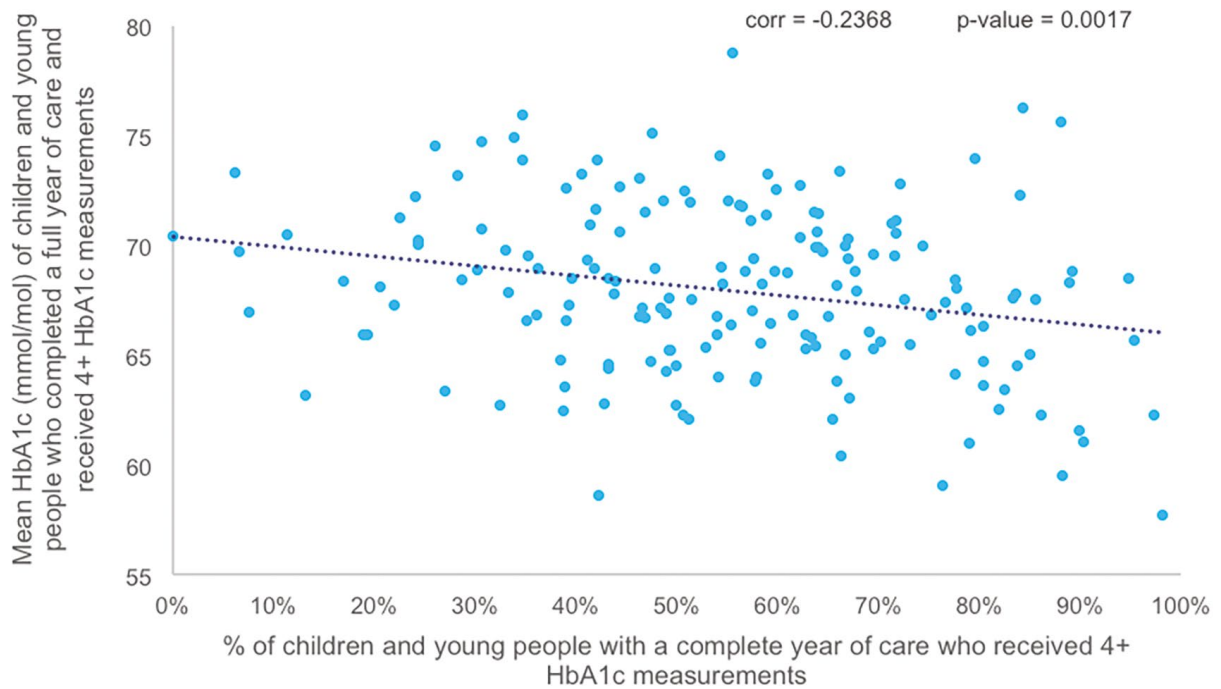
**Figure 19:** Percentage of children and young people with Type 1 diabetes with an HbA1c result within current and previous target ranges, 2011/12 - 2017/18

Table 23 shows the percentages of children and young people who achieved HbA1c targets by country and by region.

**Table 23:** Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by country and regional network, 2017/18

	≤48 mmol/mol (%)	≤53 mmol/mol (%)	<58 mmol/mol (%)	58-80 mmol/mol (%)	≥69 mmol/mol (%)	>75 mmol/mol (%)	>80 mmol/mol (%)
England and Wales	7.2	16.1	28.6	54.9	36.7	22.9	16.5
England	7.2	16.2	28.6	55.0	36.6	22.9	16.4
Wales	8.2	15.8	28.4	54.5	38.2	24.1	17.1
East of England	8.7	17.2	30.4	52.5	35.3	23.1	17.1
East Midlands	9.1	21.7	36.7	52.2	28.2	16.3	11.0
London and South East	6.4	14.6	26.1	55.5	40.0	25.4	18.4
North East and North Cumbria	8.9	17.1	31.0	55.3	33.2	19.1	13.7
North West	5.5	13.4	24.6	56.3	40.9	25.9	19.2
South Central	8.3	19.5	34.0	54.0	29.2	17.5	12.1
South West	9.6	20.6	33.8	52.0	32.7	20.2	14.2
West Midlands	6.0	14.3	25.7	57.4	38.8	24.2	16.9
Yorkshire and Humber	5.0	13.0	24.4	57.4	39.9	25.4	18.2

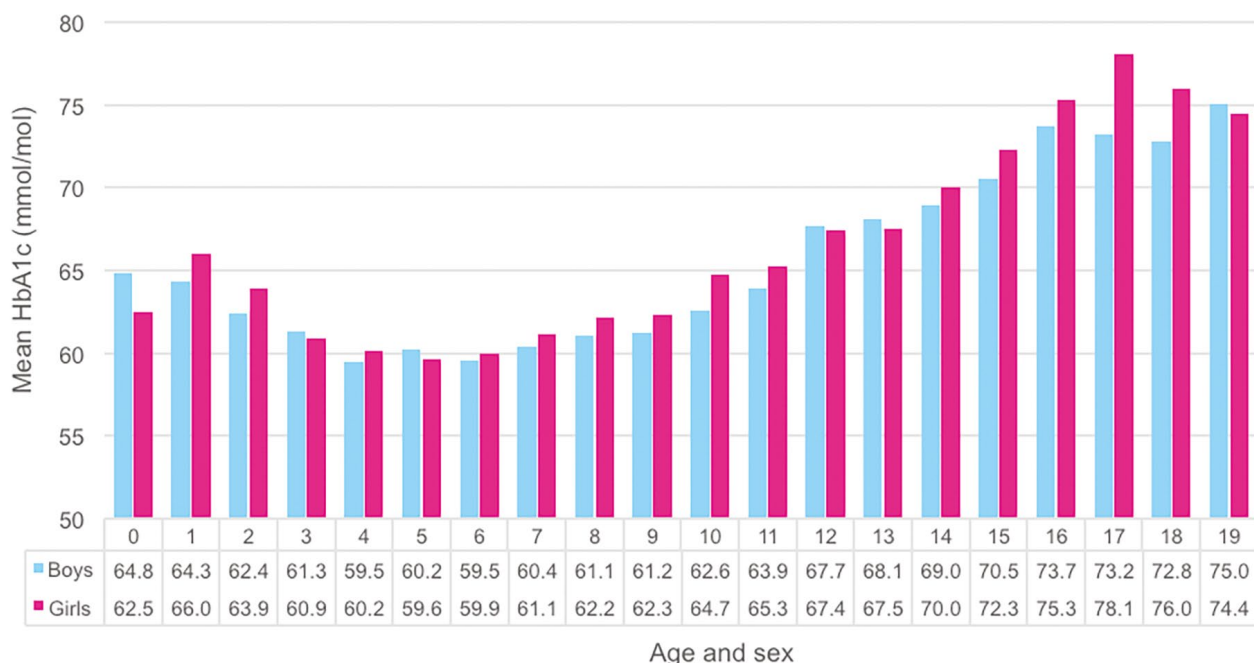
Figure 20 plots the percentage of children and young people with a complete year of care who received four or more HbA1c measurements in each unit against the unit-level mean HbA1c result of those children and young people. The downward sloping trend line indicates that PDUs with a higher percentage of children and young people receiving four or more HbA1c measurements tend to have a lower mean HbA1c. It is important to note that correlation does not imply causation and there are likely other factors that are also associated with having a lower mean HbA1c.



**Figure 20:** Scatter plot showing the association between mean HbA1c and the percentage of children and young people with a complete year of care who received 4+ HbA1c measurements in each PDU, 2017/18

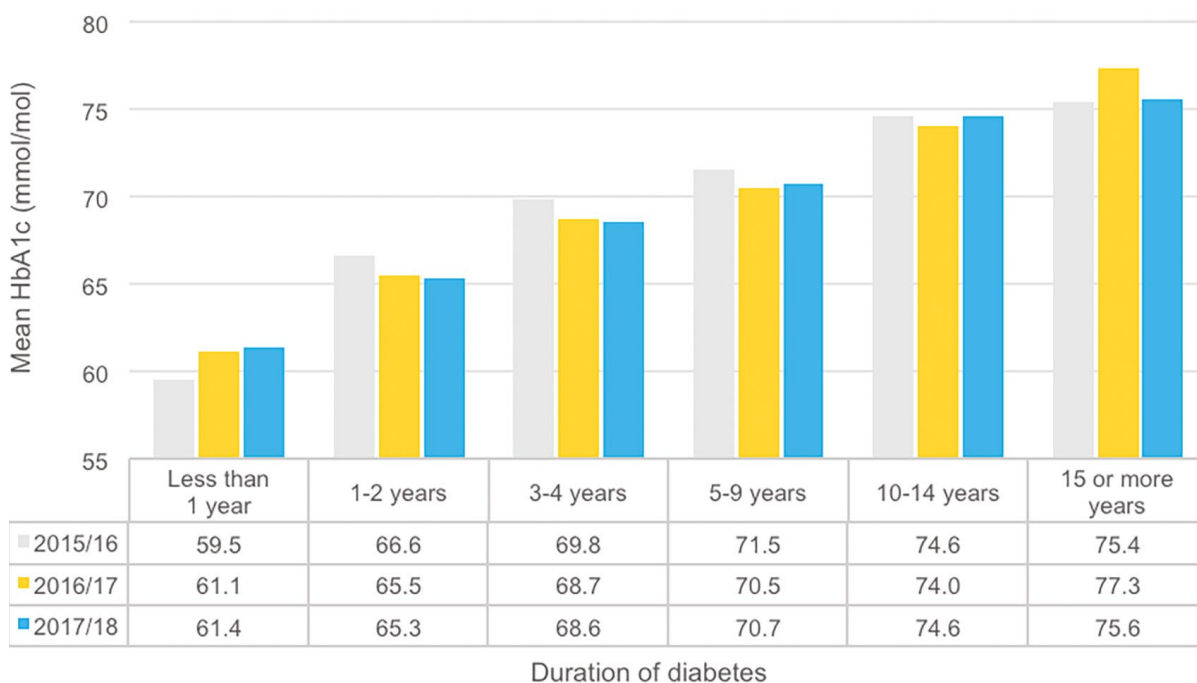
### 6.1.2.2 HbA1c outcomes according to patient characteristics

Figure 21 shows that older children tend to have higher HbA1c levels compared to those who are younger, and females tend to have higher HbA1c levels compared to males.



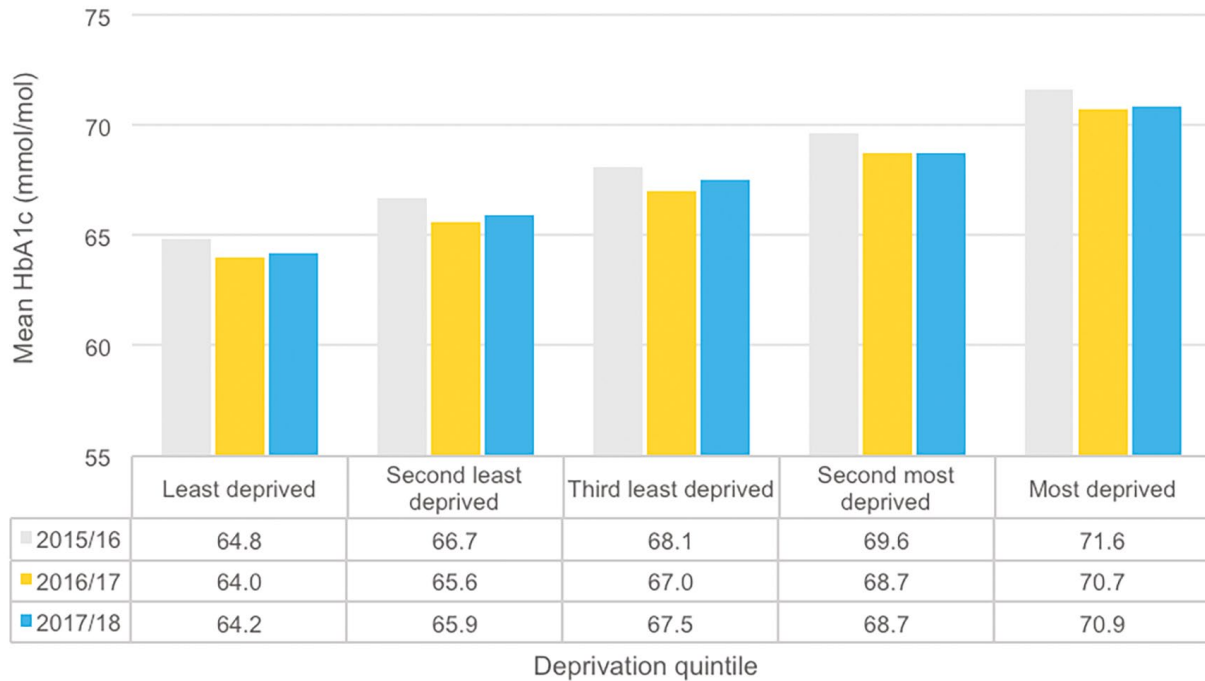
**Figure 21:** Mean HbA1c for children and young people with Type 1 diabetes by age and sex, 2017/18

Figure 22 shows that mean HbA1c increases with duration of diabetes.



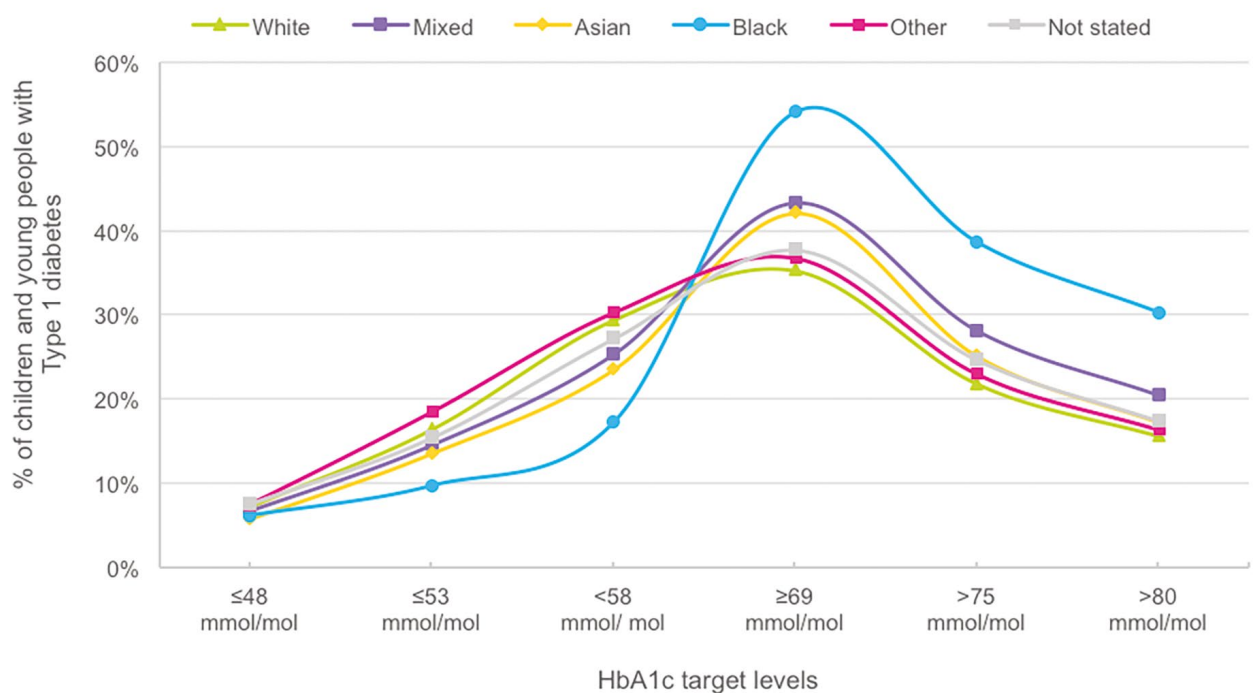
**Figure 22:** Mean HbA1c for children and young people with Type 1 diabetes by duration of diabetes, 2015/16 to 2017/18

Children and young people with Type 1 diabetes living in the most deprived areas had higher HbA1c levels compared to those living in the least deprived areas of England and Wales (Figure 23). There has been little change in this deprivation gradient since 2015/16.



**Figure 23:** Mean HbA1c for children and young people with Type 1 diabetes by deprivation quintile, 2015/16 to 2017/18

Figure 24 and Table 24 show the percentage of children and young people with Type 1 diabetes within each ethnic group achieving NICE HbA1c targets. Children and young people with Type 1 diabetes from Black and ethnic minority groups had higher HbA1c levels than White children and young people.



**Figure 24:** Percentage of children and young people with Type 1 diabetes in England and Wales achieving HbA1c targets by ethnic group, 2017/18

**Table 24:** Mean HbA1c and percentage of children and young people with Type 1 diabetes in England and Wales achieving HbA1c targets by ethnic group, 2017/18

	Mean HbA1c mmol/mol	Proportion of children and young people achieving HbA1c targets						
		Number (n)	≤48 mmol/mol (%)	≤53 mmol/mol (%)	<58 mmol/mol (%)	≥69 mmol/mol (%)	>75 mmol/mol (%)	>80 mmol/mol (%)
White	67.0	21,044	7.2	16.5	29.4	35.3	21.9	15.6
Asian	68.8	1,437	5.7	13.6	23.5	42.1	25.1	17.3
Black	74.9	958	6.1	9.7	17.2	54.1	38.6	30.3
Mixed	69.6	678	6.6	14.6	25.4	43.4	28.2	20.5
Other	67.0	603	7.5	18.6	30.3	36.8	23.1	16.4
Not stated	67.9	1,821	7.5	15.5	27.2	37.8	24.7	17.5

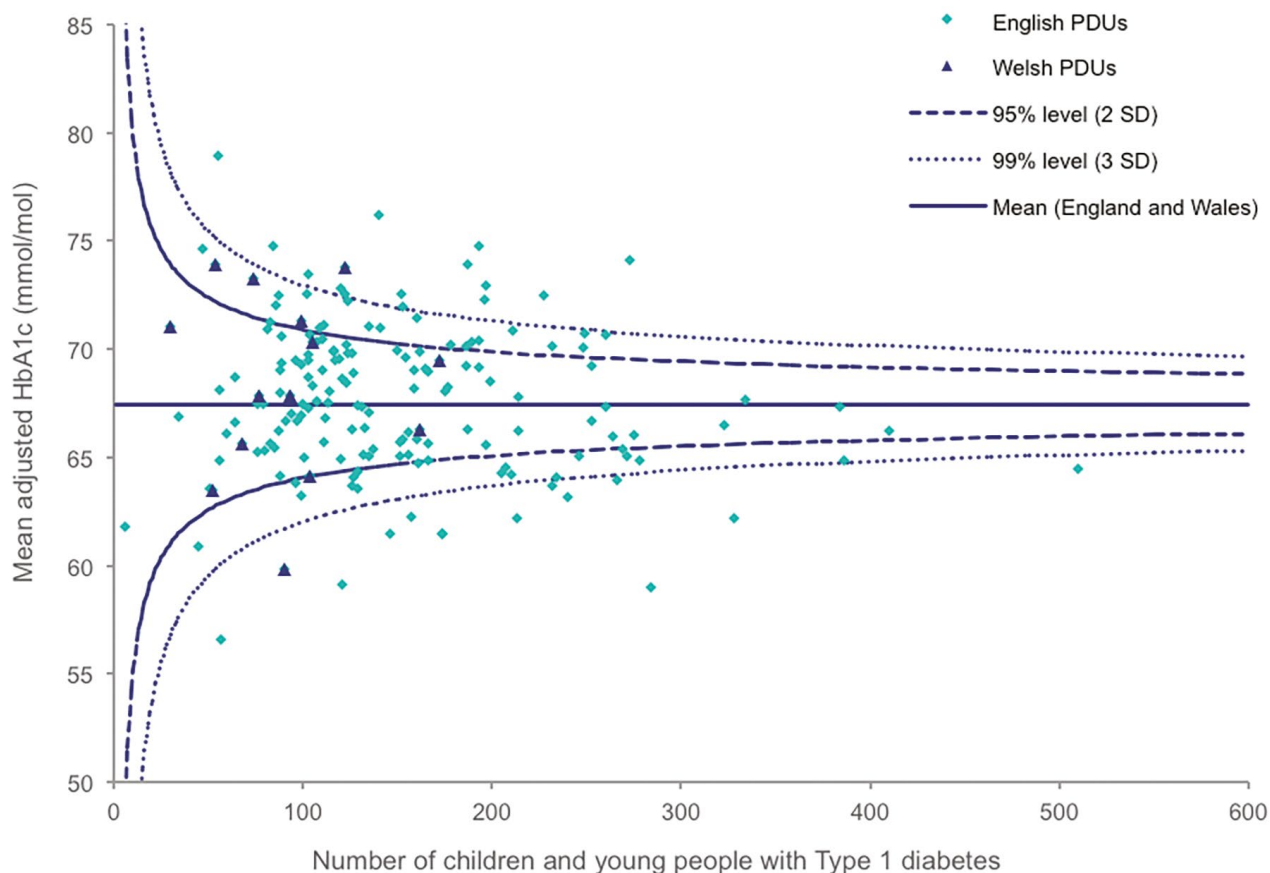
### 6.1.2.3 Adjusted HbA1c outcomes achieved by paediatric diabetes units (Type 1 diabetes)

Given the variations in HbA1c associated with different demographic and social characteristics, it is appropriate to adjust HbA1c figures to allow for equitable benchmarking of individual PDU performance. The case-mix adjustment applied to the 2017/18 data considers the effect of age, sex, ethnicity, duration of diabetes and deprivation on mean HbA1c and the likelihood of having a HbA1c lower than the treatment target of 58 mmol/mol or higher than the upper limit of 80 mmol/mol. A summary of the output of the regression models used to construct the case-mix adjusted measures can be found in the appendices of this report published on the NPDA website.

Figure 25 shows the case-mix adjusted mean HbA1c for each PDU in England and Wales, and Figures 26 and 27 show the case-mix adjusted percentage achieving an HbA1c result below 58 mmol/mol, and above 80 mmol/mol, respectively. Each graph shows that there remains considerable variation in HbA1c outcomes achieved by PDUs across England and Wales once patient characteristics have been controlled for. The horizontal navy line shows the mean HbA1c for England and Wales, and the curved lines indicate units whose results are within two standard deviations (dashed curve) or three standard deviations (dotted curve) of the mean.

HQIP guidance (HQIP, 2017) defines services with a result outside of three standard deviations of the expected value on key quality measures as 'alarm' outliers.

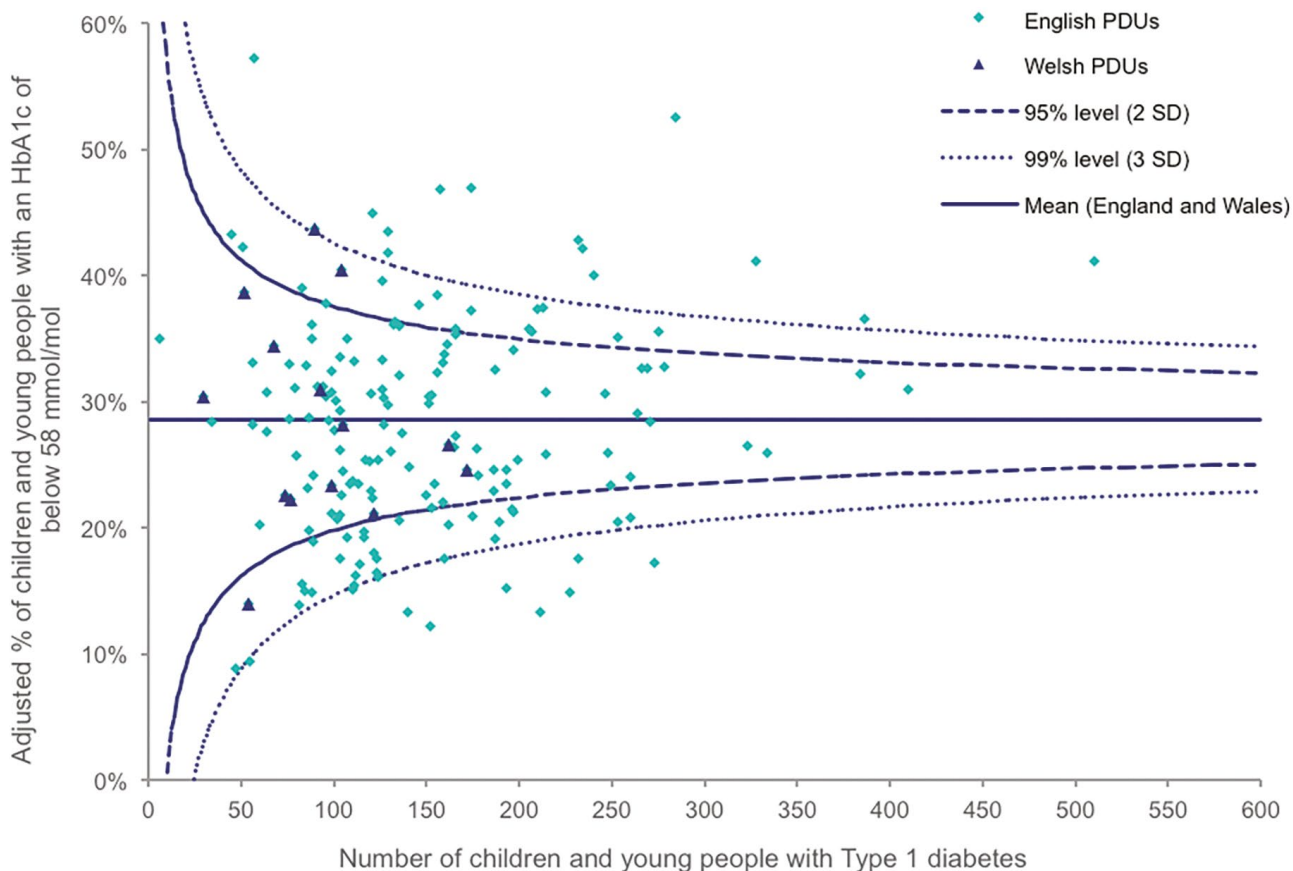
In Figure 25, PDUs above the top dotted line (>3SD) are considered 'alarms' outliers as their mean HbA1c are significantly higher (worse) than others in England and Wales.



