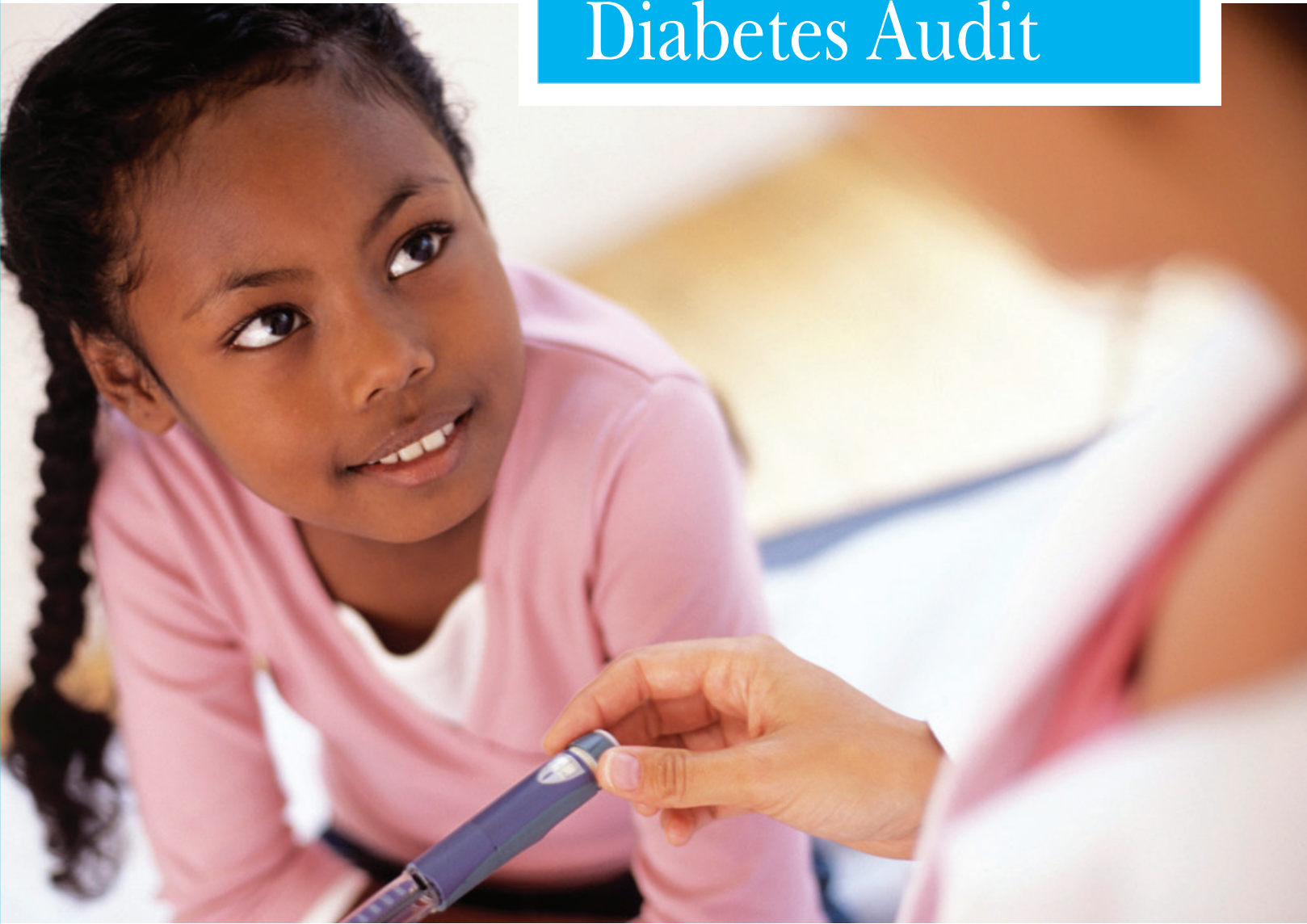


# NPDA

National Paediatric  
Diabetes Audit



National Paediatric Diabetes Audit Report 2016-17  
Care processes and outcomes



**HQIP**

Healthcare Quality  
Improvement Partnership

**RCPCH**

Royal College of  
Paediatrics and Child Health

*Leading the way in Children's Health*

# **National Paediatric Diabetes**

## **Audit 2016-17**

### **Care Processes and Outcomes**

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



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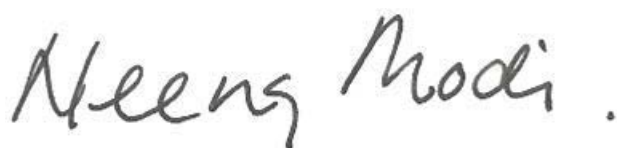
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# Foreword

I am pleased to introduce the 14th Annual Report of the National Paediatric Diabetes Audit, the seventh to be published by the Royal College of Paediatrics and Child Health. The report provides an analysis of data submitted by healthcare professionals caring for infants, children and young people with diabetes in England and Wales over 2016/17. It includes details of the prevalence of diabetes, compliance with health care checks and clinical outcomes recommended by the National Institute for Health and Care Excellence, and recommendations for improvements in care for the growing number of children with Type 1 or 2 diabetes.

It is gratifying to see continuing national improvement in overall diabetes management, and details of new national initiatives which should catalyse further progress. However, the audit continues to show variation, with inequalities in treatment widening between children and young people at both ends of the deprivation scale, and poorer outcomes associated with non-white ethnicity, adolescence, female sex and living in a deprived area. It is also apparent from the audit that the growing numbers of young people with Type 2 diabetes receiving care in paediatric diabetes units are at higher risk of poorer care and disease related complications than those with Type 1 diabetes.

I commend all staff working in paediatric diabetes units, managers, networks and commissioners to engage with and support the National Children and Young People's Diabetes Quality Programme being established by the RCPCH to catalyse improvements in care across England and Wales.

A handwritten signature in black ink that reads "Neena Modi .". The signature is written in a cursive, flowing style.

Professor Neena Modi

President, 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. Over time 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 14<sup>th</sup> annual report of the audit.

## 1.2 Audit aims

The audit's aims are to:

- Monitor the incidence and prevalence of all types of diabetes amongst children and young people receiving care from a PDU in England and Wales.
- Establish which key care processes 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 and national level
- Determine the prevalence and incidence of diabetes-related complications amongst children and young people with diabetes.

## 1.3 Audit scope

The 2016/17 NPDA included all 173 PDUs in England and Wales, and captured information on 29,153 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 (care processes) and outcome measures of performance.

## 1.5 Quality standards used

The health checks (care processes) 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](#)).

## **1.6 Comparison between regions, PDUs and patients**

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. 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 taking these factors into account.

## **1.7 Report structure**

This is the second year that the audit has reported the health check completion 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 first time, a section on admissions has been added to the Outcomes of Care chapter.

## 1.8 Overall National HbA1c results



- There have been reductions of 0.9 and 0.5 mmol/mol respectively in the national mean and median HbA1c for all children and young people being treated within a PDU in England and Wales since 2015/16. The national mean in 2016/17 was 66.9 and the median was 64.0 mmol/mol.
- There has been a 9 mmol/mol reduction in median HbA1c in England and Wales for all children and young people with diabetes over the last 7 years from 73 mmol/mol in 2009/10 to 64.0 mmol/mol in 2016/17.

## 1.9 Key findings: Type 1 diabetes



### Incidence, prevalence, and patient characteristics

- There were more male than female children and young people with Type 1 diabetes included within the audit.
- Prevalence rates of Type 1 diabetes have remained stable since 2013/14, however there have been consistent increases in prevalence amongst children aged 5-9 since 2012/13.
- There were 2807 children and young people aged 0 - 15 years old newly diagnosed with Type 1 diabetes in 2016/17, giving an incidence of 25.4 per 100,000 general population.
- Incidence was similar amongst males (25.9 per 100,000) compared to females (24.4 per 100,000).
- Seasonal variation in rates of diagnosis of Type 1 diabetes was found, with higher rates in January compared to rates in the summer months.



### Treatment regimen

- Usage of insulin pumps to deliver insulin therapy in Type 1 diabetes has increased in all age groups since 2014/15, although the gap between usage amongst those living in the least and most deprived areas has widened.
- Younger children with Type 1 diabetes, females, those living in the least deprived areas and White ethnicity compared to Black and ethnic minority groups were more likely to be using pump therapy.



### Completion of health checks

- The proportion of children and young people, aged 12 and above, with Type 1 diabetes completing a year of care receiving all seven key healthcare checks has increased from 35.5% in 2015/16 to 43.5% in 2016/17.
- There was wide variation in the percentage of children and young people with Type 1 diabetes within each PDU receiving all seven essential healthcare checks, ranging from 0% to nearly 100%.
- Just over half (52.9%) of children and young people with Type 1 diabetes completing a full year of care over the audit period had four or more HbA1c measurements recorded.
- Three quarters of children and young people newly diagnosed with Type 1 diabetes had been screened for coeliac and thyroid disease.
- Almost three-quarters (74.1%) of children and young people with Type 1 diabetes received a psychological assessment.