**Figure 25:** Funnel plot of mean adjusted HbA1c for children and young people with Type 1 diabetes in England and Wales by PDU, 2017/18



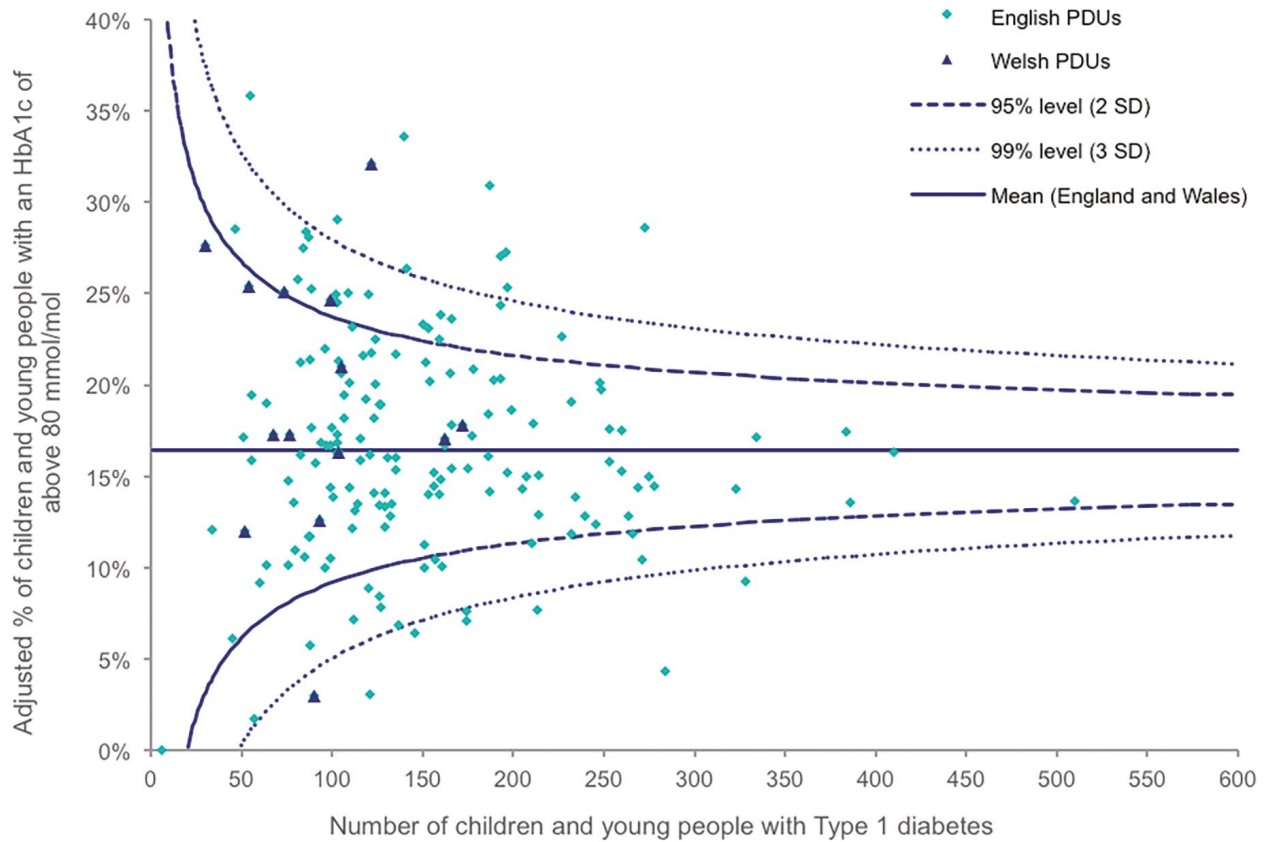
In Figure 26, PDUs below the bottom dotted line (>3SD) are 'alarm' outliers as they have a smaller adjusted percentage of patients achieving good diabetes control than others in England and Wales.



**Figure 26:** Funnel plot of the adjusted percentage of children and young people with Type 1 diabetes with an HbA1c of below 58 mmol/mol by PDU, 2017/18



In Figure 27, PDUs above the top dotted line (>3SD) are ‘alarm’ outliers as they have a significantly higher adjusted percentage of patients with an HbA1c greater than 80 mmol/mol, at greater risk of developing diabetes-related complications than patients attending other PDUs in England and Wales.



**Figure 27:** Funnel plot of the adjusted percentage of children and young people with Type 1 diabetes with an HbA1c of above 80 mmol/mol by PDU, 2017/18

### 6.1.3 HbA1c outcomes of children and young people with Type 2 diabetes

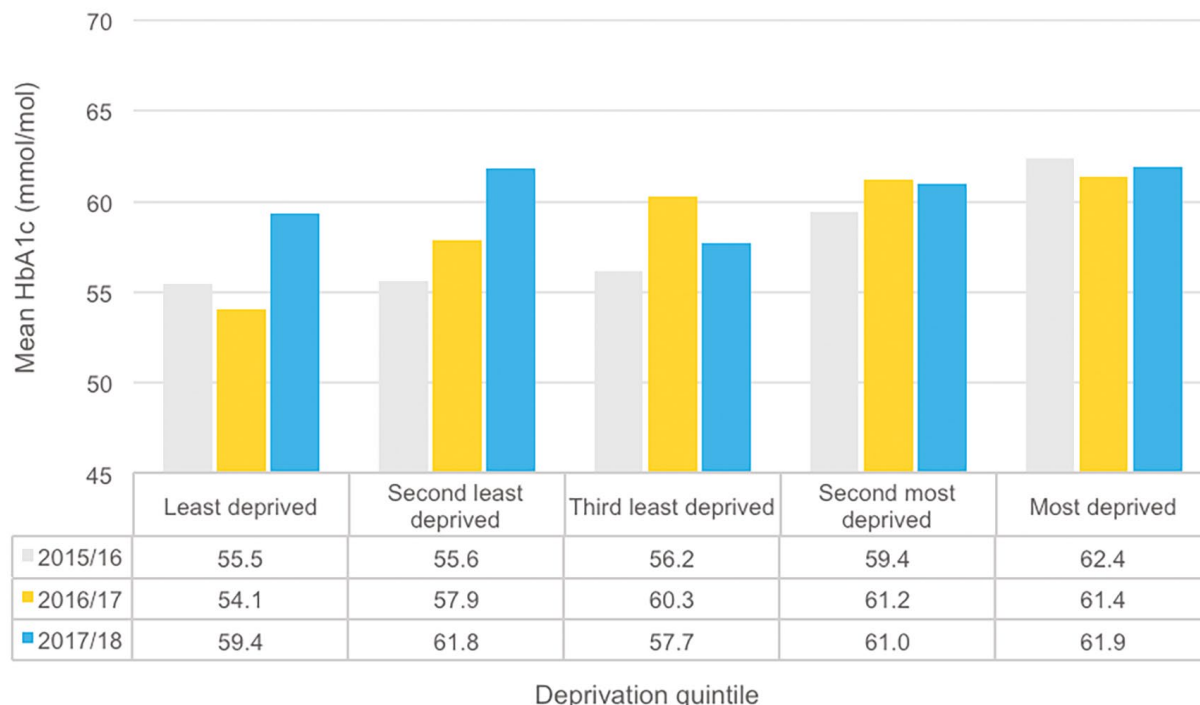
HbA1c outcomes are jointly reported for England and Wales given the small numbers of children and young people with Type 2 diabetes included within the audit.

The unadjusted mean and median HbA1c of children and young people with Type 2 diabetes in England and Wales receiving care in a PDU in 2017/18 were 61.3 and 53.0 mmol/mol, respectively (Table 25).

**Table 25:** HbA1c for all children and young people with Type 2 diabetes and one or more valid HbA1c measurements in England and Wales, 2017/18

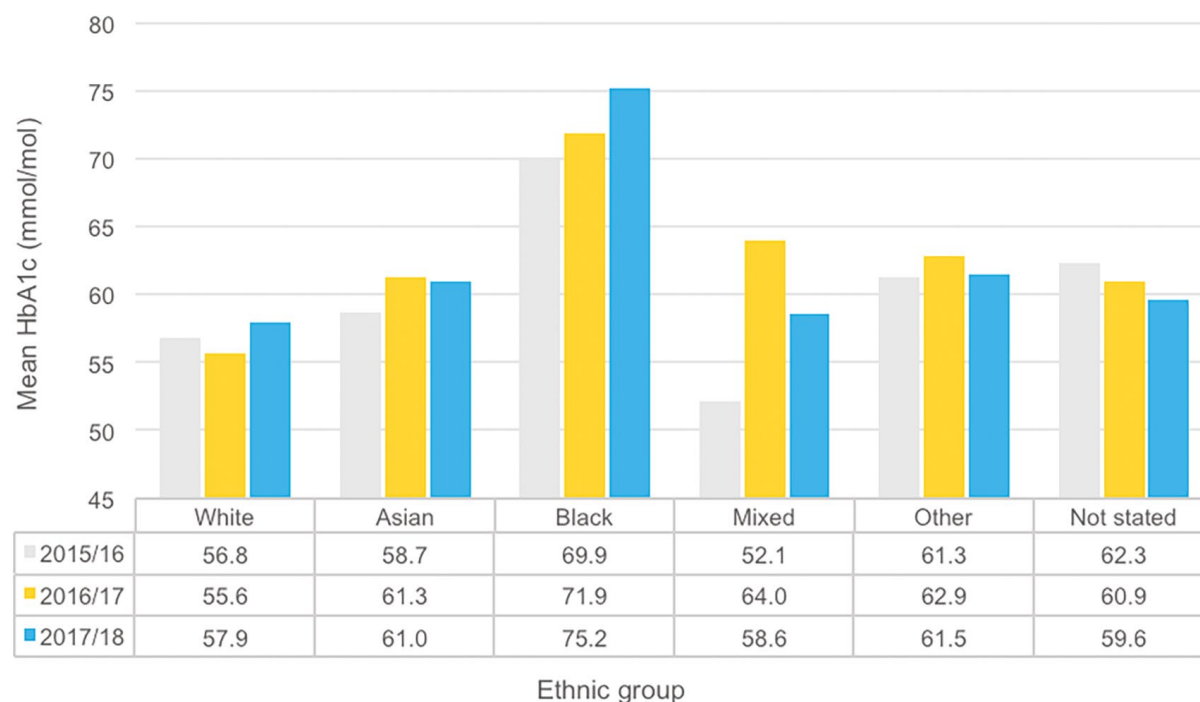
Audit year	No. of children and young people with Type 2 diabetes	HbA1c in mmol/mol			
		Mean	Standard deviation	Median	Inter-quartile range
2017/18	650	61.3	25.3	53.0	28.5
2016/17	605	60.2	24.6	52.0	33.5
2015/16	539	59.7	25.4	51.0	30.5

Figure 28 shows that the mean HbA1c of children and young people with Type 2 diabetes living in the most deprived quintiles have remained relatively unchanged. In contrast, since 2015/16, mean HbA1c levels of those in the least deprived quintiles have fluctuated. This may be because the numbers of children and young people with Type 2 diabetes reported to be living in the least deprived quintiles are smaller, compared to the numbers reported to be living in the most deprived quintiles, and therefore they are more sensitive to outlying values and natural variation.



**Figure 28:** Mean HbA1c for children and young people with Type 2 diabetes in England and Wales by deprivation quintile, 2015/16 to 2017/18

Figure 29 shows variation in mean HbA1c in those with Type 2 diabetes by ethnic group, with Black children and young people having a higher HbA1c level compared to those of other ethnic backgrounds.



**Figure 29:** Mean HbA1c for children and young people with Type 2 diabetes in England and Wales by ethnic group, 2015/16 to 2017/18

## 6.1.4 Key findings

- There has been an increase of 0.2 mmol/mol in the national mean HbA1c for all children and young people being treated within a PDU in England and Wales since 2016/17. The median HbA1c was 64.0 mmol/mol and is unchanged compared to the previous year.
- The national unadjusted mean HbA1c for children and young people with Type 1 diabetes was increased by 0.02 mmol/mol to 67.5 mmol/mol in 2017/18 compared to 2016/17 and the median was unchanged at 64.0 mmol/mol.
- Older age, female gender, living in the more deprived areas, non-white ethnicity and longer duration of disease continue to be associated with higher HbA1c levels in children and young people with Type 1 diabetes.
- Considerable variation in HbA1c target outcomes amongst children and young people with Type 1 diabetes persists between PDUs even after case-mix adjustment.
- The unadjusted mean and median HbA1c of children and young people with Type 2 diabetes in England and Wales receiving care in a PDU in 2017/18 were 61.3 and 53.0 mmol/mol, respectively, with the latter reflecting a 1 mmol/mol increase since 2016/17.
- There was variation in mean HbA1c in those with Type 2 diabetes by ethnic group, with Black children and young people having a higher HbA1c level compared to those of other ethnic backgrounds.

## 6.1.5 HbA1c recommendations

### **Multidisciplinary paediatric diabetes teams should:**

- Aim for all children to achieve the HbA1c target set by NICE (individualised for the child) from diagnosis with emphasis on self-management education and psychological support.
- Actively work towards improving the blood glucose levels of children and young people that are currently out of target range, paying attention to the care needs of those with persistently high HbA1c levels, and adapt communications and structured education provision to be able to meet the different needs of patient groups with characteristics associated with suboptimal glucose management.
- View ethnic differences and variation associated with deprivation in HbA1c outcomes as challenges to be proactively engaged with and overcome rather than acceptable reasons for sub-optimal diabetes control.

### **Commissioners should:**

- Support Quality Improvement strategies aimed at improving diabetes management.
- Resource providers of paediatric diabetes care to promote and provide education and self-management strategies leading to improved HbA1c.
- Be aware of the socioeconomic and patient demographic factors associated with poorer diabetes management, and ensure services catering to higher percentages of for children and young people from vulnerable subgroups are resourced sufficiently to meet their needs.
- Be aware of the cultural diversity amongst the paediatric diabetes population and ensure community groups and schools are sufficiently aware and trained to help young people to further improvements in diabetes control especially amongst vulnerable subgroups.

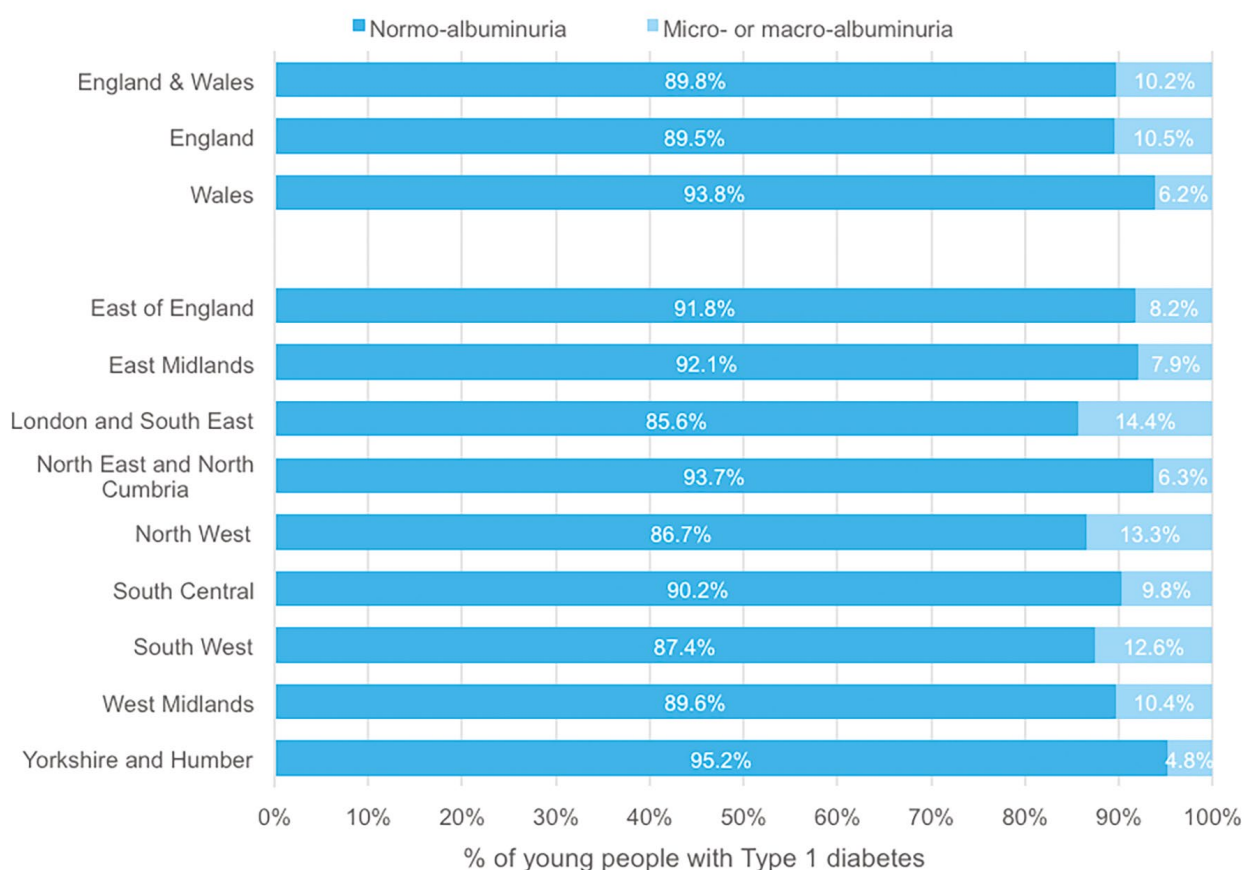
## 6.2 Small vessel (microvascular) disease

People with diabetes are at increased risk of microvascular disease including chronic kidney disease (nephropathy) and eye disease (retinopathy). However, maintaining optimal blood glucose levels can minimise these risks. Research in adults with Type 1 diabetes has shown that an 11 mmol/mol (1%) decrease in HbA1c has the potential to reduce the risk of diabetes-related complications by half, including retinopathy and nephropathy (The Diabetes Control and Complications Trial Research Group, 1993).

### 6.2.1 Kidney disease

#### 6.2.1.1 Kidney disease in young people with Type 1 diabetes

Two-thirds (n = 11,024) of young people with Type 1 diabetes aged 12 years and above were recorded as receiving an albuminuria screen during the audit period. Of those, 96.4% (n = 10,631) had a valid interpretation of their urinary albumin level. Increased risk of kidney disease is indicated by the presence of either micro- or macro-albuminuria. Figure 30 shows that 10.2% of young in England and Wales were recorded as having micro- or macro-albuminuria; the percentage varied across regions.



**Figure 30:** Percentage of young people with Type 1 diabetes aged 12 years and older with albuminuria by country and region, 2017/18

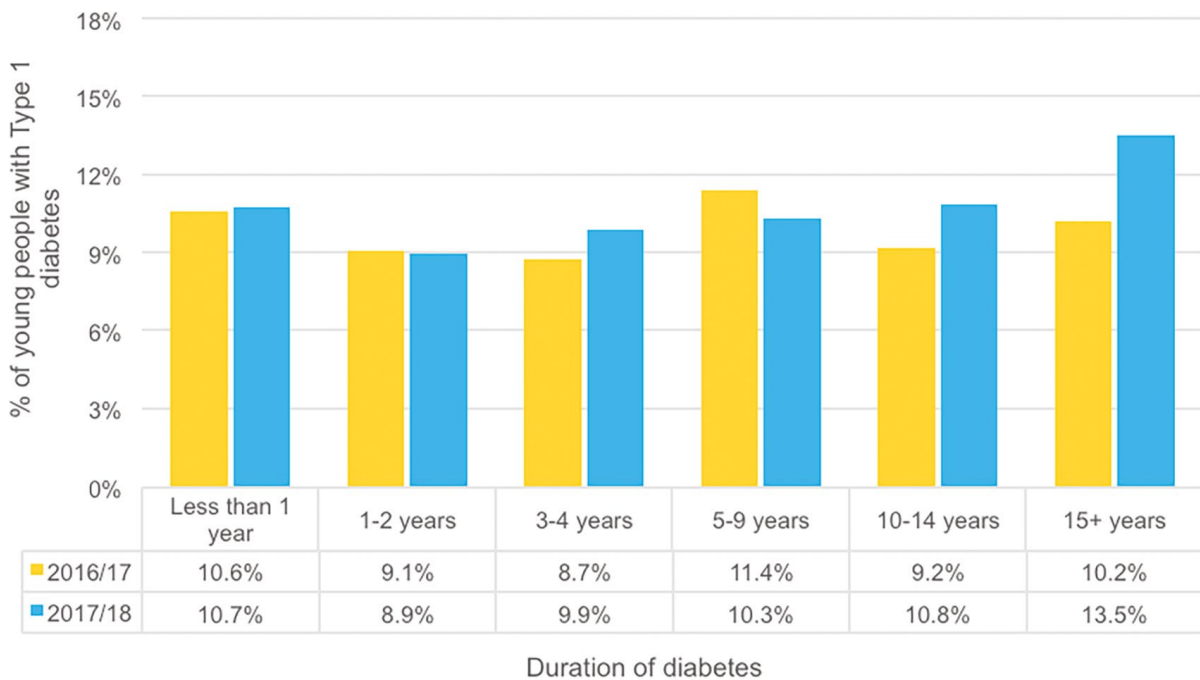
Reporting of percentages with micro or macro albuminuria in previous audit years included young people whose interpretation of a urinary albumin level was 'unknown' or missing, the percentages of which were also presented. To allow direct comparison, data from previous audit years in this section are presented without the inclusion of missing data so that the denominator for each audit year only includes those who had a valid interpretation of a urinary albumin level. In 2017/18, the percentage of missing or unknown albumin results was 3.8%. This is similar to the rates in previous audit years; it was 2.0% and 2.7% in 2015/16 and 2016/17, respectively.

Table 26 shows that the percentage of young people with Type 1 diabetes aged 12 years and above with albuminuria remained stable since 2015/16.

**Table 26:** Percentage of young people with Type 1 diabetes aged 12 years and above with albuminuria, 2015/16 to 2017/18

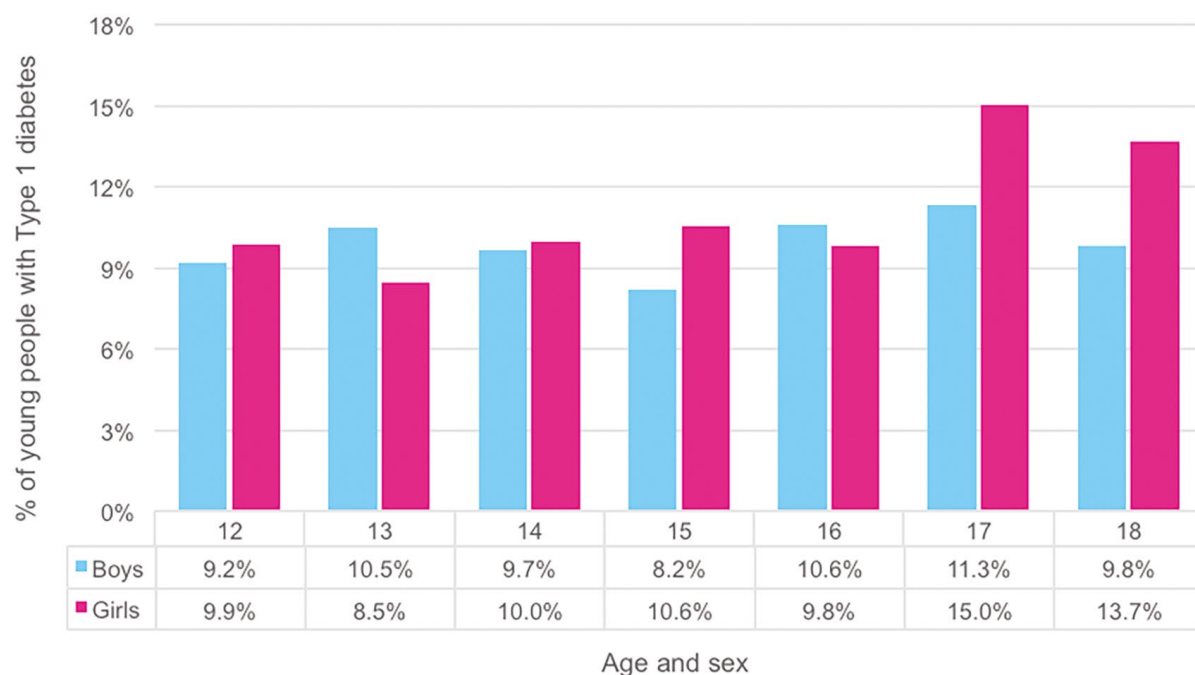
	No. of young people with T1 diabetes	Normo-albuminuria (%)	Micro- or macro-albuminuria (%)
2017/18	10,631	89.8%	10.2%
2016/17	9,938	90.0%	10.0%
2015/16	9,364	90.1%	9.9%

Figure 31 shows little variation in the presence of albuminuria by duration of diabetes between the audit years, apart from those with a duration of Type 1 diabetes of 15 years or more.



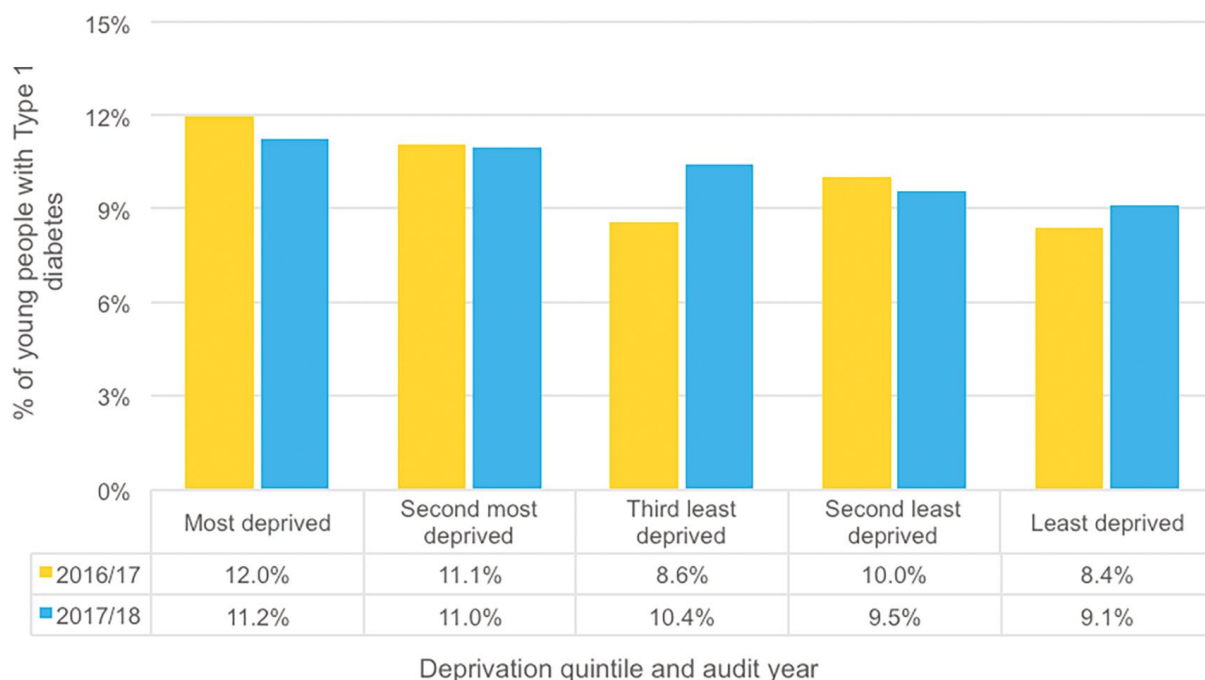
**Figure 31:** Percentage of young people with Type 1 diabetes aged 12 years and above with albuminuria by duration, 2016/17 and 2017/18

Figure 32 shows little difference in rates of albuminuria by age and sex, apart from a trend for a higher prevalence amongst girls above the age of 16



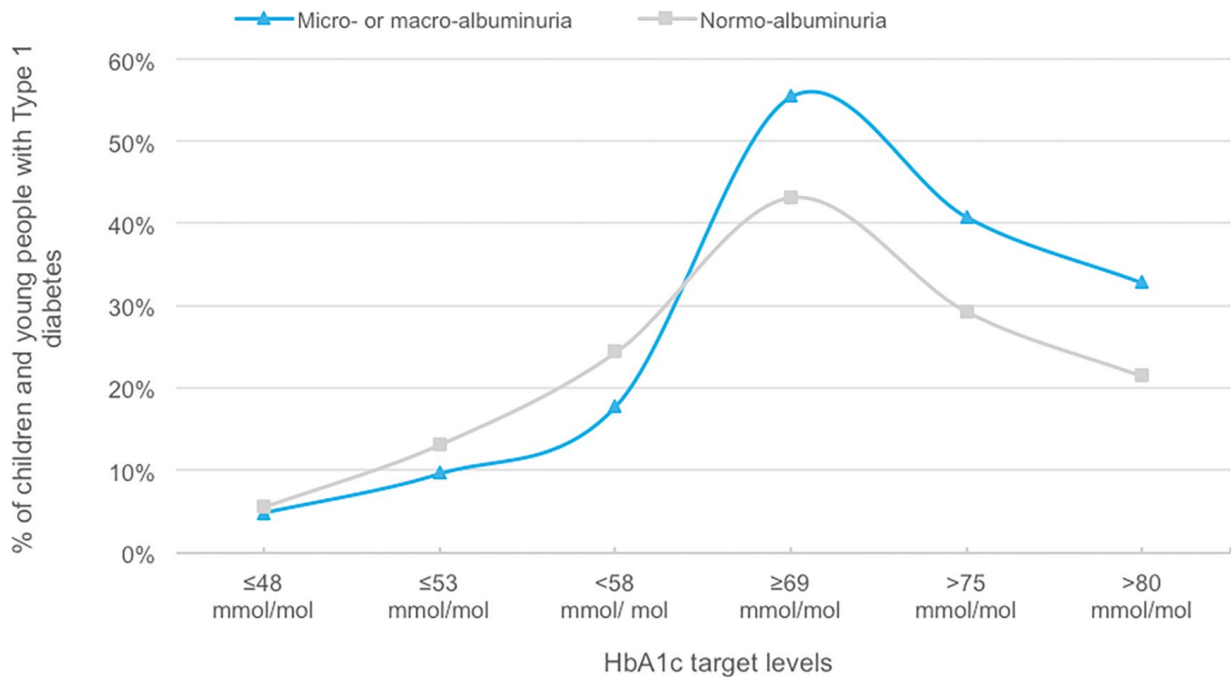
**Figure 32:** Percentage of young people with Type 1 diabetes aged 12 years and above with albuminuria by age and sex, 2017/18

Figure 33 shows a higher prevalence of albuminuria amongst young people aged 12 and above living in the most deprived areas compared to those in less deprived areas in both audit years.



**Figure 33:** Percentage of young people with Type 1 diabetes aged 12 years and above with albuminuria by deprivation quintile, 2016/17 and 2017/18

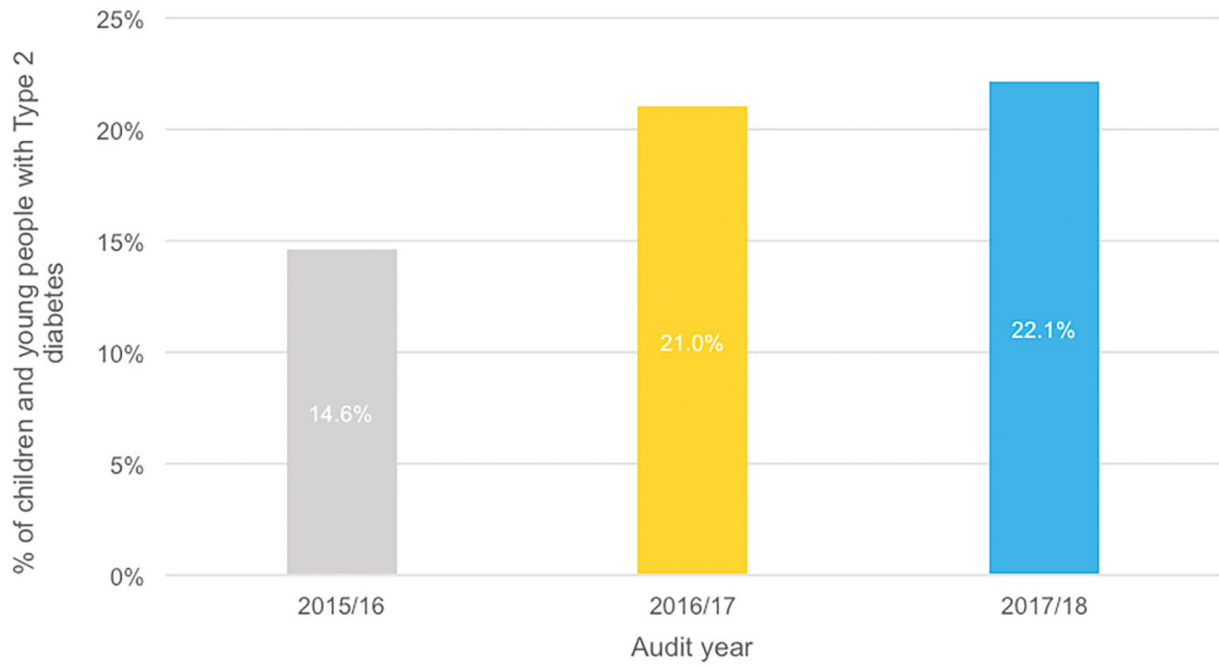
Figure 34 shows that young people with Type 1 diabetes with albuminuria had poorer HbA1c outcomes compared to those with normo-albuminuria.



**Figure 34:** Percentage of young people with Type 1 diabetes achieving HbA1c targets by presence of albuminuria, 2017/18

### 6.2.1.2 Kidney disease in young people with Type 2 diabetes

Figure 35 shows that albuminuria was present in 22.1% of children and young people with Type 2 diabetes with a valid interpretation of their urinary albumin level (n=321) in 2017/18; and that the percentage has increased slightly year on year since 2015/16. The percentage of children and young people with Type 2 diabetes with albuminuria is twice that recorded for young people with Type 1 diabetes (10.2%) – indicating that children and young people with Type 2 diabetes are at a greater risk of kidney disease.



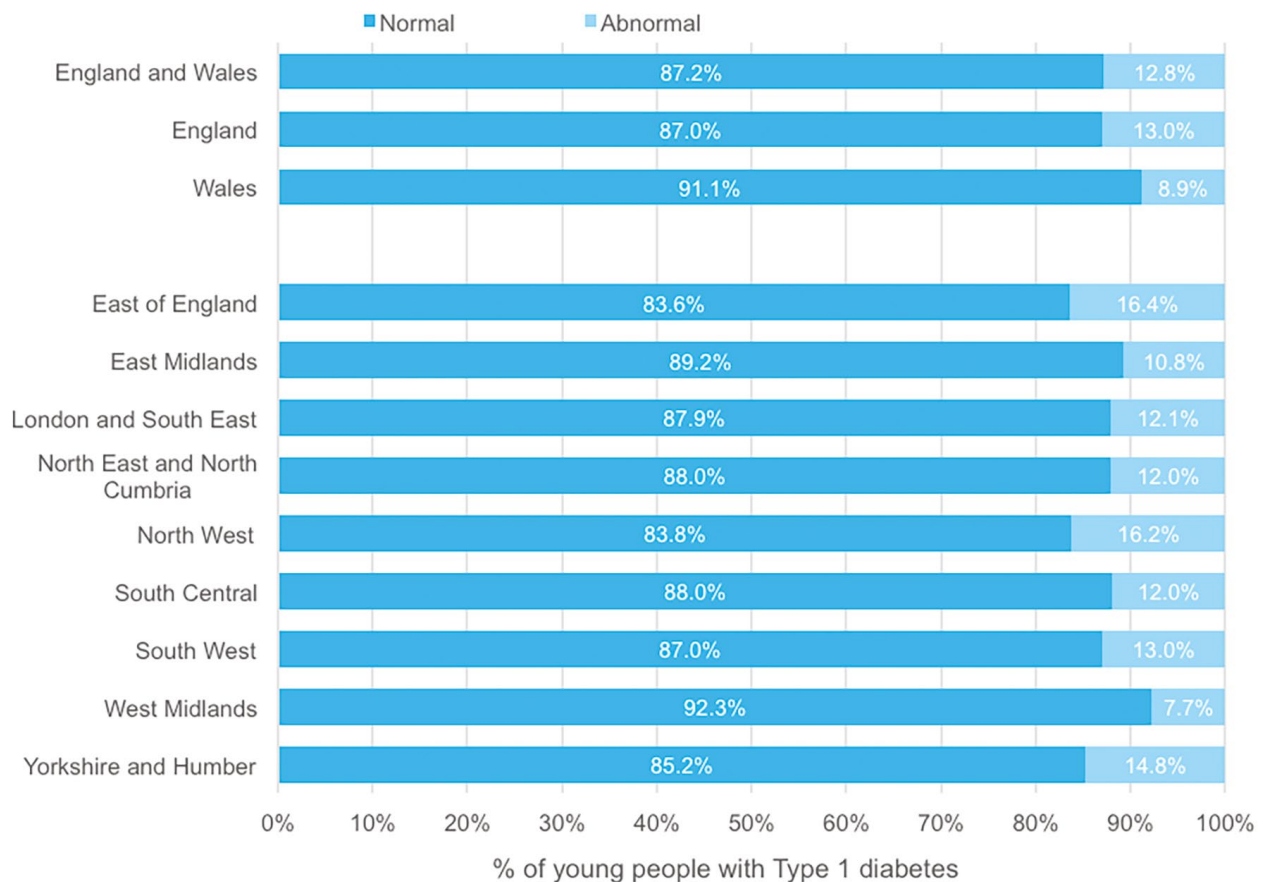
**Figure 35:** Percentage of children and young people with Type 2 diabetes with albuminuria in England and Wales, 2016/17 and 2017/18



## 6.2.2 Eye Disease

### 6.2.2.1 Eye disease in young people with Type 1 diabetes

There were 11,579 young people with Type 1 diabetes aged 12 years and above recorded as receiving an eye screen during the audit period. Of those, 96.2% (n = 11,134) had a valid eye screen result recorded. Figure 36 shows that 12.7% of young people with Type 1 diabetes aged 12 and above had an abnormal eye screen result recorded within the audit period; the percentage varied by country and by region.



**Figure 36:** Percentages of young people with Type 1 diabetes aged 12 years and older with normal/abnormal retinopathy screening results by country and region, 2017/18

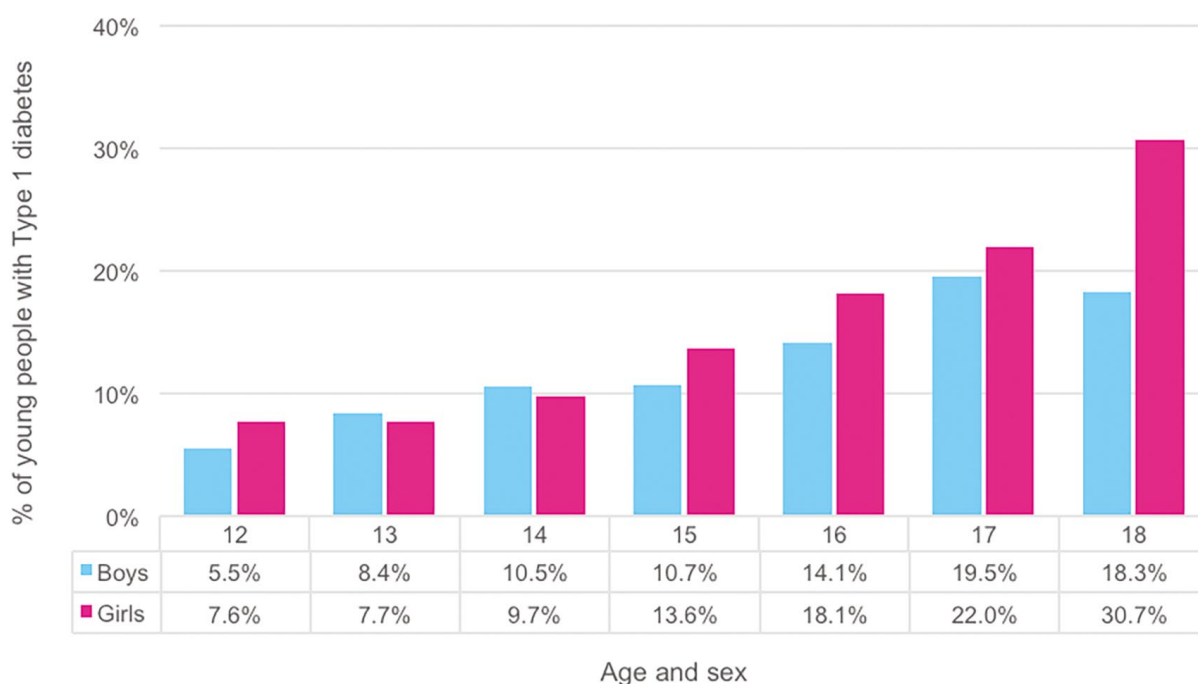
Reporting of percentages with normal or abnormal screening results in previous audit years included young people with a recorded screening date but no recorded result, the percentages of which were also presented. To allow direct comparison, data from previous audit years in this section are presented without the inclusion of missing or unknown data so that the denominator for each audit year only includes those with a result recorded. In 2017/18, the percentage of missing or unknown results was 3.8% which is lower than previous audit years; it was 9.7% and 8.2% in 2015/16 and 2016/17, respectively. This difference is attributable to amendments made to the NPDA dataset in 2017/18.

Table 27 shows a decrease in the percentage of young people with Type 1 diabetes aged 12 years and above with an abnormal eye screening result recorded in every audit year since 2015/16.

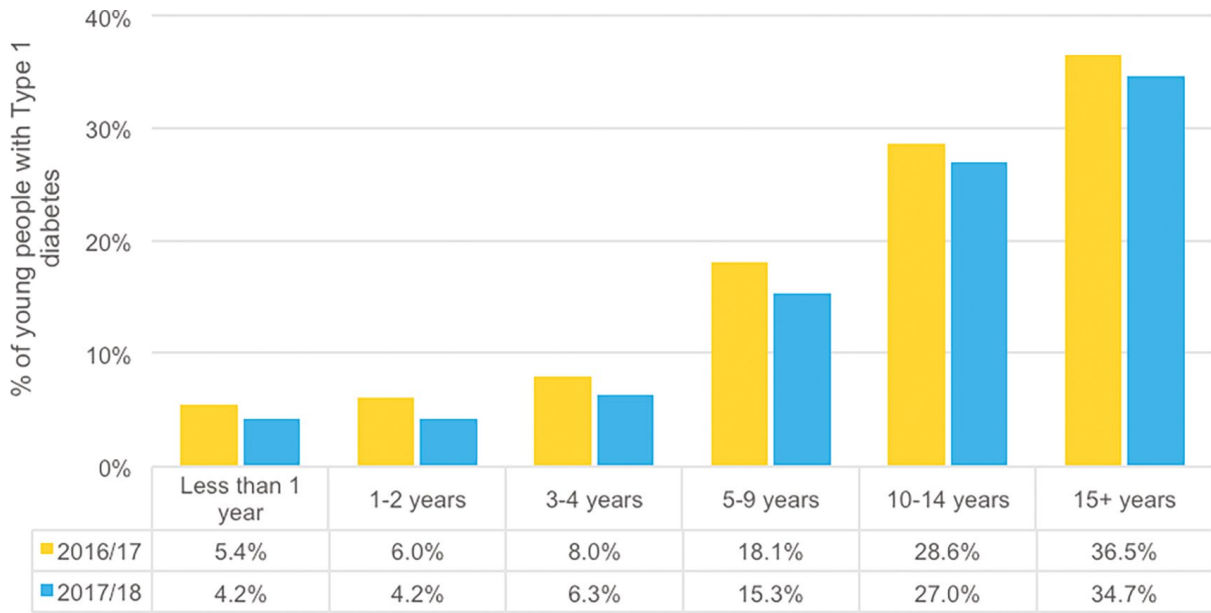
**Table 27:** Percentage of young people with Type 1 diabetes aged 12 years and above with a normal/ abnormal eye screening result, 2015/16 to 2017/18

	No. of young people with T2 diabetes	Normal (%)	Abnormal (%)
2017/18	11,134	87.2	12.8
2016/17	9,938	85.2	14.8
2015/16	9,788	84.7	15.3

The prevalence of retinopathy increased with age and was highest amongst adolescent girls (Figure 37). The prevalence also increased with longer duration of diabetes (Figure 38).



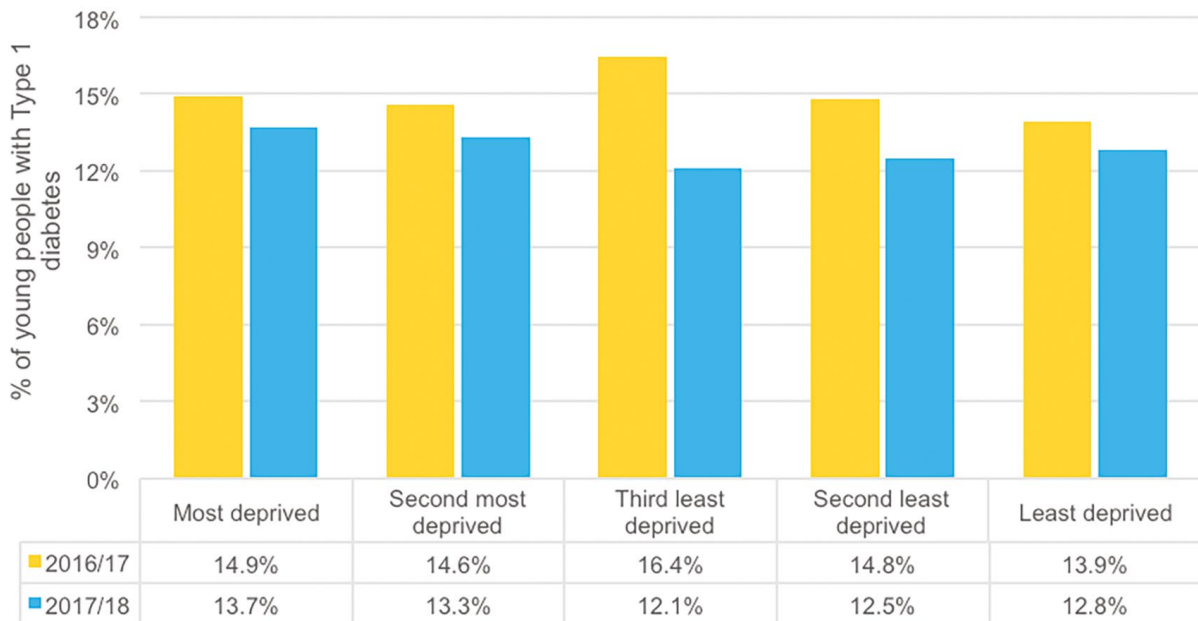
**Figure 37:** Percentage of young people with Type 1 diabetes aged 12 years and older with retinopathy by age and gender, 2017/18



Duration of diabetes and audit year

**Figure 38:** Percentage of young people with Type 1 diabetes aged 12 years and older with retinopathy by duration of diabetes, 2017/18

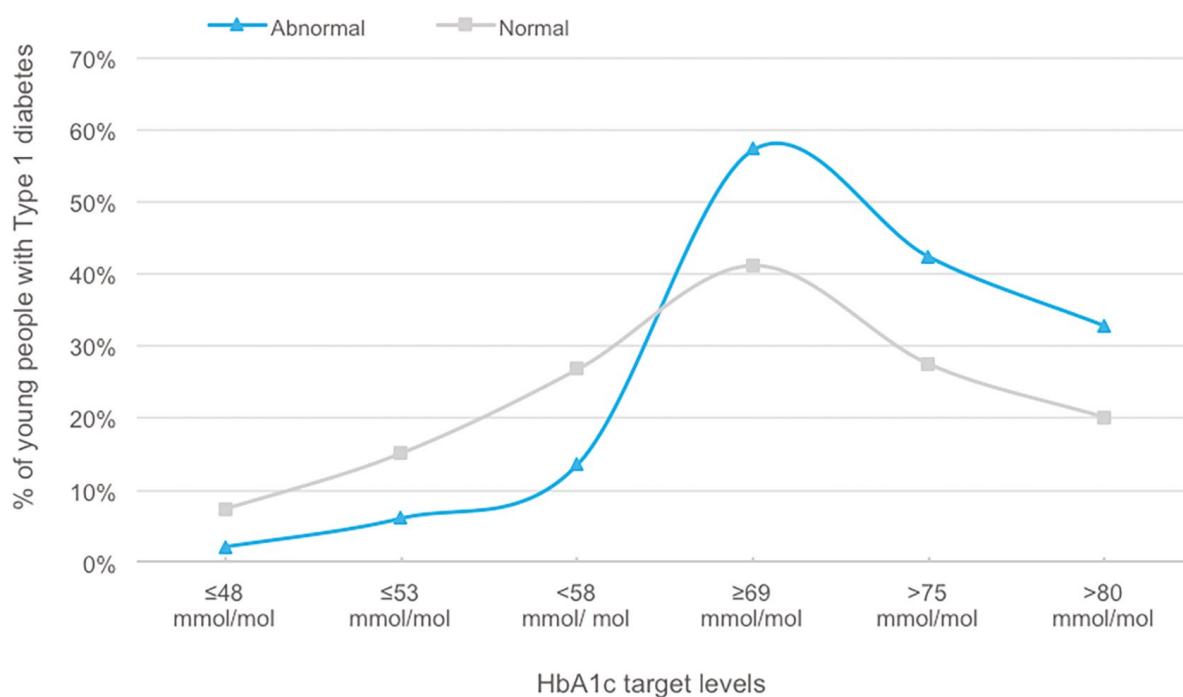
Figure 39 shows that the prevalence of retinopathy reduced in all quintiles compared to 2016/17.



Deprivation quintile and audit year

**Figure 39:** Percentage of young people with Type 1 diabetes aged 12 years and older with abnormal eye screening by deprivation quintile, 2017/18

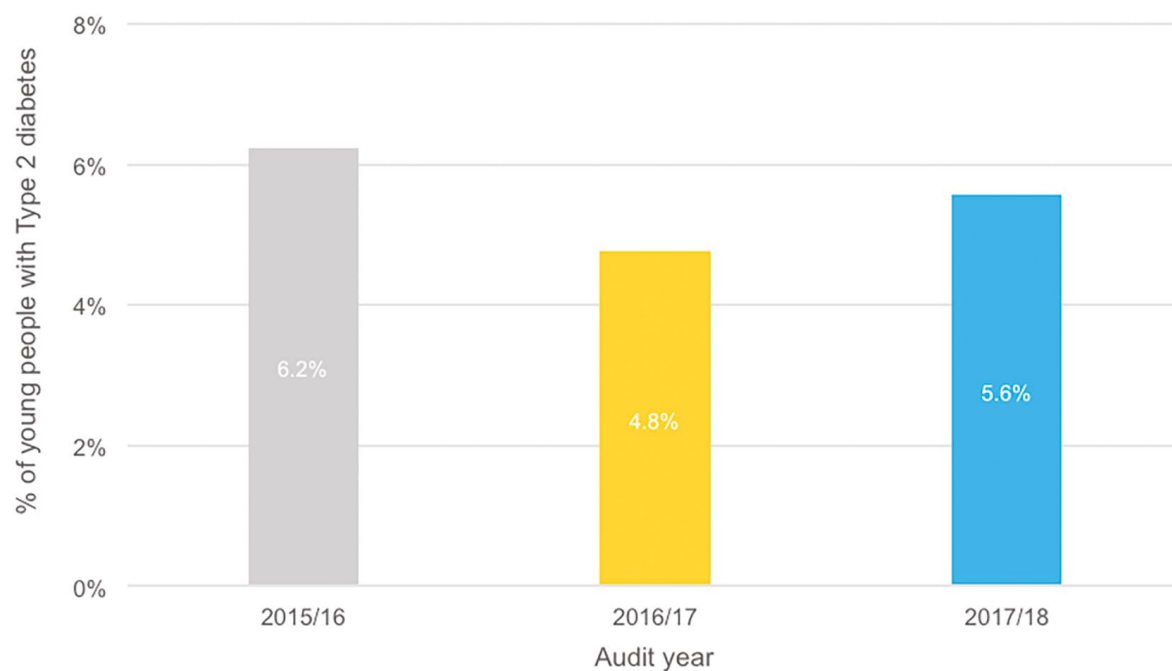
Figure 40 shows that young people with Type 1 diabetes with an abnormal eye screening result had poorer HbA1c outcomes compared to those with a normal eye screening result.



**Figure 40:** Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by presence of albuminuria, 2017/18

### 6.2.2.2 Eye disease in young people with Type 2 diabetes

Figure 41 shows that 5.6% of young people with Type 2 diabetes aged 12 years and above with a valid eye screening result (n=324) had an abnormal result. This was less than half the rate of retinopathy found amongst young people with Type 1 diabetes (12.7%).



**Figure 41:** Eye screening results for young people aged 12 years and above with Type 2 diabetes, 2015/16 to 2017/18

## 6.3 Large vessel disease - Cardio Vascular Disease (CVD) risk factors

People with diabetes are at an increased risk of cardiovascular disease secondary to macrovascular risk factors including high blood pressure, abnormal lipid levels and high body mass index.

### 6.3.1 Blood pressure and cholesterol

High blood pressure and/or raised blood cholesterol increases lifetime risk of cardiovascular disease, including stroke and heart disease. In adults with Type 1 diabetes, maintaining normal blood pressure and cholesterol within target (less than 5 mmol/L) reduces this risk. Although screening of total cholesterol levels is no longer a mandatory requirement for children and young people with Type 1 diabetes following NICE guidance NG18 (2015), results are still presented where data have been submitted. Diastolic and systolic blood pressure measurements were converted to age- and sex- adjusted centiles using survey data between 1995 and 1998 from the general population aged between 4 and 24 years old (Jackson et al., 2007).

#### 6.3.1.1 Blood Pressure and cholesterol in young people with Type 1 diabetes

Table 28 shows the percentages of young people aged 12 and above with Type 1 diabetes with a recorded blood pressure in the audit period (n=14,868) classified as 'high normal' (91st -98th centile) or 'high' blood pressure (>98th centile). Over a quarter of young people (26.7%) with Type 1 diabetes had high blood pressure (hypertension); this represents a small increase compared to the figure reported in the 2016/17 audit (25.8%).

**Table 28:** Percentage of young people with Type 1 diabetes aged 12 years and above falling within blood pressure targets by country and region, 2017/18

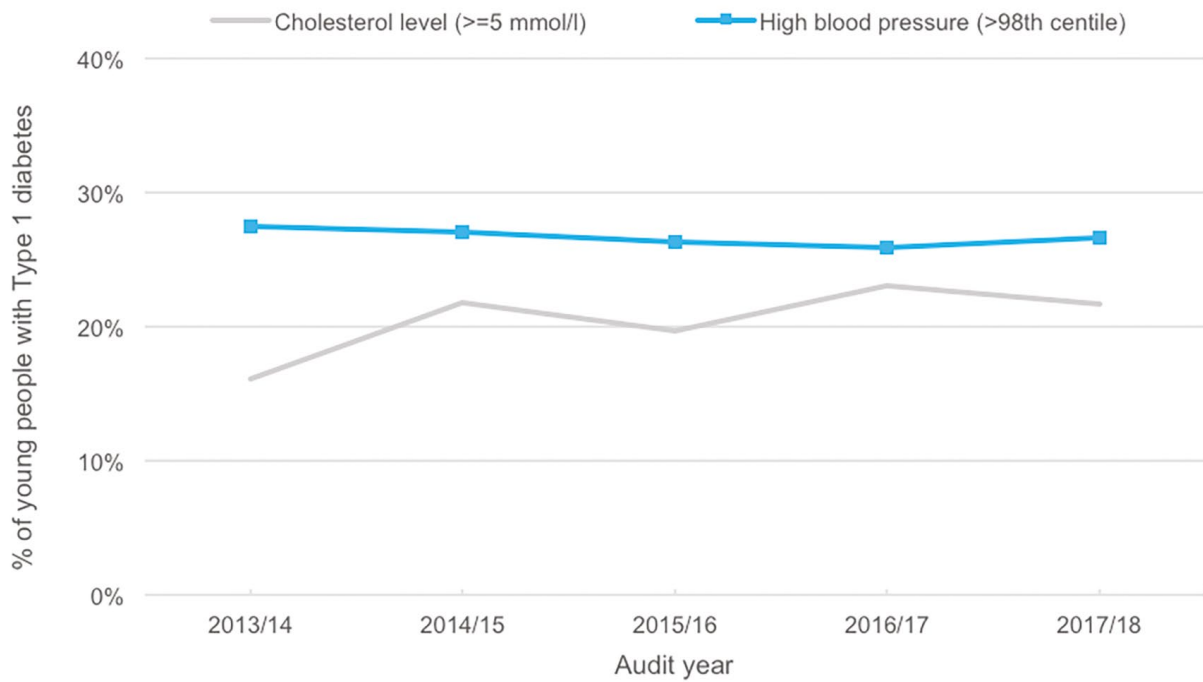
	'High normal' blood pressure (91st-98th centile)			'High' blood pressure (>98th centile)		
	Diastolic (%)	Systolic (%)	Diastolic and/or systolic (%)	Diastolic (%)	Systolic (%)	Diastolic and/or systolic (%)
England and Wales	28.0	9.7	34.0	26.0	4.4	26.7
England	27.9	9.6	33.8	26.1	4.4	26.7
Wales	29.4	11.4	37.8	24.3	3.4	25.5
East of England	27.2	9.5	34.1	27.9	5.4	28.8
East Midlands	29.5	10.1	36.6	32.3	4.5	33.6
London and South East	27.4	8.9	32.5	22.4	2.8	22.2
North East and North Cumbria	23.8	4.1	27.3	23.8	2.1	24.4
North West	27.0	9.8	32.3	27.0	3.3	26.7
South Central	29.7	9.4	36.1	21.0	4.5	23.4
South West	30.4	10.7	35.1	31.7	5.5	30.0
West Midlands	27.5	11.4	34.5	28.9	5.5	30.9
Yorkshire and Humber	29.7	11.2	36.8	25.2	7.1	27.2

Table 29 shows the percentages of young people aged 12 and above with Type 1 diabetes with a recorded cholesterol screen (n=10,583) within the target for total blood cholesterol. It shows that 21.7% exceeded the higher ( $\geq 5$  mmol/l) target for total blood cholesterol. This represents a small decrease compared to the figure reported in the 2016/17 audit (23.0%).

**Table 29:** Percentage of young people with Type 1 diabetes aged 12 years and above falling within cholesterol targets by country and region, 2017/18

	4 mmol/l or more (%)	5 mmol/l or more (%)
England and Wales	64.7	21.7
England	64.6	21.6
Wales	66.6	23.0
East of England	63.2	20.8
East Midlands	59.2	18.7
London and South East	67.1	23.2
North East and North Cumbria	61.5	23.1
North West	67.0	23.3
South Central	63.9	19.1
South West	63.7	20.7
West Midlands	64.2	21.2
Yorkshire and Humber	64.5	21.4

Figure 42 shows the percentages of young people aged 12 years and older with Type 1 diabetes with 'high' blood pressure ( $>98$ st centile) and the percentage above the target for total blood cholesterol ( $\geq 5$  mmol/l) reported to the audit since 2013/14. There was a gradual fall in the percentage of young people with Type 1 diabetes with 'high' blood pressure up to 2016/17. The percentage of young people with high cholesterol has varied over the last five audit cycles.



**Figure 42:** Percentage of young people aged 12 and above with Type 1 diabetes with high blood pressure and total blood cholesterol above the target level, 2013/14 to 2017/18

### 6.3.1.2 Blood Pressure and cholesterol in patients with Type 2 diabetes

Table 30 shows the percentage of children and young people with Type 2 diabetes with a recorded blood pressure in the audit period (n=604) classified as 'high normal' (91st -98th centile) or 'high' blood pressure (>98th centile). Almost half (44.9%) of children and young people with Type 2 diabetes had high blood pressure. Table 31 shows the percentage of children and young people with Type 2 diabetes with a recorded cholesterol screen (n=447) above the target for total blood cholesterol. It shows that 33.8% exceeded the higher target for total blood cholesterol (>=5 mmol/l).

**Table 30:** Percentage of children and young people with Type 2 diabetes with 'high' or 'high-normal' blood pressure, 2016/17 and 2017/18

	'High normal' blood pressure (91st-98th centile)			'High' blood pressure (>98th centile)		
	Diastolic (%)	Systolic (%)	Diastolic and/or systolic (%)	Diastolic (%)	Systolic (%)	Diastolic and/or systolic (%)
2017/18	22.2	16.9	34.1	42.7	13.1	44.9
2016/17	24.5	15.8	36.2	42.2	13.6	45.6

**Table 31:** Percentage of children and young people with Type 2 diabetes falling above cholesterol targets, 2016/17 and 2017/18

	4 mmol/l or more (%)	5 mmol/l or more (%)
2017/18	74.9	33.8
2016/17	75.9	36.2

## 6.3.2 Body Mass Index

Higher Body Mass Index (BMI, weight/height<sup>2</sup>) is associated with increased cardiovascular risk. To allow direct comparisons across different ages and genders BMI has been standardised using appropriate UK 1990 centile charts. The following categories of BMI are shown based on the UK 1990 standards (Pan & Cole, 2012):

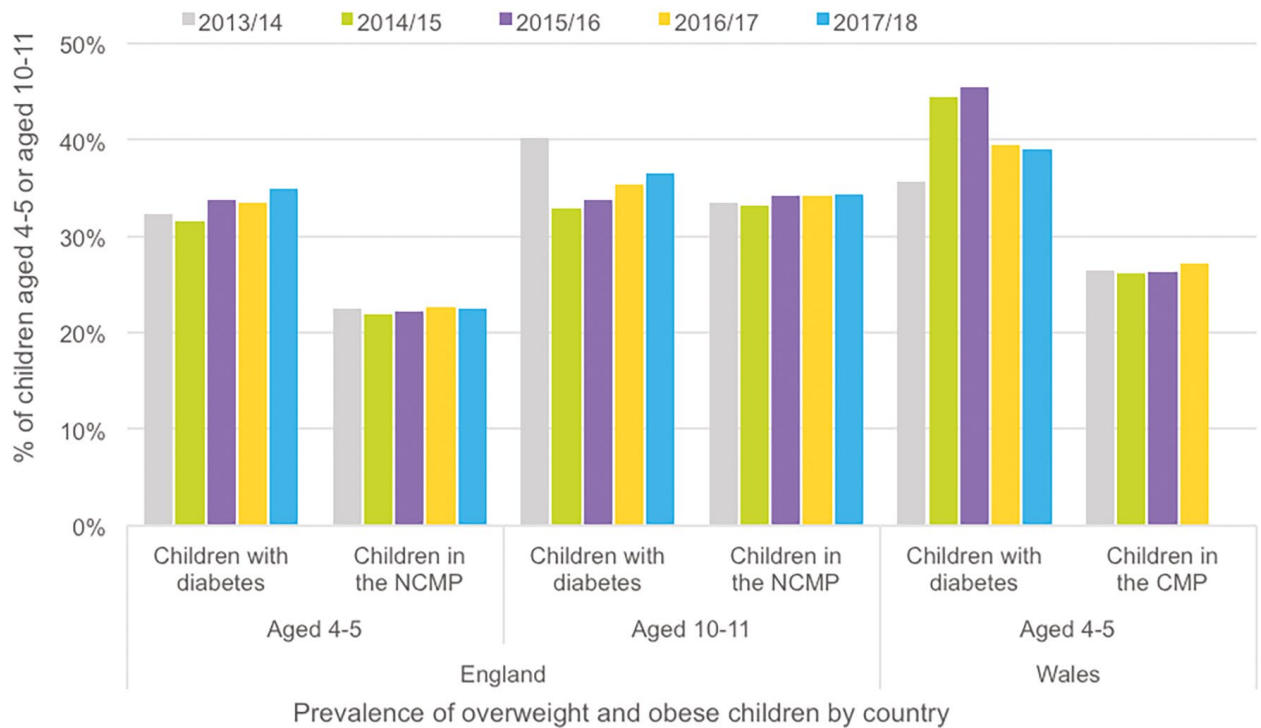
1. Underweight: below the 2nd centile
2. Healthy weight: between the 2nd and 85th centile
3. Overweight: between the 85th and 95th centile
4. Obese: above the 95th centile

Comparisons can be made with the National Child Measurement Programme in England (NHS Digital, 2018) and the Child Measurement Programme in Wales (Public Health Wales, 2017). These programmes measure the height and weight of all children in Reception class (aged 4 to 5 years old) in both countries and Year 6 (aged 10 to 11 years old) in England.

Figure 43 shows the prevalence of obese and overweight children with diabetes compared against the prevalence within wider population in England and Wales since 2013/14. For 2017/18, in England 34.9% of children aged 4 to 5 years old with diabetes were overweight or obese (an increase from 33.4% in 2016/17) compared to 22.3% in the National Child Measurement Programme for England. In Wales, 39.0% of children diabetes aged 4 to 5 years were overweight or obese (down from 39.4% in 2016/17) compared to 27.1% in the Child Measurement Programme for Wales. The prevalence of overweight and obese children aged 10 to 11 years old with diabetes in England was 36.5% (an increase from 35.3% in 2016/17) compared to 34.3% of the wider cohort within the National Child Measurement Programme for England.

These findings indicate that there is a higher prevalence of obesity and overweight among young children with diabetes compared to children of similar ages in the wider population.



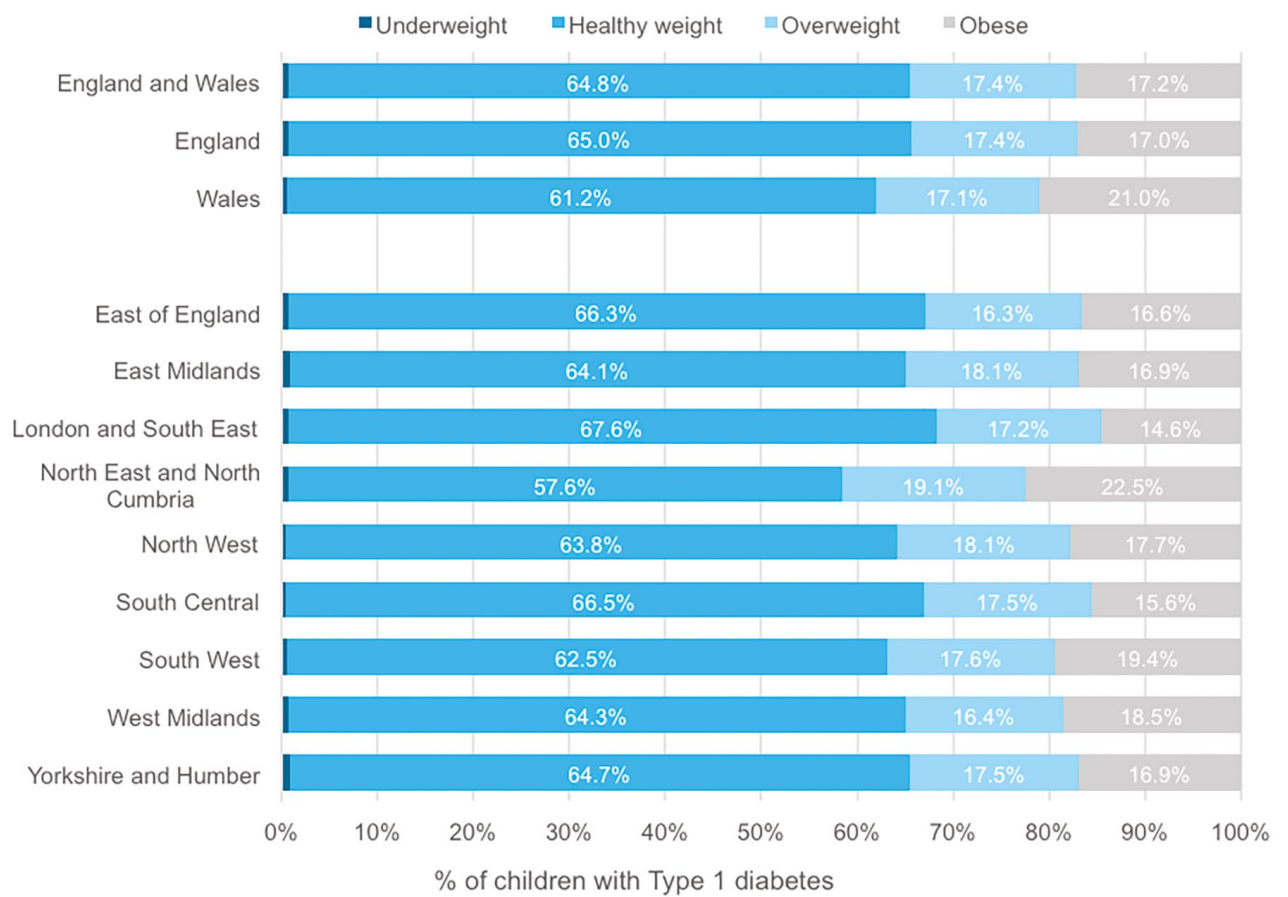


**Figure 43:** Percentage of obese and overweight children with diabetes, aged 4 to 5 and age 10 to 11 years old, and the percentage of obese and overweight children in the wider population by country, 2014/15 to 2017/18<sup>2</sup>

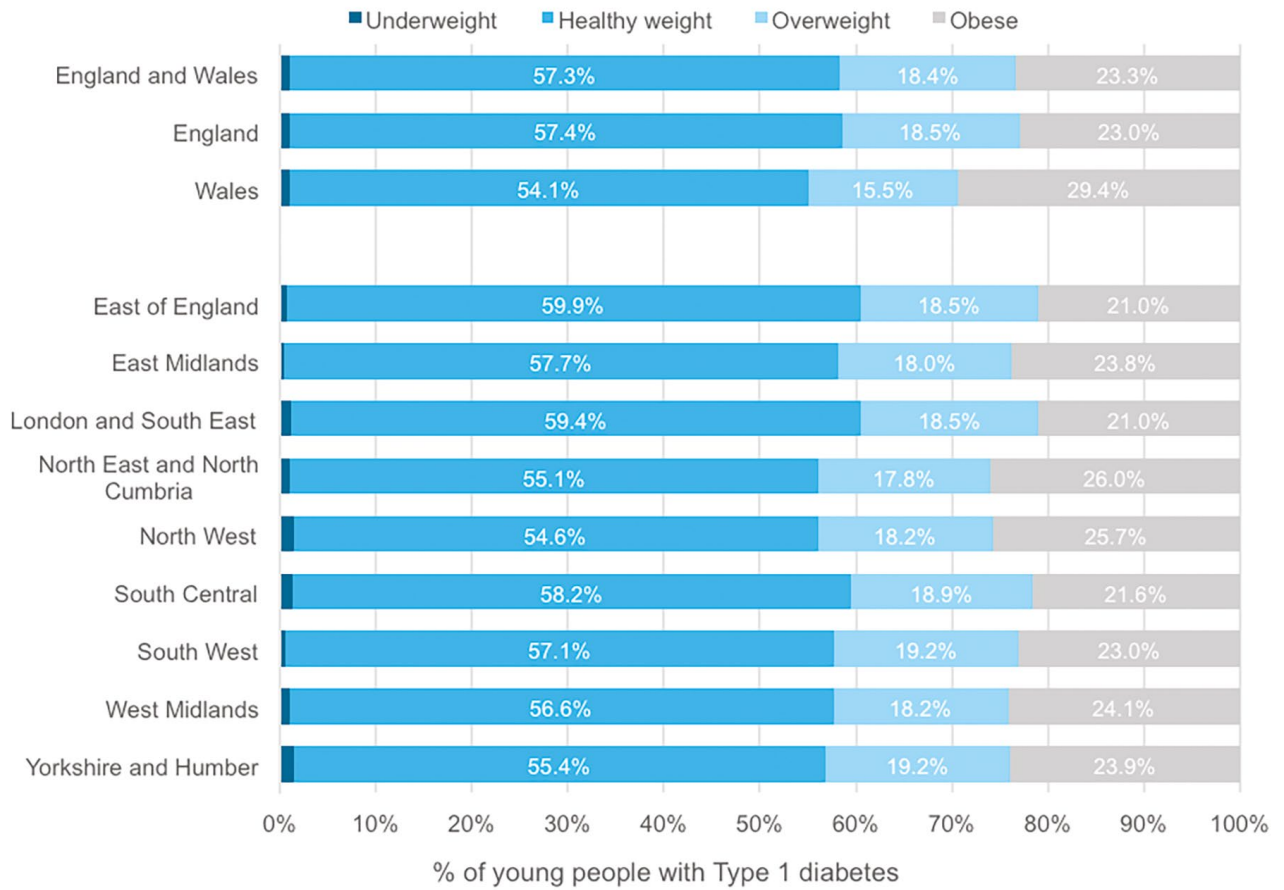
### 6.3.2.1 Body Mass Index and Type 1 diabetes

Figure 44 and Figure 45 show the percentage of children and young people with Type 1 diabetes included in the audit within each BMI category by country and region. It shows that a higher percentage of those aged 0-11 years had a healthy weight (64.8%) compared to those aged 12 years and above (57.3%), and that a higher percentage of children and young people with Type 1 diabetes were overweight or obese than were underweight.

<sup>2</sup> 2017/18 CMP data for Wales was not available at the time of writing (it is due to be published in March 2019)

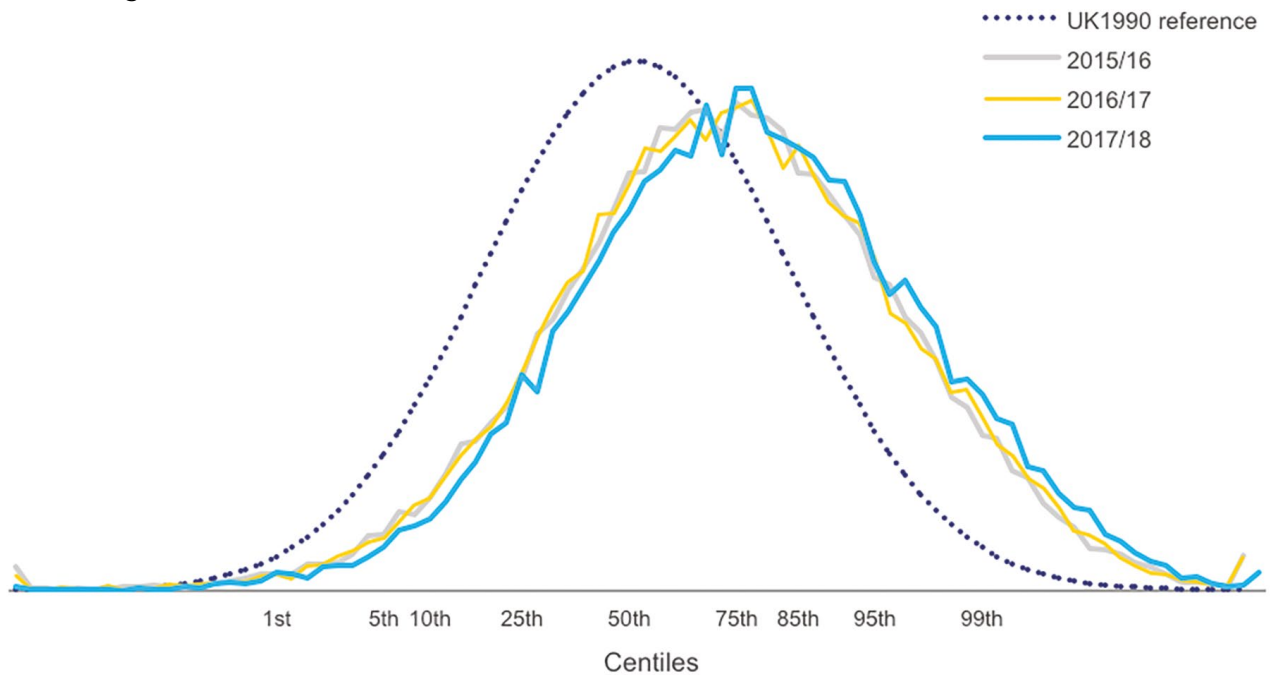


**Figure 44:** Percentage of children aged 0-11 years with Type 1 diabetes within BMI categories by country and region, 2017/18



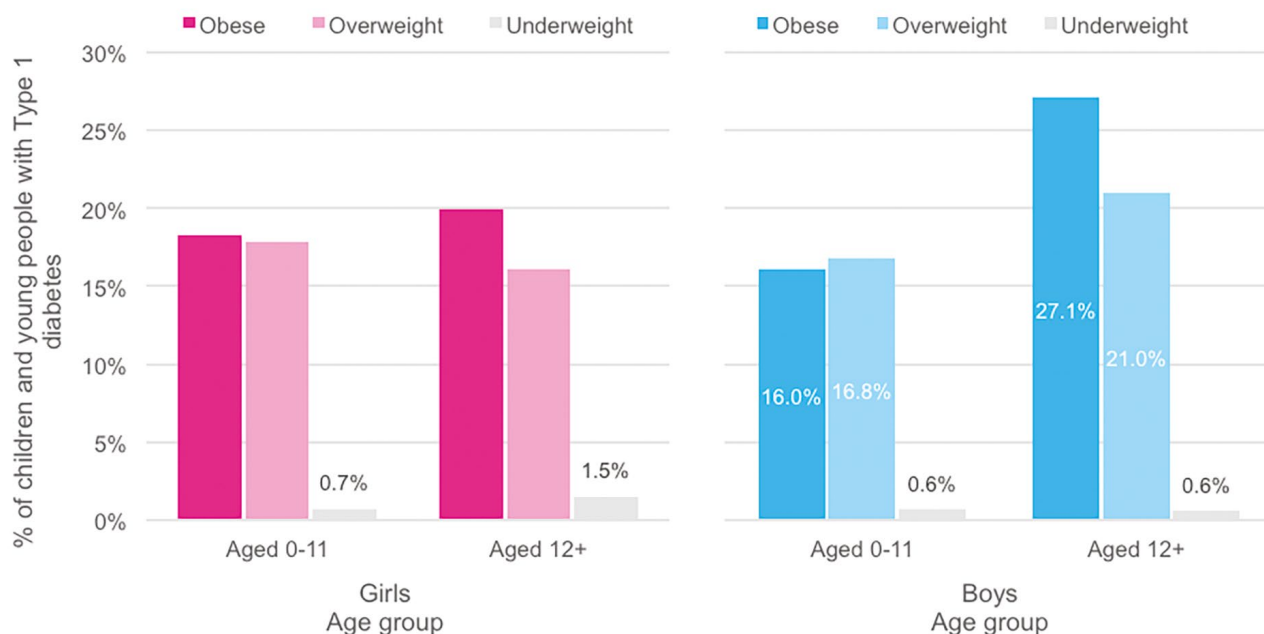
**Figure 45:** Percentage of young people 12 years and older with Type 1 diabetes within BMI categories by country and region, 2017/18

Figure 46 shows the distribution of BMI of children and young people with Type 1 diabetes since 2015/16 compared to the 1990 reference population. It shows that overall, children and young people with Type 1 diabetes have a higher BMI than the general population with a trend towards increasing BMI over time.



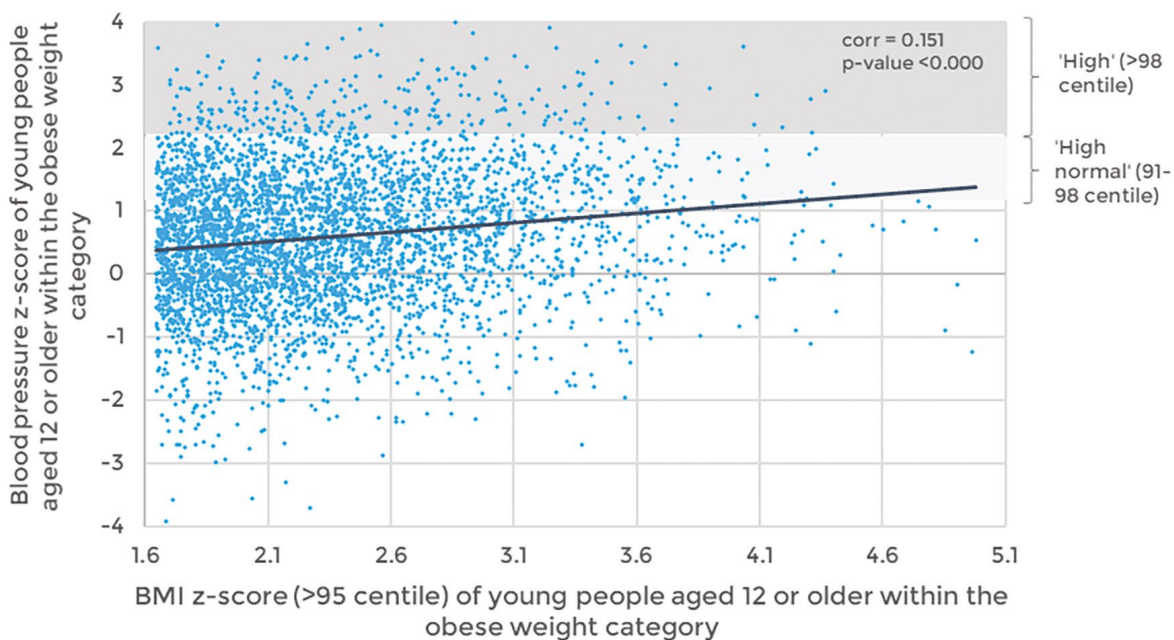
**Figure 46:** Distribution of body mass index of children and young people with Type 1 diabetes in 2015/16, 2016/17 and 2017/18 compared to the 1990 reference population

Almost half (48.1%) of boys with Type 1 diabetes aged 12 and above were recorded as being either overweight or obese; the figure was lower for boys aged 0 to 11 (32.8%). There was a small difference in the prevalence of obesity and overweight amongst girls across the different age groups (Figure 47).



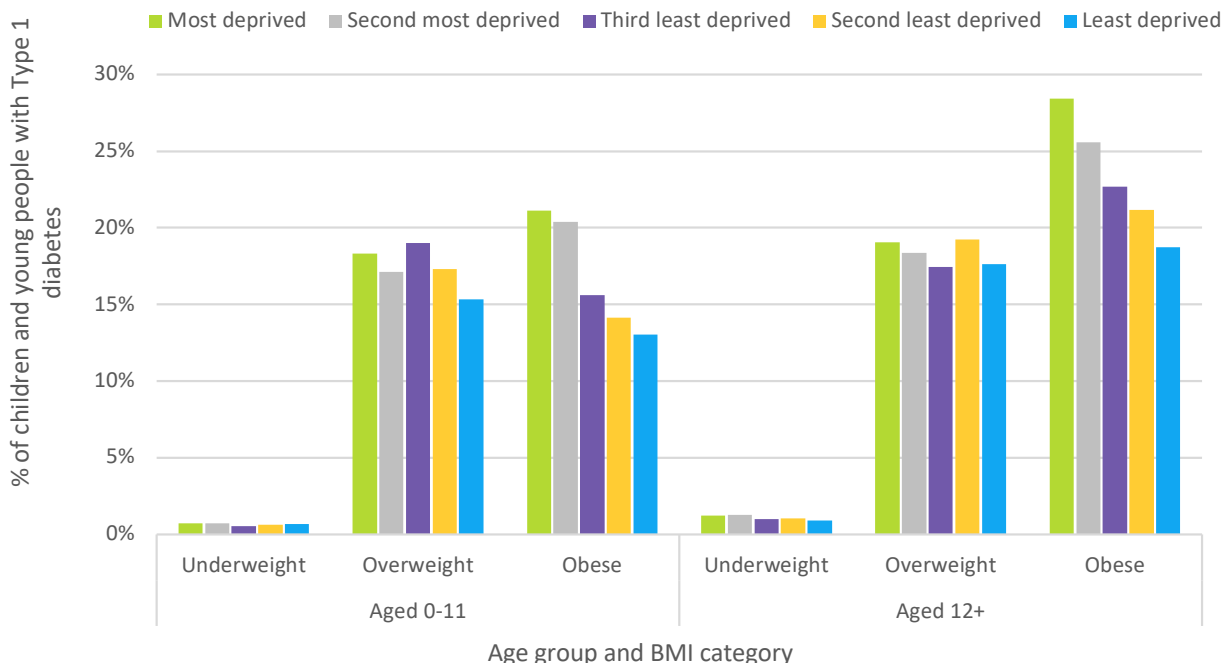
**Figure 47:** Percentage of children and young people with Type 1 diabetes who were in the underweight, overweight or obese category by age group and sex, 2017/18

Figure 48 plots the BMI z-scores of young people aged 12 and above within the obese weight category against their blood pressure z-scores. A z-score or standard deviation score indicates how many units (of the standard deviation) a child or young person's BMI or blood pressure is above or below the average value for their age and sex. The upward sloping trendline indicates that there is a positive correlation between having a high BMI and a high blood pressure. Correlation does not imply causation and there are likely additional factors that are associated with being obese and having a high blood pressure.



**Figure 48:** Scatter plot showing BMI z-scores and blood pressure z-scores of young people aged 12 and above within the obese weight category, 2017/18

Figure 49 shows the percentage of children and young people with Type 1 diabetes categorised as underweight, overweight or obese by deprivation quintile. It shows that the prevalence of obesity is higher among children and young people with Type 1 diabetes living in more deprived areas compared those in less deprived areas.



**Figure 49:** Percentage of children and young people with Type 1 diabetes within each body mass index category by deprivation quintile, 2017/18

### 6.3.2.2 Body Mass Index and Type 2 diabetes

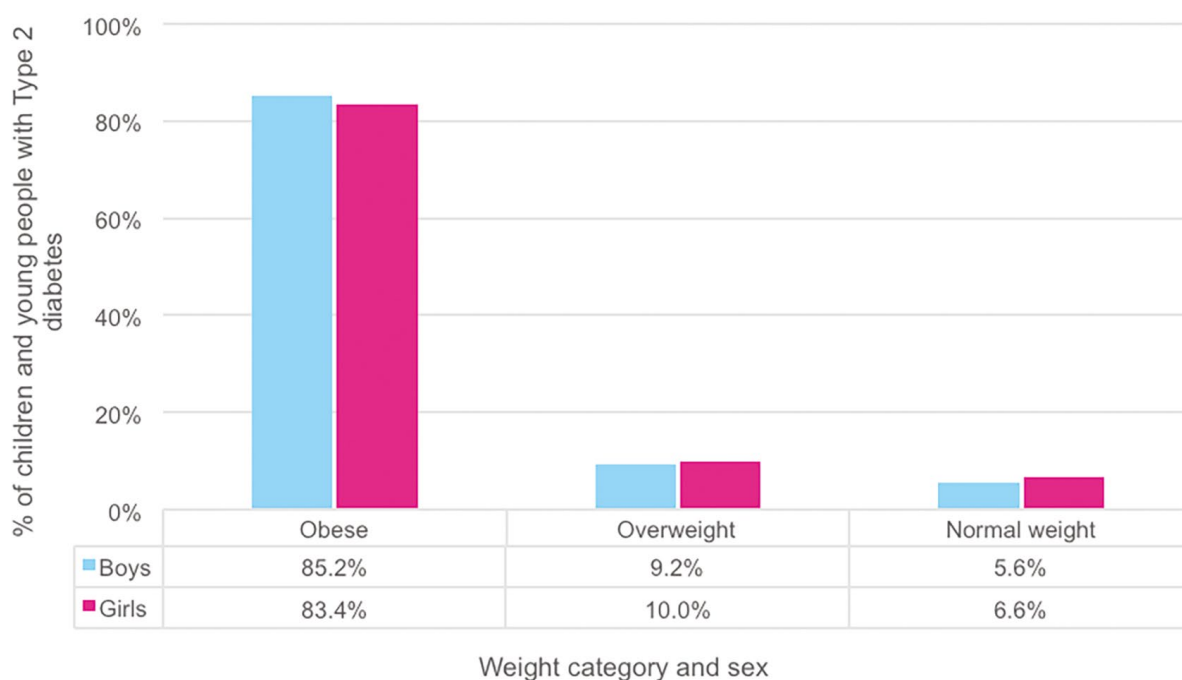
Table 32 shows the percentage of children and young people with Type 2 diabetes in each BMI category for England and Wales in 2016/17 and 2017/18. It shows that the majority of children and young people with Type 2 diabetes were obese.

**Table 32:** Body mass index categories for children and young people with Type 2 diabetes, 2016/17 and 2017/18

	No. of children and young people with T2 diabetes	Under-weight (%)	Healthy weight (%)	Overweight (%)	Obese (%)
2017/18	677	0.0	5.9	9.5	84.6
2016/17	658	*	6.2	8.1	85.4

\*indicates a percentage derived from a number <5

Figure 50 shows that there was little variation in the percentage of children and young people with Type 2 diabetes within each weight category when broken down by sex.



**Figure 50:** Percentage of children and young people with Type 2 diabetes who were in the normal weight, overweight or obese category by sex, 2017/18

## 6.3.3 Micro- and macro-vascular outcomes key findings

### Microvascular disease and risk factors

- Albuminuria was found in 10.2% of young people aged 12 years and above with Type 1 diabetes.
- The prevalence of albuminuria in Type 1 diabetes was higher amongst those living in the most deprived areas.
- Abnormal retinopathy screening was found in 12.7% of young people aged 12 and above with Type 1 diabetes. The prevalence of retinopathy fell between 2016/17 and 2017/18 from 14.8% to 12.7%.
- The risk of retinopathy increased with age and was highest amongst adolescent females. It was slightly higher amongst those living in more deprived areas and the risk was lower in all deprivation quintiles compared to 2016/17.
- Albuminuria was found in 22.1% of children and young people with Type 2 diabetes; twice the rate observed in those with Type 1 diabetes.
- Abnormal eye screening results were found in 5.6% of young people with Type 2 diabetes; less than half the rate recorded amongst young people with Type 1 diabetes.

### Macrovascular disease and risk factor

- High blood pressure (hypertension) was found in 26.7% of young people aged 12 years and older with Type 1 diabetes.
- 21.7% of young people aged 12 years and older with Type 1 diabetes had a total blood cholesterol level exceeding the target of 5 mmol/l.
- 17.4% of children aged 0 to 11 years with Type 1 diabetes were overweight, and 17.2% were obese; of those ages 12 years and above, 18.4% were overweight and 23.3% obese. These figures exceeded the background prevalence for overweight and obesity seen in England and Wales. Hypertension was found in 44.9% of children and young people with Type 2 diabetes; double that seen in Type 1 diabetes.
- 84.6% of children and young people with Type 2 diabetes were obese, 44.9% had high blood pressure, and 33.8% exceeded the higher target for total blood cholesterol ( $\geq 5$  mmol/l).

## 6.3.4 Micro and macrovascular recommendations

### Multidisciplinary paediatric diabetes teams should:

- Prioritise improving blood glucose levels to reduce the lifetime risk of developing complications.
- Be aware of the significantly higher prevalence of albuminuria and hypertension amongst children and young people with Type 2 diabetes compared to those with Type 1.

### Commissioners should:

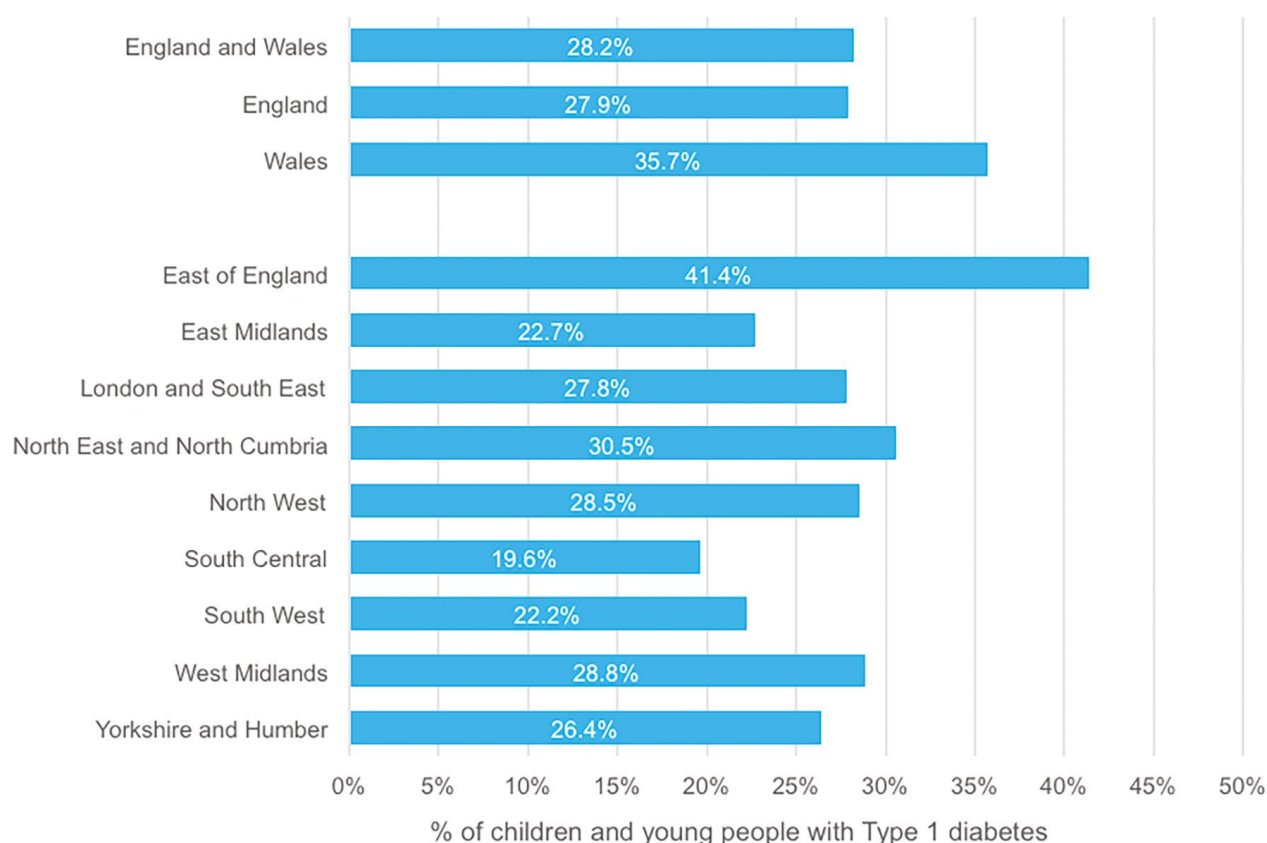
- Ensure that PDUs are resourced so that children and young people with diabetes have access to individually tailored MDT support to promote a healthy diet and active lifestyle.

## 6.4 Psychological assessment

Psychological assessment and access to psychology services should be available to all children and young people and their families with diabetes. Diabetes teams should be aware that children and young people with diabetes have a greater risk of emotional and behavioural difficulties. All children and young people with diabetes and their family members or carers (as appropriate) should be offered emotional support after diagnosis, which should be tailored to their emotional, social, cultural and age-dependent needs.

### 6.4.1 Psychological outcomes of children and young people with Type 1 diabetes

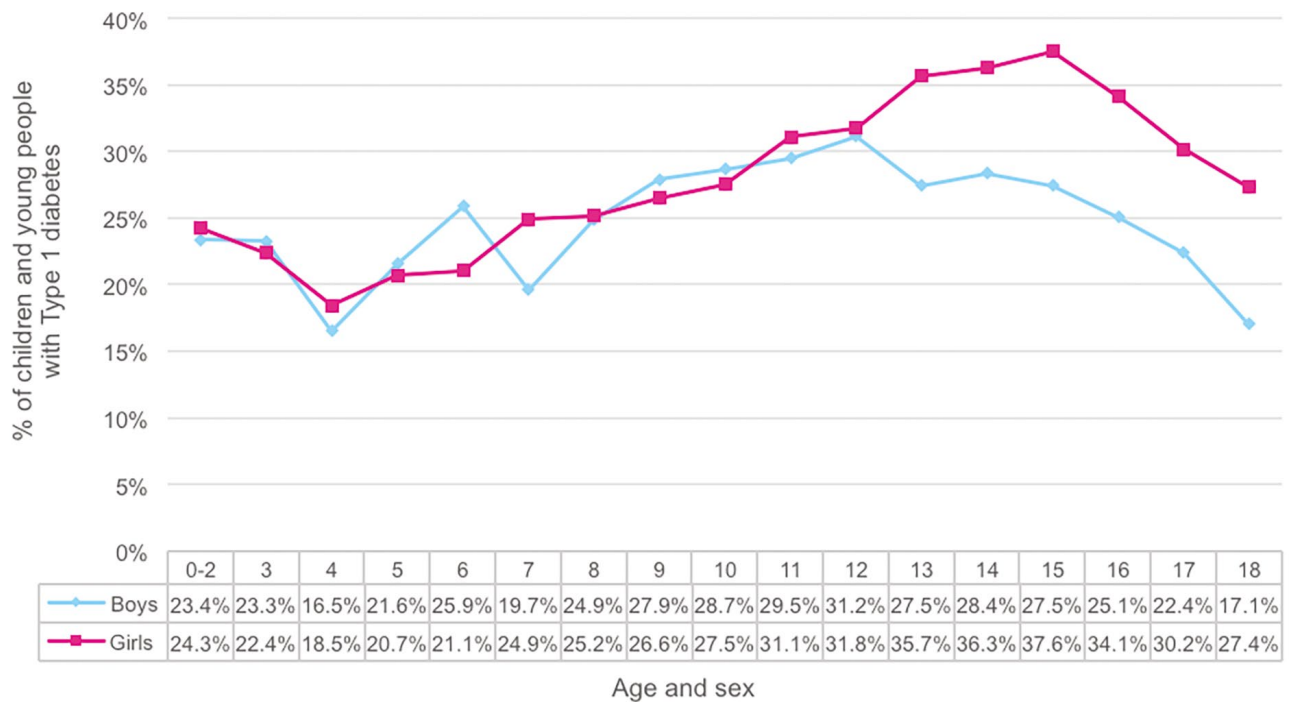
There were 23,359 (82.5%) children and young people with Type 1 diabetes recorded as having a psychological screening assessment within the audit period, 20,114 (86.1%) of whom had a known outcome of the assessment recorded. Of the 20,114 children and young people with Type 1 diabetes, 28.2% (n = 5,672) were assessed as requiring additional psychological or CAMHS support outside of multidisciplinary team (MDT) clinics (hereafter 'additional psychological support'); percentages varied by country and by region (Figure 51). Since changes were made to how psychological outcomes data was reported in 2017/18, it is not possible to make direct comparisons against data collected in previous audit years.



**Figure 51:** Percentage of children and young people with Type 1 diabetes assessed as requiring additional psychological support by country and region, 2017/18

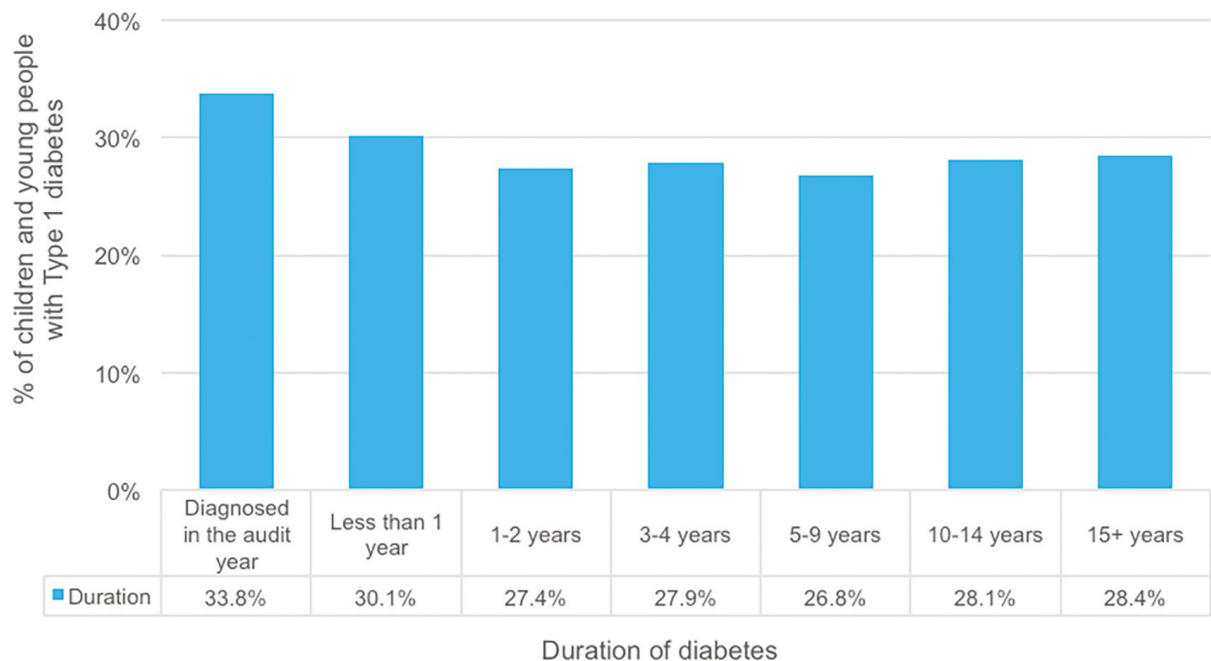


Figure 52 shows that the percentage of younger boys and girls assessed as requiring additional psychological support varied up to age eight; from age eight to 12, there was a stable increase in the percentage for both boys and girls. However, rates diverged thereafter as more adolescent girls were recorded as requiring additional support compared to adolescent boys.



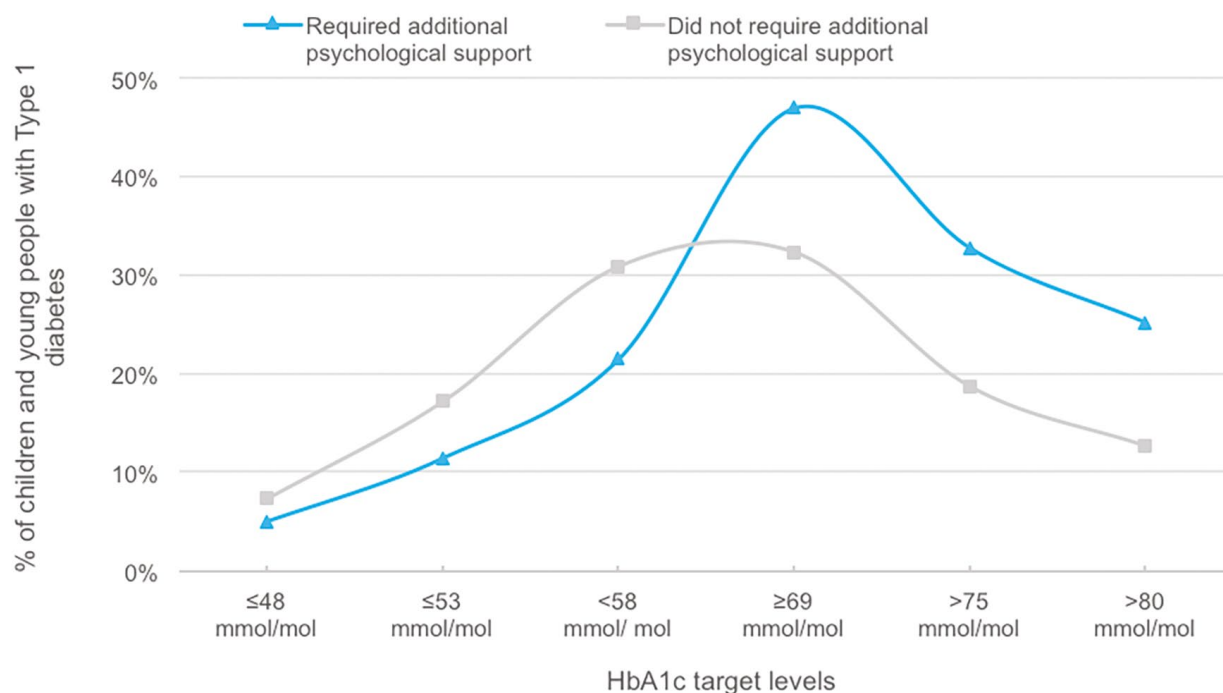
**Figure 52:** Percentage of children and young people with Type 1 diabetes who were assessed as requiring additional psychological support by age and sex, 2017/18

Figure 53 shows that the percentage of children and young people with Type 1 who were assessed as requiring additional psychological support was highest amongst those who were newly, or recently, diagnosed.



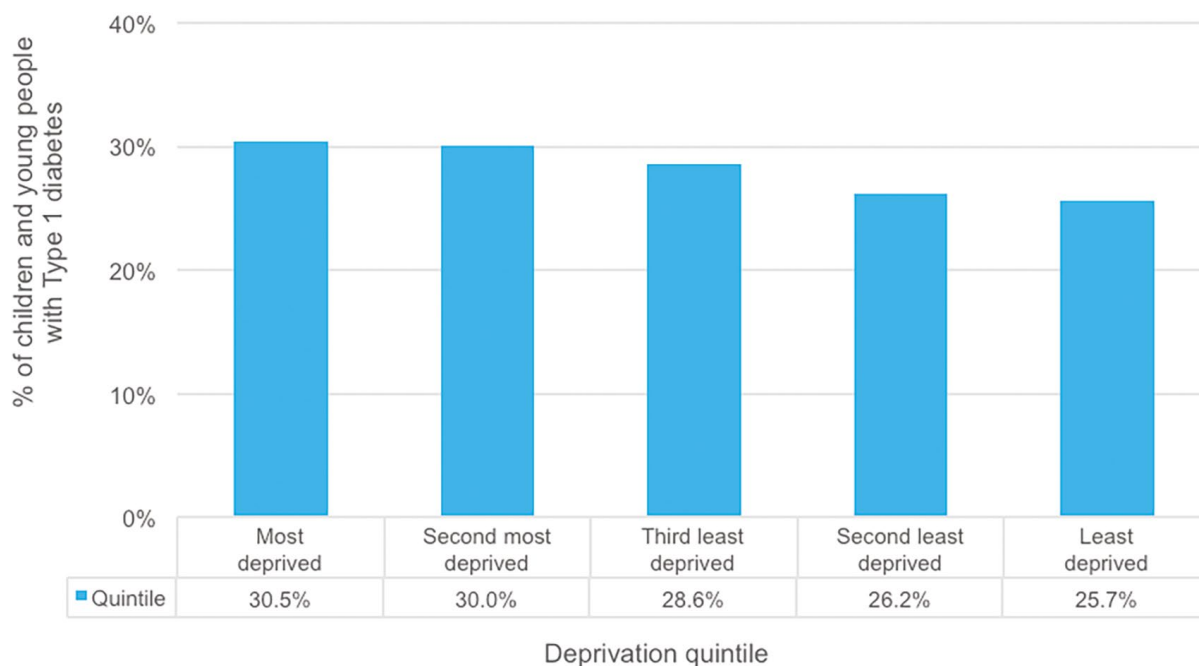
**Figure 53:** Percentage of children and young people with Type 1 diabetes assessed as requiring additional psychological support by duration of Type 1 diabetes, 2017/18

Figure 54 shows that children and young people with Type 1 diabetes who required additional psychological support had poorer HbA1c outcomes compared to those who did not require additional psychological support.



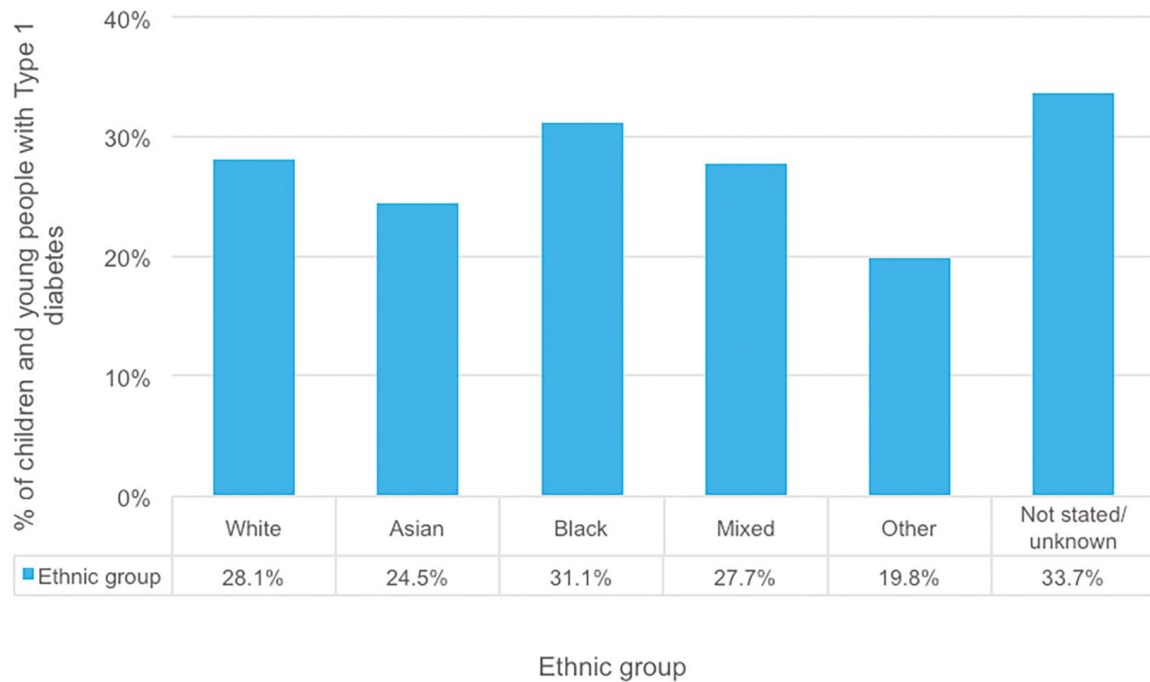
**Figure 54:** Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by outcome of psychological assessment, 2017/18

Figure 55 shows that the percentage of children and young people with Type 1 diabetes who were assessed as requiring additional psychological support or CAMHS support outside of MDT clinics was highest amongst those who were living in the most deprived areas.



**Figure 55:** Percentage of children and young people with Type 1 diabetes assessed as requiring additional psychological support or CAMHS support outside of MDT clinics within each deprivation quintile, 2017/18

Figure 56 shows that the percentage of children and young people with Type 1 diabetes who were assessed as requiring additional psychological support varied according to ethnic category. Of those with a stated ethnicity, the percentage was highest amongst in the Black ethnic group.



**Figure 56:** Percentage of children and young people with Type 1 diabetes assessed as requiring additional psychological support within each ethnic category, 2017/18

## 6.4.2 Psychological outcomes of children and young people with Type 2 diabetes

There were 530 (71.1%) children and young people with Type 2 diabetes recorded as receiving a psychological assessment within the audit period, 417 (78.7%) of whom had a known outcome of the assessment recorded.

Of the children and young people with Type 2 diabetes with a known result, almost one-third (30.2%) were assessed as requiring additional psychological or CAMHS support outside of MDT clinics (Table 33).

**Table 33:** Outcome of assessment for need of Child and Adolescent Mental Health Services/ psychological support of children and young people with Type 2 diabetes by country, 2016/17

	No. of children and young people with Type 2 diabetes	Required additional support (%)	Did not require additional support (%)
England and Wales	417	30.2	69.8

### 6.4.3 Key findings

- Nearly a third of (28.2%) children and young people with Type 1 diabetes with a recorded psychological assessment and outcome were assessed as requiring additional psychological or CAMHS support outside of MDT clinics.
- Amongst children and young people with Type 1 diabetes, there was a higher proportion of adolescent girls recorded as requiring additional psychological support compared to adolescent boys.
- The percentage of children and young people with Type 1 diabetes assessed as requiring additional psychological support was highest amongst those who were either newly or recently diagnosed, amongst those living in the most deprived areas, and amongst those within the Black ethnic category.
- Children and young people with Type 1 diabetes were more likely to be recorded as requiring additional psychological support if they had an HbA1c above the target of 58 mmol/mol.
- There were 126 (30.2%) children and young people with Type 2 diabetes assessed as requiring additional psychological or CAMHS support outside of MDT clinics.

### 6.4.4 Recommendations

#### **Multidisciplinary paediatric diabetes teams should:**

- Be aware of the complex psychological needs of children and young people with diabetes, and work with commissioners, local health boards and others involved in commissioning services to ensure that care pathways are in place that enable all children and young people with diabetes to be reviewed in a timely way by an expert psychologist and/or CAMHS when necessary.
- Recognise the impact of diagnosis and ensure that psychological support is integrated into routine care at diagnosis.
- Consider whether the higher rates of need of psychological support amongst adolescent girls reflects higher psychological distress compared to adolescent boys, or under-diagnosis of psychological distress amongst the latter group.

#### **The National Children and Young People's Diabetes Network should:**

- Develop regional and/or national agreement on the best way to utilise expert psychologists in the clinical setting.
- Promote the integral role of the Psychologist within paediatric diabetes services.

## 6.5 Hospital Admissions

Diabetes-related hospital admission rates in this section have been calculated from data submitted by PDUs. Previous hospital admission reports from the NPDA have utilised linked admission data taken from Hospital Episode Statistics (HES) in England, and the Patient Episode Database for Wales (PEDW) (RCPCH, 2014 and 2017), hence rates are not directly comparable. However, the NPDA reported admissions data submitted by PDUs for the first time in the 2016/17 core report to encourage submission of higher quality admissions data, which permits regional and unit level comparisons.

Results in this section are presented for children and young people with Type 1 diabetes only due to small numbers with other types of diabetes. In 2017/18, 167 out of 173 PDUs submitted admission data for children and young people with Type 1 diabetes. This was an increase from 158 out of 173 PDUs in the 2016/17 audit. There were 6,348 diabetes-related admissions within the 2017/18 audit year reported for 4,780 children and young people with Type 1 diabetes.

## 6.5.1 Diabetes-related admission

Table 34 shows the percentage of children and young people with Type 1 diabetes admitted at least once with a diabetes-related admission, not associated with diagnosis, within the audit year.

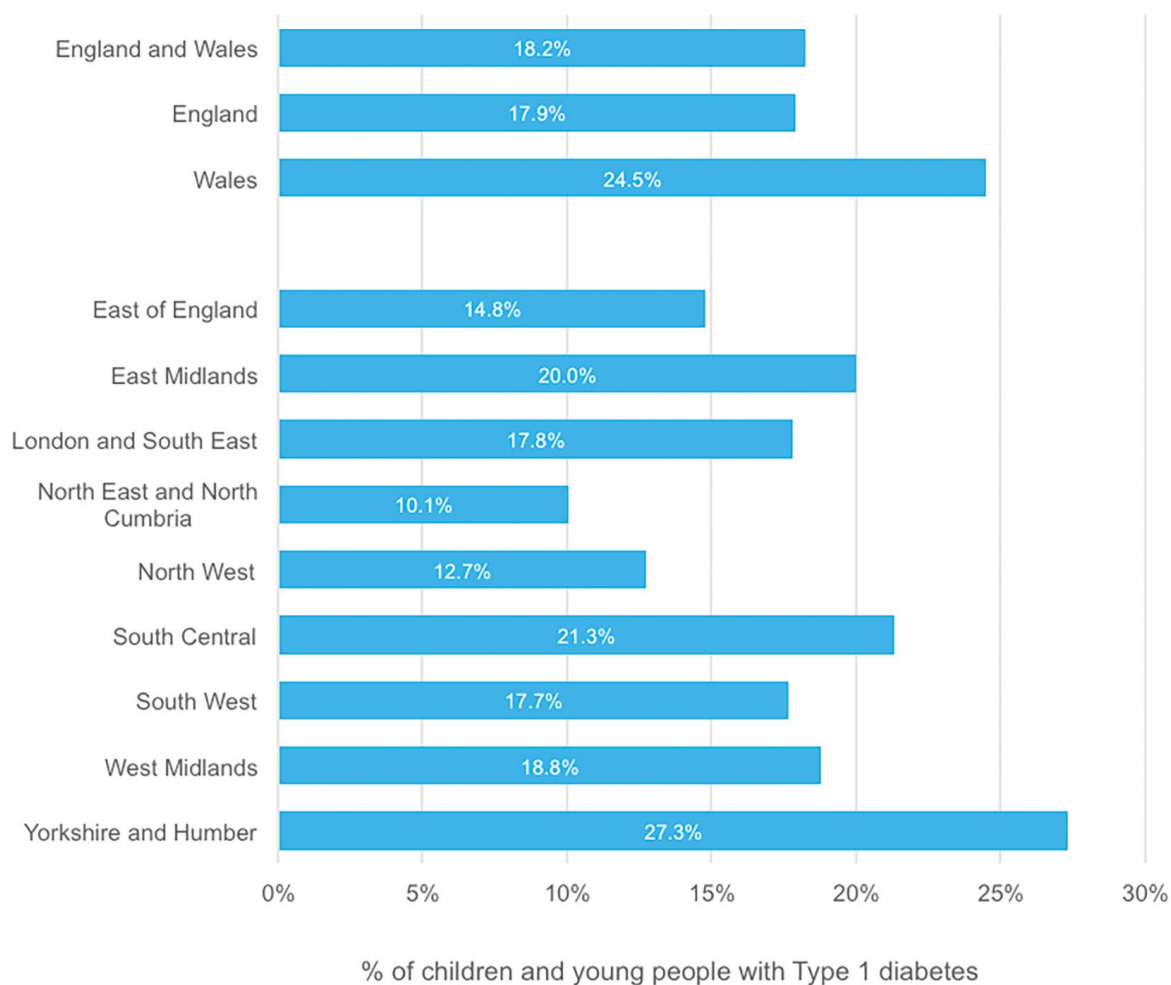
**Table 34:** Percentage of children and young people with Type 1 diabetes admitted at least once for a diabetes-related reason that was not associated with diagnosis, 2017/18

	No. of children and young people with T1 diabetes	DKA (%)	Hypo-glycaemia (%)	Ketosis without Acidosis (%)	Stabilisation (%)	Other (incl. surgery) (%)
England and Wales	27,481	2.7%	1.3%	1.4%	2.2%	5.8%
England	26,034	2.6%	1.3%	1.3%	2.2%	5.8%
Wales	1,447	3.6%	1.9%	2.0%	2.1%	5.3%
East of England	2,991	2.9%	1.6%	1.9%	1.9%	9.3%
East Midlands	1,899	1.4%	1.3%	1.2%	3.3%	4.0%
London and South East	6,278	2.7%	1.1%	1.0%	2.1%	4.2%
North East and North Cumbria	1,548	2.6%	1.3%	0.5%	0.8%	5.1%
North West	3,205	3.1%	1.2%	1.4%	2.2%	5.4%
South Central	2,441	2.5%	1.8%	1.9%	2.4%	7.7%
South West	2,211	2.5%	1.3%	1.5%	2.3%	5.7%
West Midlands	2,780	1.8%	0.9%	1.4%	1.8%	5.6%
Yorkshire and Humber	2,681	3.7%	1.2%	1.4%	2.4%	6.6%

## 6.5.3 DKA at diagnosis

Figure 57 shows that for England and Wales combined, 18.2% of all newly diagnosed patients in 2017/18 (n= 2,844) had DKA at diagnosis of Type 1 diabetes. This finding is lower than the 23.9% incidence rate reported in the previous NPDA Hospital Admissions Report (RCPCH, 2017), but higher than the rate (16.6%) reported for 2016/17. There was significant variation in rates of DKA at diagnosis between regions, which considered alongside the lower national rate compared to previous analysis suggests data completeness and quality issues with incomplete submission of admission data by participating PDUs in the 2017/18 audit.

A comprehensive data completeness and quality report is now provided on submission of admission data to the NPDA which should help to drive improvement in data completeness and quality of data submitted. Data quality and completeness needs to improve before PDU submitted admission data can be considered representative of admission trends in England and Wales.



**Figure 57:** Percentage of children and young people with Type 1 diabetes who had DKA at diagnosis in 2017/18, by region and country

## 6.5.4 Key findings

- The number of units submitting admissions data increased from 158 to 167 with only 6 PDUs failing to submit admissions data in 2017/18.
- Significant variation in reported admission rates between regions suggests incompleteness of data submission amongst units who did submit admissions data.
- Data quality and completeness needs to improve further before PDU submitted admission data can be considered representative of admission trends in England and Wales.

## 6.5.5 Recommendations

- All PDUs participating in the NPDA should submit a complete dataset, enabling benchmarking and associated QI activity around admission avoidance.
- Please refer to the NPDA Hospital Admissions Report ([RCPCH, 2017](#)) for recommendations for avoidance of diabetes-related admissions.

## 7. Treatment regimen and diabetes monitoring

The NPDA collects treatment regimen data and data on usage of real-time continuous glucose monitors (CGM) amongst children and young people with diabetes. Data is collected to observe trends in usage rather than ascribe outcomes related to different treatments. Where a treatment regimen changes throughout the audit year the latest regimen is used for the analysis.

### 7.1 Treatment regimen

#### 7.1.1 Type 1 diabetes

There were 27,322 children and young people with Type 1 diabetes with a valid treatment regimen recorded within the audit period. Table 23 provides a breakdown of the treatment regimens recorded by nation and region for children and young people with Type 1 diabetes (Table 35).

**Table 35a:** Percentage of children and young people with Type 1 diabetes using an insulin injection treatment regimen, alone or with other blood glucose lowering medication, by country and region, 2017/18

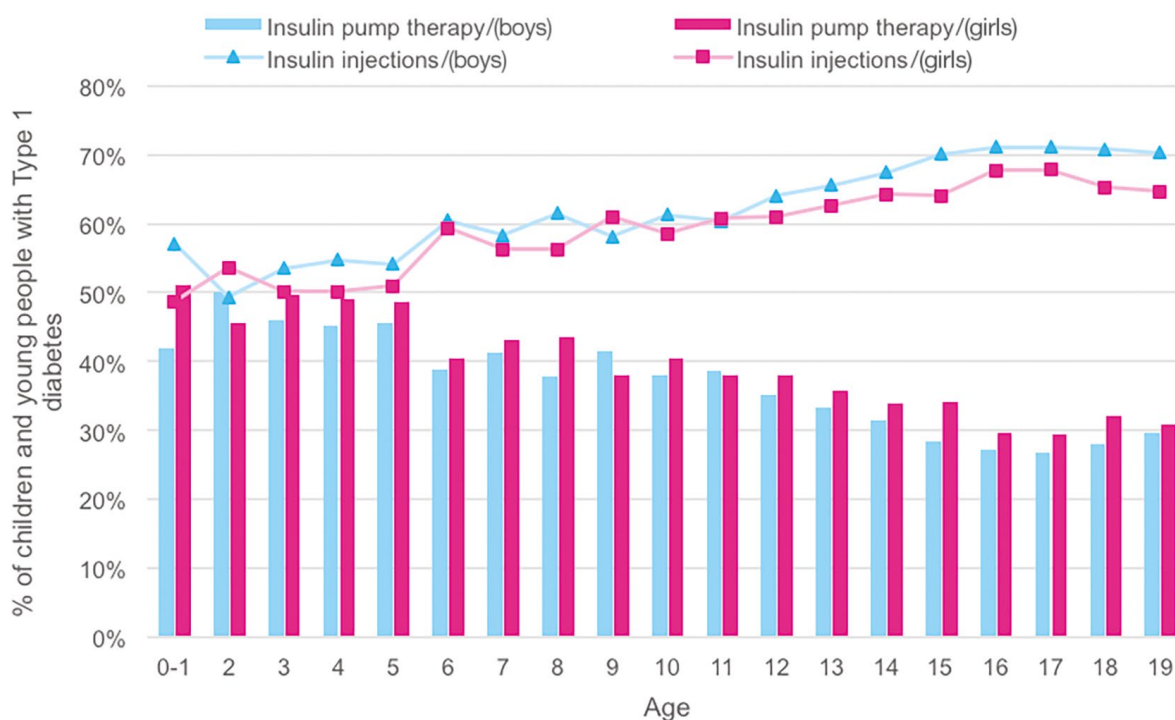
	No. of children and young people with T1 diabetes	1 to 3 insulin injections		4 or more insulin injections	
		Only (%)	And other BGLM† (%)	Only (%)	And other BGLM† (%)
England and Wales	27,322	5.2	0.2	57.9	0.8
England	25,918	4.5	0.2	58.5	0.9
Wales	1,404	17.9	0.0	48.2	*
East of England	2,962	2.2	*	65.9	0.8
East Midlands	1,808	5.1	*	55.1	0.7
London and South East	6,217	6.9	0.3	55.1	0.9
North East and North Cumbria	1,563	9.9	0.4	49.4	0.8
North West	3,380	4.4	*	58.4	0.9
South Central	2,406	4.1	*	59.0	0.7
South West	2,152	3.3	*	65.1	0.6
West Midlands	2,770	2.6	*	61.7	1.8
Yorkshire and Humber	2,660	1.4	*	56.6	0.5

† And other blood glucose lowering medication \* Signifies number less than 5

**Table 35b:** Percentage of children and young people with Type 1 diabetes using an insulin pump treatment regimen, alone or with other blood glucose lowering medication, by country and region, 2017/18

	No. of children and young people with T1 diabetes	Insulin pump therapy	
		Only (%)	And other BGLM† (%)
England and Wales	27,322	35.7	0.2
England	25,918	35.8	0.2
Wales	1,404	33.5	*
East of England	2,962	30.7	0.3
East Midlands	1,808	38.9	*
London and South East	6,217	36.7	0.1
North East and North Cumbria	1,563	39.2	0.4
North West	3,380	36.2	*
South Central	2,406	36.0	*
South West	2,152	30.9	*
West Midlands	2,770	33.2	0.5
Yorkshire and Humber	2,660	41.3	*

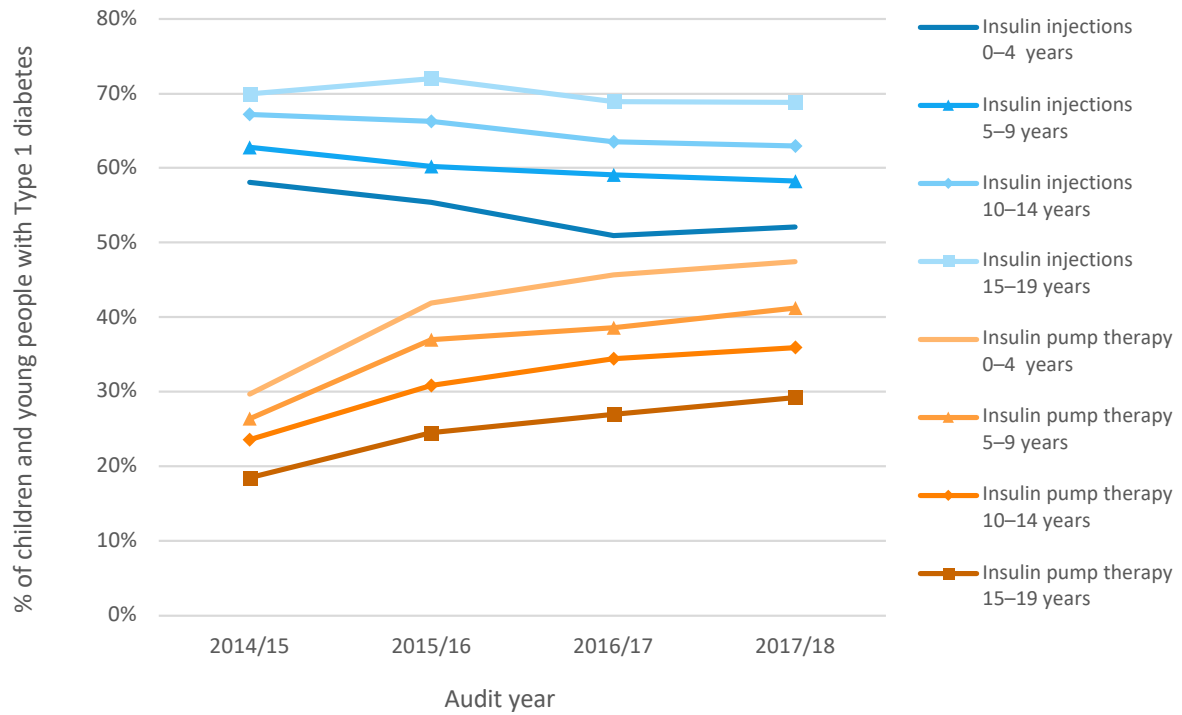
Figure 58 shows the breakdown of insulin regimens amongst those with a recorded sex and age. Younger children were more likely to be using insulin pump therapy in keeping with the trend seen in other European and transatlantic cohorts (Sherr et al., 2016), and pump usage was more prevalent in females.



**Figure 58:** Percentage of children and young people with Type 1 diabetes recorded as using insulin injections or insulin pump therapy by age and sex, 2017/18

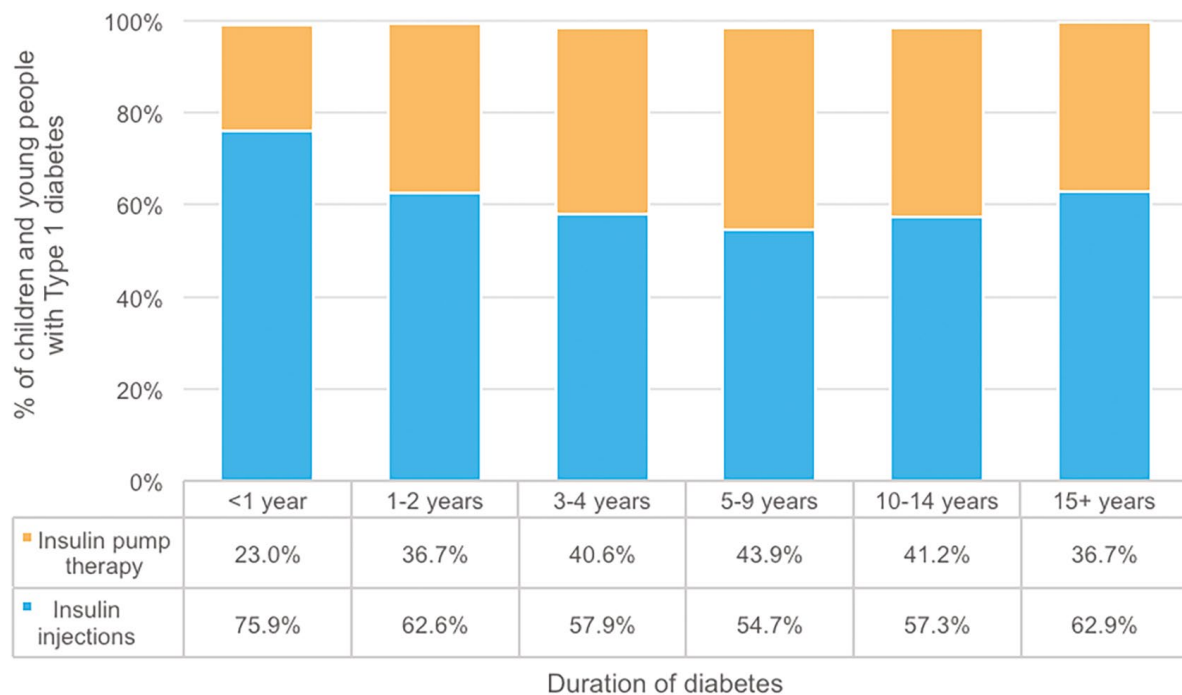


Since 2014/15, there has been an increase in insulin pump usage for all age groups with a corresponding reduction in use of insulin injections (Figure 59).



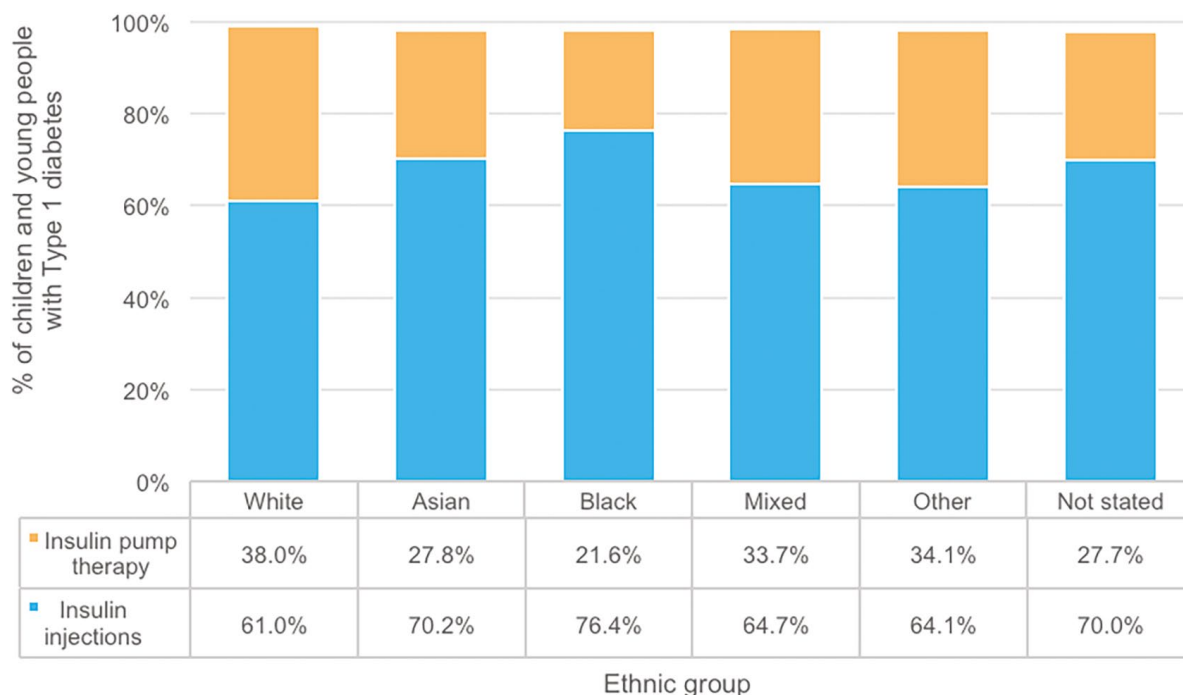
**Figure 59:** Percentage of children and young people either on daily insulin injections or pump therapy by age group, 2014/15 to 2017/18

Figure 60 shows that the pump therapy usage and use of insulin injections varied according to duration. Three-quarters (75.9%) of those in their first year of diagnosis of Type 1 diabetes were using insulin injections, compared to just over half (54.7%) of those with a diagnosis of between 5 and 9 years prior to the start of the audit year.



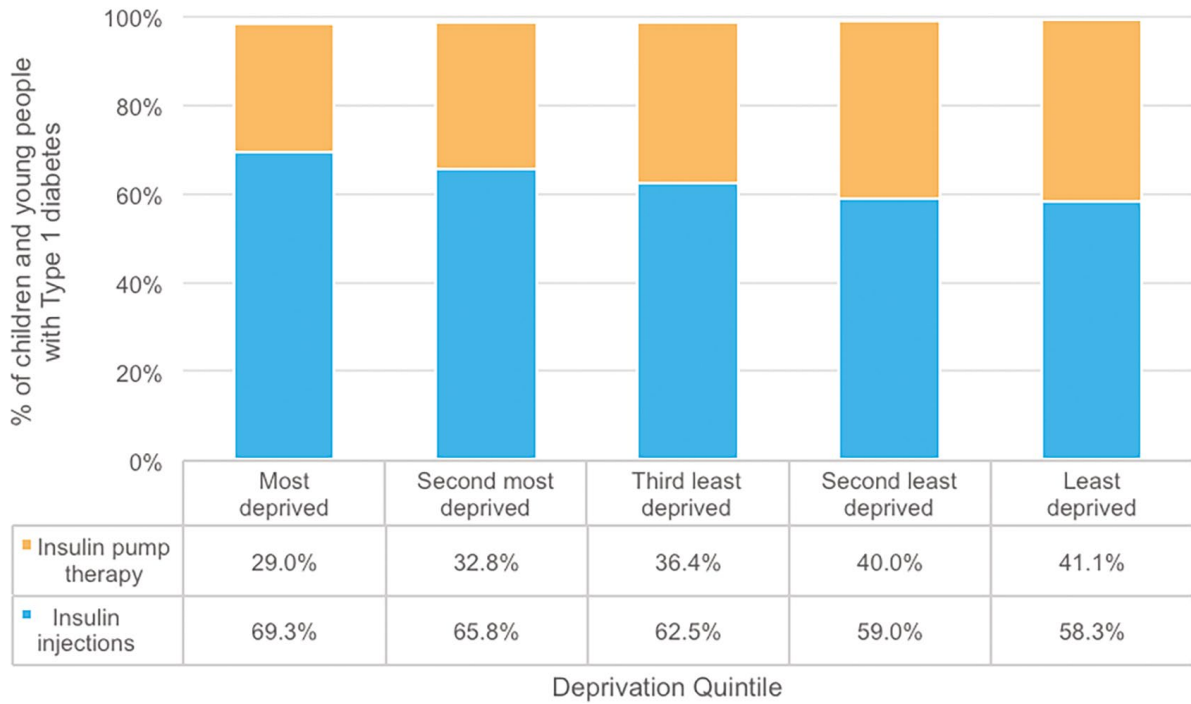
**Figure 60:** Percentage of children and young people either on daily insulin injections or pump therapy by duration of diabetes for England and Wales, 2017/18

Figure 61 shows that White ethnicity was associated with higher pump usage, compared to Asian and Black ethnic groups.

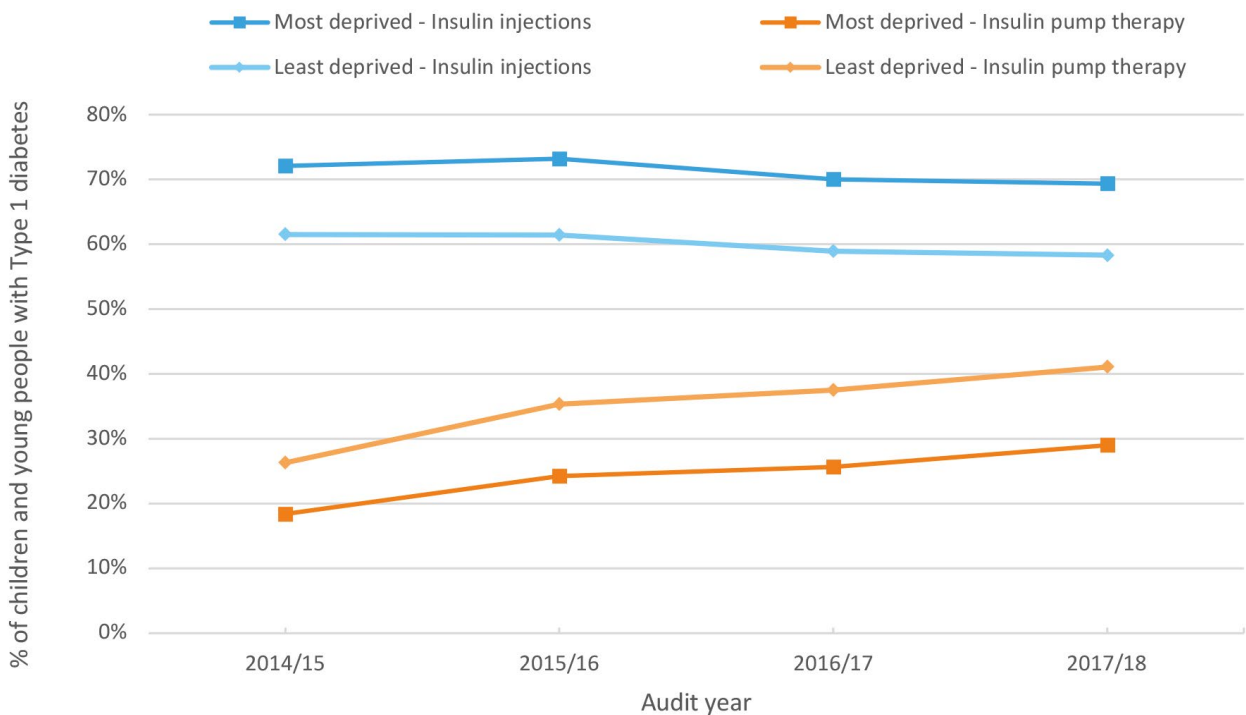


**Figure 61:** Percentage of children and young people using daily insulin injections or pump therapy by ethnic category for England and Wales, 2017/18

Insulin pump therapy is more prevalent in those living in the least deprived areas, whereas use of insulin injections was more prevalent amongst those living in the most deprived areas (Figure 62). Despite increases in insulin pump usage compared to insulin injections in all quintiles of deprivation, the gap between the most and least deprived areas has widened with time. Figure 63 shows that in 2014/15 the percentage on insulin pump therapy for the most and least deprived areas was 18.4% versus 26.3% (a difference of 7.9 percentage points), whereas in 2017/18 the gap had widened to 29.0% versus 41.1%, respectively (a difference of 12 percentage points).

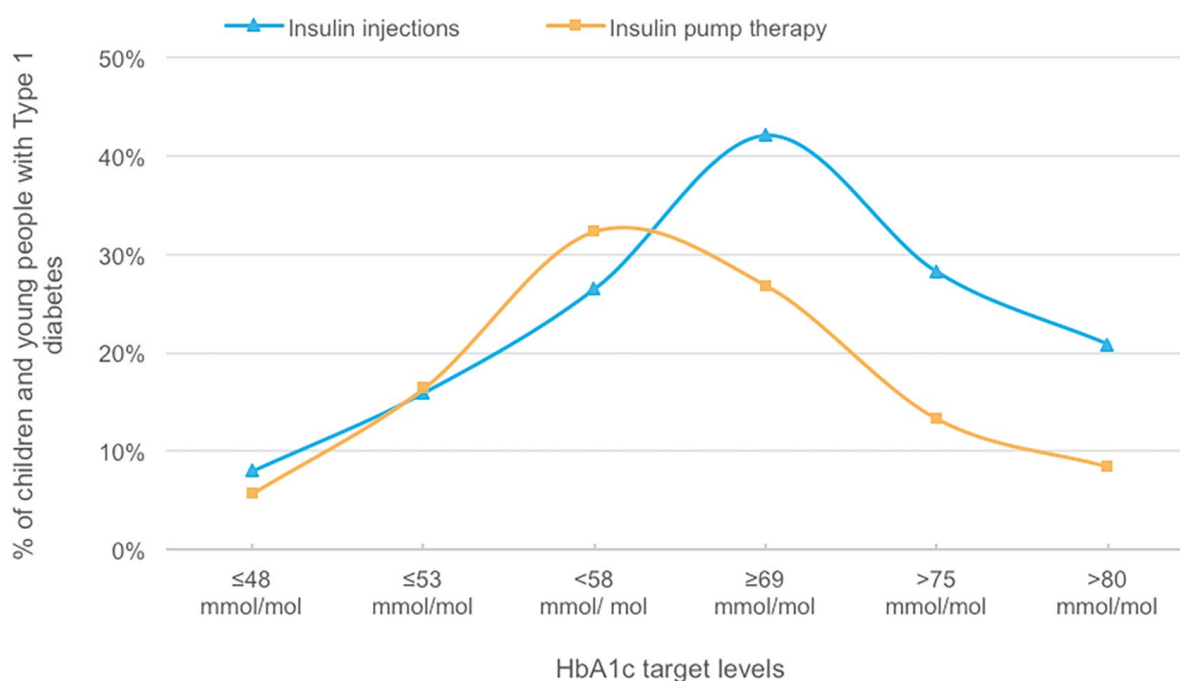


**Figure 62:** Percentage of children and young people with Type 1 diabetes using insulin injections or pump therapy by deprivation quintile, 2017/18



**Figure 63:** Percentage of children and young people with Type 1 diabetes using insulin injections or insulin pump therapy by 'least' and 'most' deprived quintile, 2014/15 to 2017/18

Figure 64 shows a general trend for children and young people with Type 1 diabetes using insulin injections having poorer HbA1c outcomes compared to those using insulin pump therapy. This data does not take into account the influence of deprivation, age, duration of diabetes or other factors which may influence the choice of insulin regimen and have been shown to impact upon diabetes control, and so these results should be interpreted with caution.



**Figure 64:** Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by treatment regimen, 2017/18

## 7.1.2 Treatment regimen of children and young people with Type 2 diabetes

Table 36 shows the breakdown of diabetes treatment regimen for children and young people with Type 2 diabetes. Data was either missing or reported as 'unknown' for almost one-quarter (22.4%) of children and young people with Type 2 diabetes.

The majority of those with Type 2 diabetes were either managing their diabetes with diet alone (no insulin) or with diet in combination with insulin, however given that there was a cohort on insulin alone, and data was missing, caution should be taken when interpreting these results.

**Table 36:** Percentage of children and young people with Type 2 diabetes on each treatment regimen, 2017/18

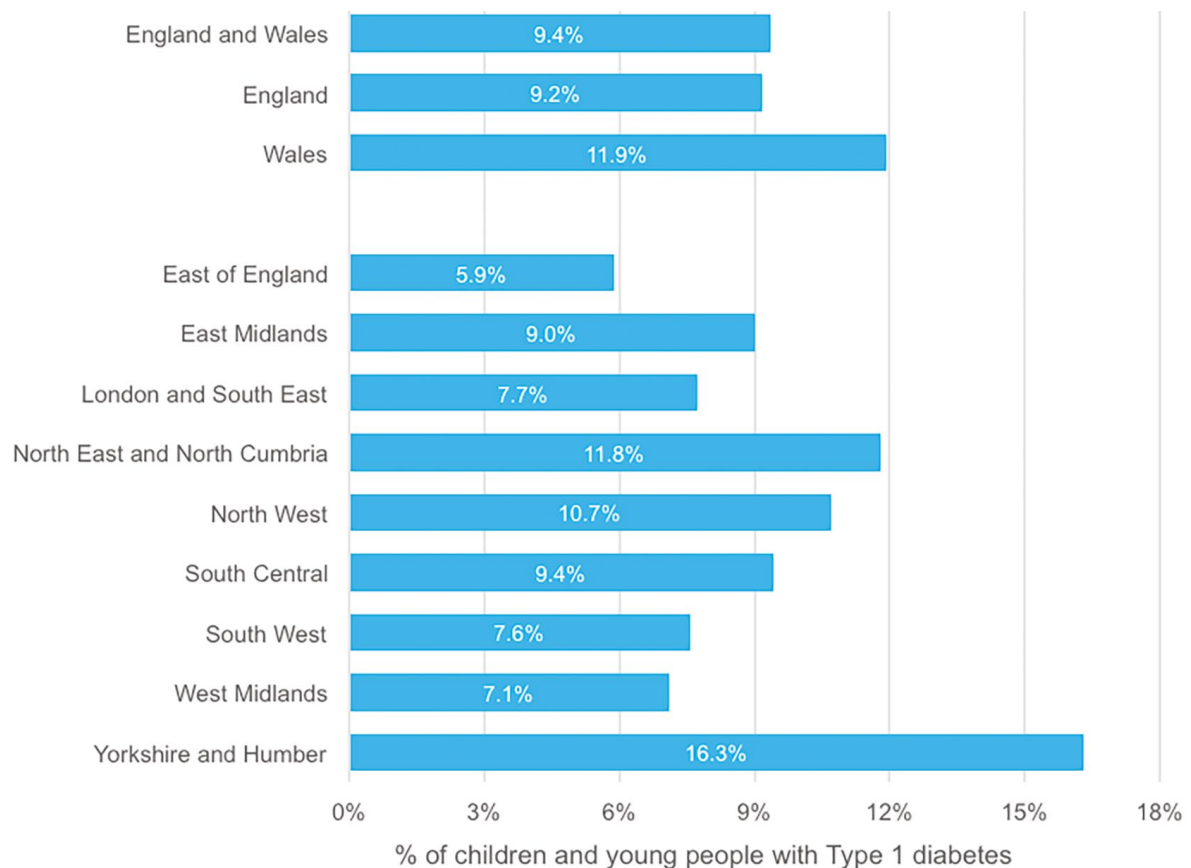
Treatment regimen		England and Wales
No. of children and young people with Type 2 diabetes with a recorded treatment regimen (n)		578
Dietary management	Only (%)	12.6
	And other BGLM† (%)	52.1
1 to 3 insulin injections	Only (%)	4.2
	And other BGLM† (%)	11.9
4 or more insulin injections	Only (%)	9.3
	And other BGLM† (%)	8.0
Insulin pump	Only (%)	*
	And other BGLM† (%)	1.2

† And other blood glucose lowering medication \* Signifies a percentage derived from a number less than 5

## 7.2 Continuous glucose monitoring

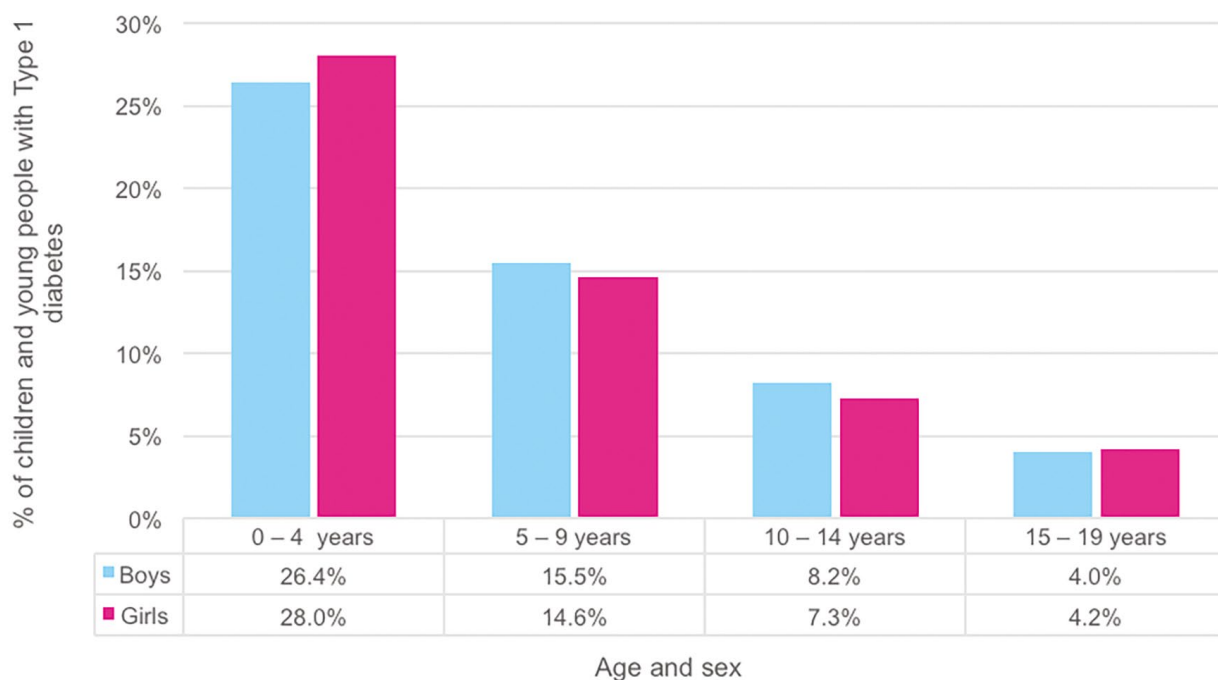
### 7.2.1 Continuous glucose monitoring use among children and young people with Type 1 diabetes

There were 22,077 children and young people with Type 1 diabetes with a negative or positive indication of use of CGM with alarms reported within the audit period. Of those, 9.4% were using real-time; percentages varied by country and region (Figure 65). These results should be interpreted with caution given that 22.0% (n = 6,223) of children and young people with Type 1 diabetes had an unknown or missing entry; percentages of missing data also varied by region.



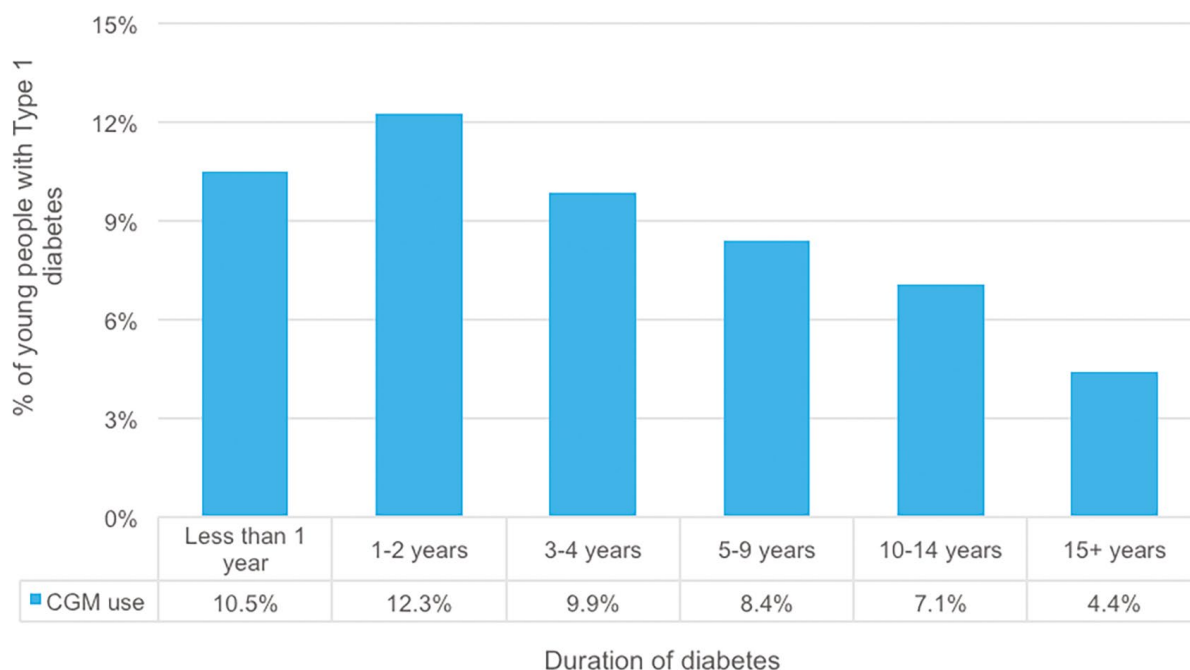
**Figure 65:** Percentage of children and young people with Type 1 diabetes using a real-time continuous glucose monitor (CGM) with alarms, 2017/18

Figure 66 shows that younger children with Type 1 diabetes were more likely to be using CGM than those who were older.



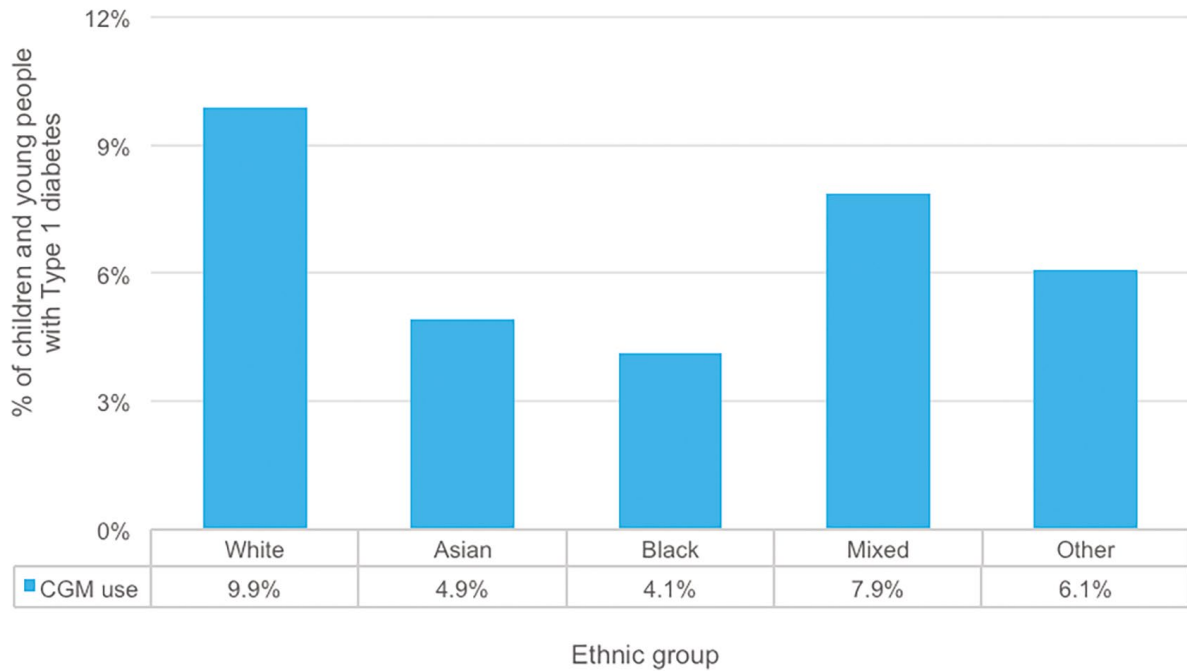
**Figure 66:** Percentage of children and young people with Type 1 diabetes using a real-time continuous glucose monitor (CGM) with alarms by age and sex, 2017/18

Figure 67 shows that subsequent to the first year of diabetes, the proportion of children and young people with Type 1 diabetes using CGM with alarms decreased with duration of diabetes.



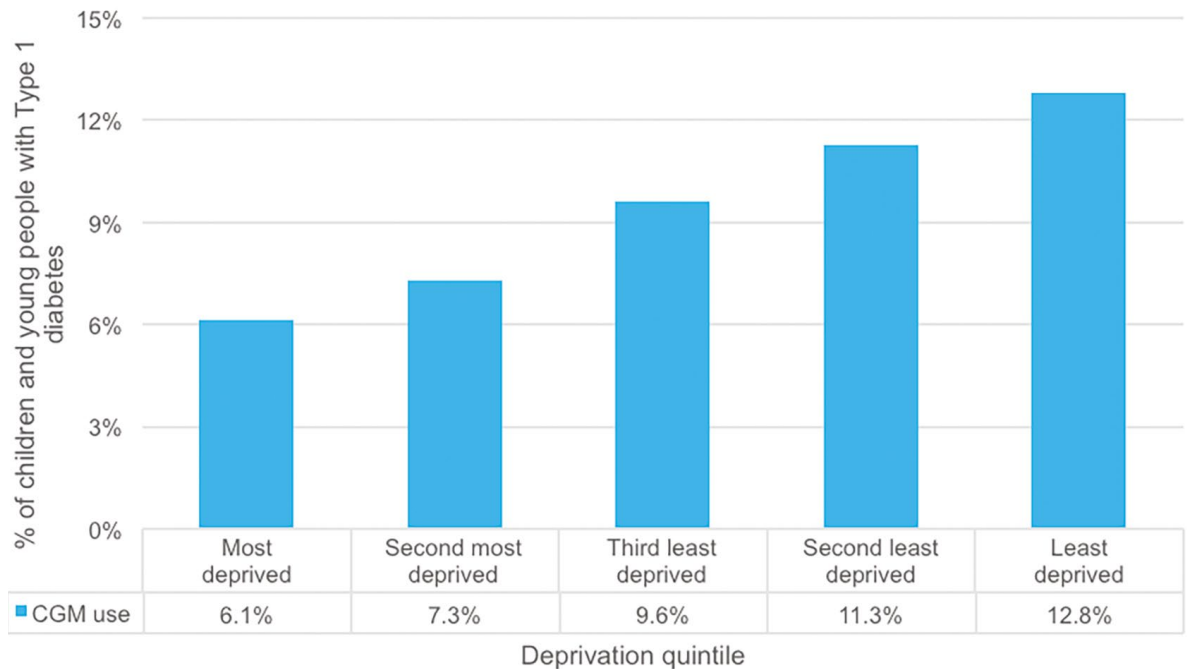
**Figure 67:** Percentage of children and young people with Type 1 diabetes using a real-time continuous glucose monitor (CGM) with alarms by duration of diabetes, 2017/18

Figure 68 shows that White ethnicity was associated with higher CGM usage.



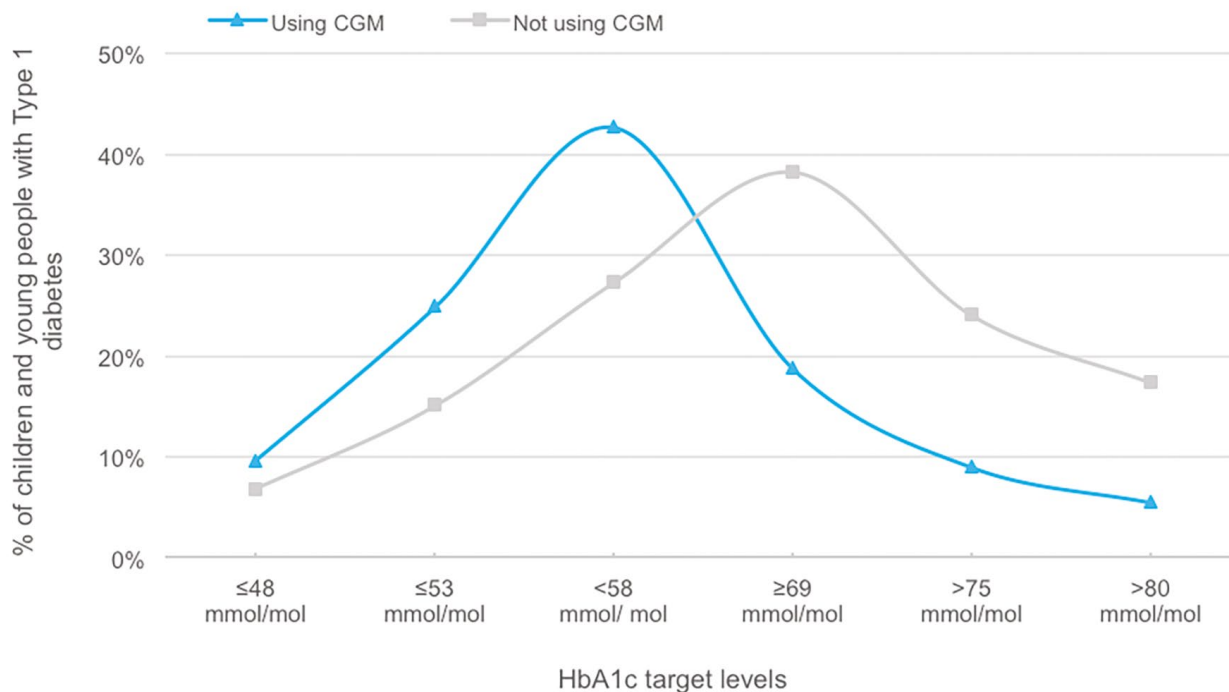
**Figure 68:** Percentage of children and young people with Type 1 diabetes using a real-time continuous glucose monitor (CGM) with alarms by ethnic group, 2017/18

Figure 69 shows that children and young people with Type 1 diabetes living in the least deprived areas were more than twice as likely to be using CGM compared to those living in the most deprived areas.



**Figure 69:** Percentage of children and young people with Type 1 diabetes using a real-time continuous glucose monitor (CGM) with alarms by deprivation quintile, 2017/18

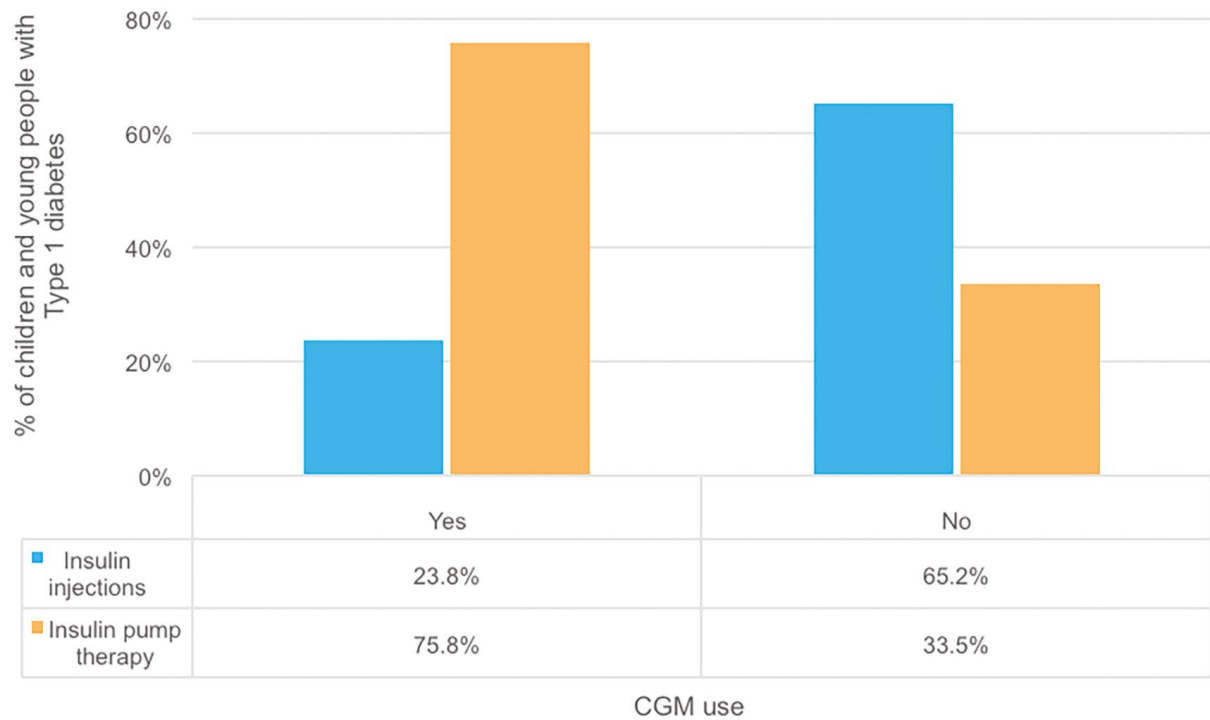
Figure 70 shows that children and young people with Type 1 diabetes using CGM had better HbA1c outcomes compared to those who were not using CGM. These results do not take into account the influence of deprivation, age, duration of diabetes or other factors which may influence CGM usage and which have been shown to impact upon diabetes control, and so these results should be interpreted with caution.



**Figure 70:** Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by CGM usage, 2017/18



Figure 71 shows that children and young people using CGM were more likely to be using insulin pump therapy than insulin injections.



**Figure 71:** Percentage of children and young people with Type 1 diabetes using insulin injections or insulin pump therapy by CGM usage, 2017/18

### 7.2.2 Continuous glucose monitoring use among children and young people with Type 2 diabetes

Of the 525 children and young people with Type 2 diabetes with a positive or negative indication of use of CGM with alarms, five (0.1%) were recorded as using it.

## 7.3 Key findings

- Usage of insulin pumps to deliver insulin therapy in Type 1 diabetes has increased in all age groups since 2014/15.
- Increased usage of pump therapy was associated with female gender, younger age, living in least deprived areas and White Ethnicity.
- Increased usage of CGM with alarms was associated with younger age, living in least deprived areas and White Ethnicity.
- The gap between pump usage amongst children and young people with Type 1 diabetes living in the most and least deprived areas has widened with time, from 18.4% versus 26.3% (a difference of 7.9 percentage points) in 2014/15, to 29.0% versus 41.1%, in 2017/18, respectively (a difference of 12 percentage points).
- Children and young people with Type 1 diabetes using CGM with alarms were more likely to be using insulin pump therapy than insulin injections.
- Pump and CGM usage amongst children and young people with Type 1 diabetes was associated with better HbA1c outcomes. A causal relationship cannot be inferred given that lower HbA1c is associated with younger age and living in the least deprived areas and there is higher representation of children and young people with these characteristics within the cohorts of pump and CGM users.
- Most children and young people with Type 2 diabetes manage their diabetes with diet alone, or in combination with insulin.
- Treatment regimen data were either missing or reported as 'unknown' for almost one-quarter (22.4%) of children and young people with Type 2 diabetes.

## 7.4 Recommendations

### **Multidisciplinary paediatric diabetes teams should:**

- Improve the completeness of the recording and submission of treatment regimen and CGM usage data for children and young people with both Type 1 and Type 2 diabetes.
- Be aware of deprivation gradients associated with choice of insulin regimen and CGM usage.

### **Regions and commissioners should:**

- Ensure that PDUs have appropriate IT facilities to record treatment regimens in children and young people with diabetes.
- Allow the usage of treatment regimens tailored to suit the individual needs of the patient to provide the best possible diabetes control in line with local prescribing policy and in keeping with NICE (2015) guidance, and acknowledge and address barriers to doing so.

## 8. Thyroid and coeliac disease

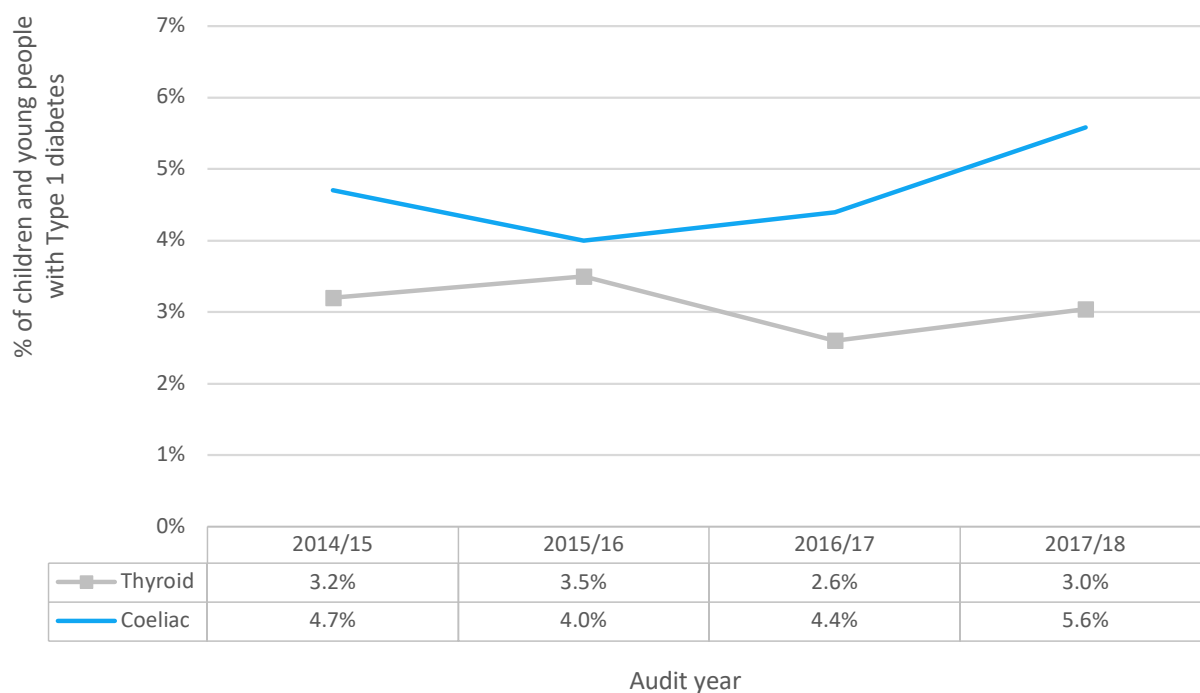
### 8.1 Thyroid and coeliac disease amongst children and young people with Type 1 diabetes

Table 37 shows that of the 27,739 children and young people with Type 1 diabetes included in the audit, 3.0% were recorded as receiving treatment for thyroid disease, and 5.6% had been recommended a gluten-free diet (taken to be indicative of coeliac disease). The figure for coeliac disease is higher compared to 2016/17 (4.4%); this is possibly due to amendments made to the dataset in 2017/18 affecting data quality, and it is higher compared to an international collaborative study that found a prevalence rate of 3.5% across three continents (Craig et al., 2017). Therefore, caution is advised when interpreting coeliac disease findings for this audit year.

**Table 37:** Percentage of children and young people with Type 1 diabetes with thyroid or coeliac disease by country and region in England and Wales, 2017/18

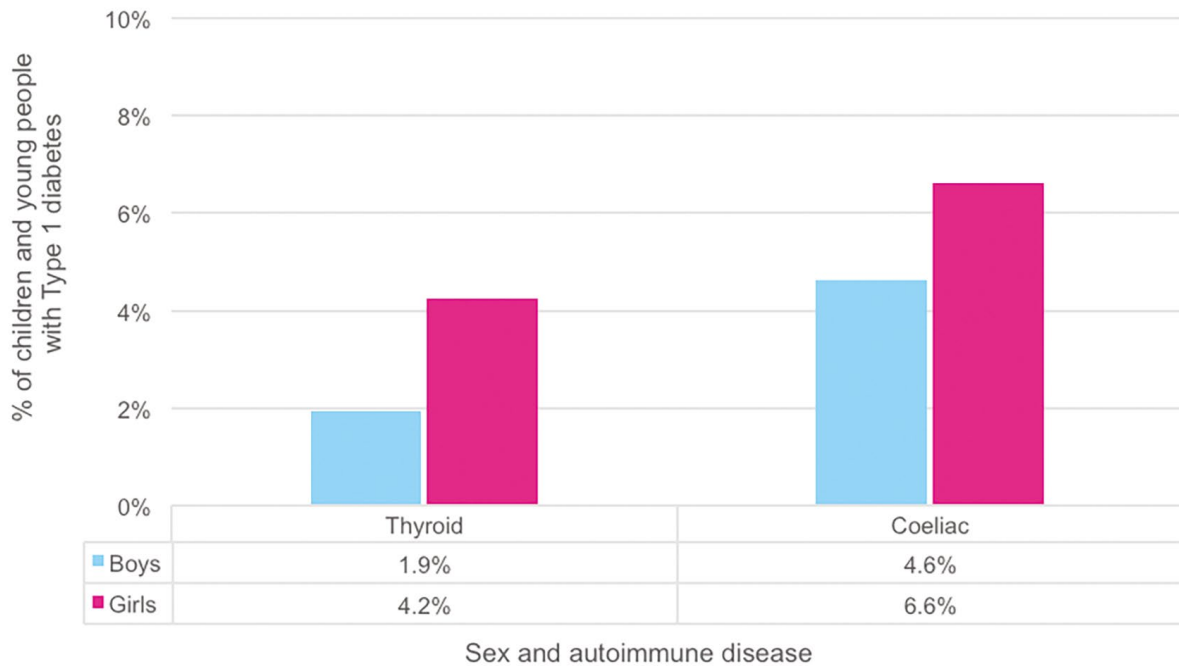
	No. of children and young people with Type 1 diabetes	Thyroid disease† (%)	Coeliac disease (%)
England and Wales	28,300	3.0	5.6
England	26,853	3.0	5.5
Wales	1,447	3.4	6.3
East of England	3,150	3.7	5.0
East Midlands	1,946	3.2	6.0
London and South East	6,456	2.8	5.3
North East and North Cumbria	1,592	3.5	5.8
North West	3,504	2.2	5.6
South Central	2,441	2.7	6.3
South West	2,211	4.2	4.5
West Midlands	2,869	2.5	5.7
Yorkshire and Humber	2,681	3.4	6.1

Figure 72 shows year on year variation in prevalence of thyroid and coeliac disease.



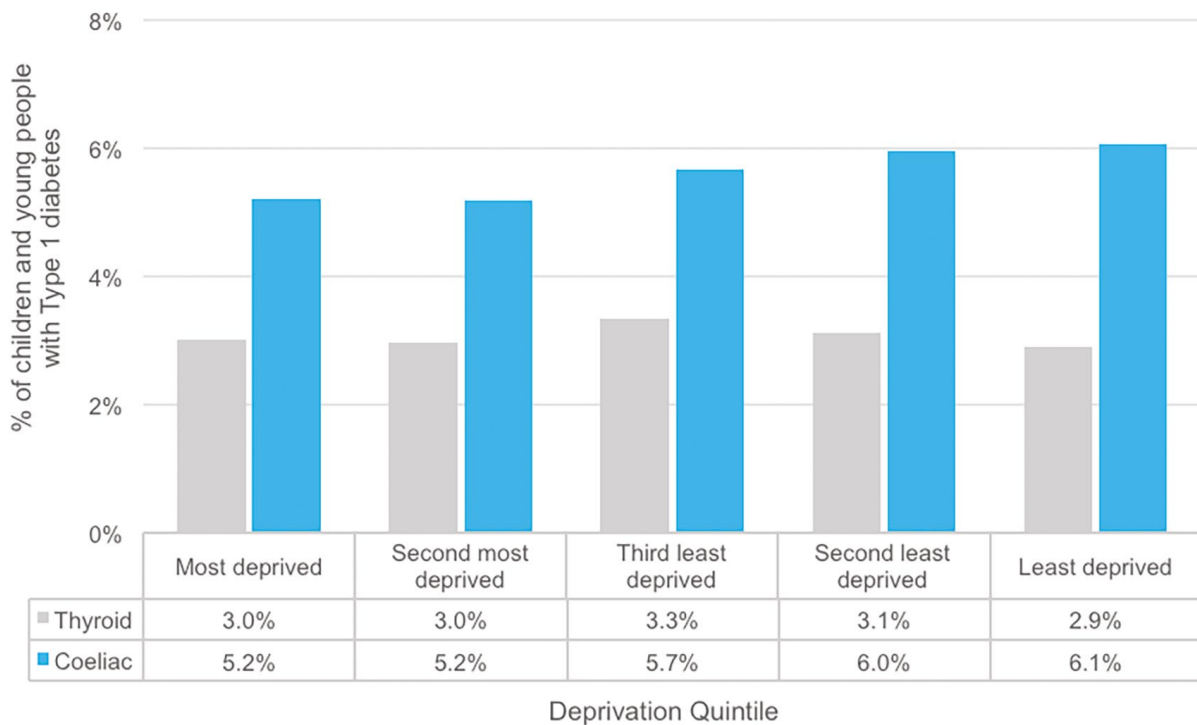
**Figure 72:** Percentage of children and young people with Type 1 diabetes with thyroid or coeliac disease in England and Wales, 2014/15 to 2017/18

Figure 73 shows that there was higher prevalence of both autoimmune conditions amongst girls compared to boys, despite there being a slightly higher prevalence of Type 1 diabetes amongst boys.



**Figure 73:** Percentage of children and young people with Type 1 diabetes and comorbid coeliac or thyroid disease by sex, 2016/17 to 2017/18

There was no clear association between prevalence of either autoimmune condition amongst children and young people with Type 1 diabetes and areas of deprivation (Figure 74).



**Figure 74:** Percentage of children and young people with Type 1 diabetes and comorbid coeliac or thyroid disease by deprivation quintile, 2016-17

## 8.2 Key findings

- 5.6% of children and young people in England and Wales with Type 1 diabetes coeliac disease, and 3.0% were receiving treatment for thyroid disease.
- Prevalence of both co-morbid autoimmune disorders was higher amongst girls compared to boys.

## 8.3 Recommendations

- Health care professionals should be aware of the higher rates of treatable co-morbid autoimmune diseases amongst children and young people with Type 1 diabetes and screen for them according to NICE guidelines.

## 9. Conclusion

This 2017/18 NPDA report shows a welcome increase in the provision of most key health checks recommended for children and young people with diabetes since the previous audit year, but also that national average HbA1c results have not improved for the first time in six years. However, PDUs and the National Children and Young People's Diabetes Network have shown commitment to working together to improve the care and outcomes of children and young people with diabetes and to reducing the variation in both described within the report, using the national network structures and the National Children and Young People's Diabetes Quality Programme to support lasting and meaningful improvement.

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### HQIP Support

- Ms Sophia Olatunde, Project Manager, NCAPOP, Healthcare Quality Improvement Partnership
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# National paediatric Diabetes Audit (NPDA)

Annual report 2017-18

Care processes and outcomes

Published by RCPCH May 2019



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