## Blood glucose diabetes control targets (HbA1c)

- The national unadjusted mean HbA1c for children and young people with Type 1 diabetes was 67.3 mmol/mol, and the median was 64.0 mmol/mol. Both represent a decrease of 1 mmol/mol compared to 2015/16.
- There has been an increase in the percentage of children and young people with Type 1 diabetes achieving good HbA1c levels (<58 mmol/mol) over the last year from 26.6% in 2015/16 to 28.9% in 2016/17. Over the last 7 years the percentage achieving an HbA1c <58 mmol/mol has almost doubled from 15.8% in 2010/11.
- There has been a reduction in the percentage of children and young people with Type 1 diabetes with poor HbA1c (>80mmol/mol) from 17.9% in 2015/16 to 16.4% in 2016/17. Over the last 7 years the percentage achieving an HbA1c >80 mmol/mol has almost halved from 28.7% in 2010/11.
- Older children and young people with Type 1 diabetes had poorer HbA1c levels compared to younger children.
- Considerable variability in HbA1c target outcomes persists between PDUs even after case-mix adjustment.



## Microvascular complications

- Consistent with results of the 2015/16 audit, Albuminuria was found in 9.7% of young people aged 12 years and above with Type 1 diabetes who were screened in the audit year.
- The prevalence of albuminuria in Type 1 diabetes was higher amongst those living in the most deprived areas.
- Retinopathy was found in 13.6% of young people aged 12 and above with Type 1 diabetes who received screening in the audit year.
- The risk of retinopathy increased with age and was highest amongst adolescent females. There was little or no variation in the prevalence of abnormal eye screening results by deprivation quintile.



## Macrovascular complications and risk factors

- High blood pressure (hypertension) was found in 25.8% of young people aged 12 years and older with Type 1 diabetes screened in the audit year.
- 23.0% 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 or less.
- 16.8% of children aged 0 to 11 years with Type 1 diabetes were overweight, and 16.7% were obese. These figures rose to 18.1% and 21.3%, respectively, for young people aged 12 years and above.
- 78.6% of children and young people with Type 2 diabetes were obese.
- 3.2% of young people with Type 1 diabetes aged 12 and above with a recorded smoking status were current smokers.



## Outcomes of psychological assessment

- 34.0% of children and young people with Type 1 diabetes required referral and were seen by expert CAMHS/psychology services in 2016/17 for emotional wellbeing support.



### Hospital admissions

- Not all PDUs participating in the NPDA submitted admissions data
- Incidence of diabetes-related admissions was lower than reported in the NPDA Admissions Report (NPDA, 2017) which combined PDU-submitted data with data from the HES and PEDW databases.
- 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 before PDU submitted admission data can be considered representative of admission trends in England and Wales.



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

- 4.4% of children and young people in England and Wales with Type 1 diabetes were following a gluten free diet indicative of coeliac disease, and 2.6% were receiving treatment for thyroid disease.
- Prevalence of both co-morbid autoimmune disorders was higher amongst females compared to males.



### Structured patient education

- Just over two thirds (72%) of children and young people with Type 1 diabetes were recorded as receiving structured patient education in 2016/17, similarly to the previous audit year.
- There was considerable variation in the percentages recorded as receiving structured patient education between regions and between England and Wales, with twice as many children and young people in England receiving it in England compared to Wales.



## 1.10 Key findings: Type 2 diabetes



### Incidence, prevalence, and patient characteristics

- 715 children and young people under the age of 25 with Type 2 diabetes in England and Wales were reported to the audit of whom 172 were diagnosed in the audit year, an increase of 77 from 2015/16.
- There were proportionally more females, those of non-White ethnicity, and those living in the most deprived areas amongst the cohort with Type 2 diabetes.



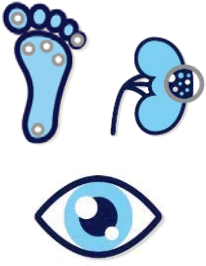
### Completion of health checks

- Completion rates for health checks were lower for children and young people with Type 2 diabetes compared to those with Type 1.
- The proportion of children and young people with Type 2 diabetes receiving all seven key health checks was 21.3%.



### 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 2016/17 were 60.2 and 52.0 mmol/mol, respectively.
- There were differences in HbA1c target outcomes associated with deprivation and ethnicity. In general, for both type of diabetes children and young people had poorer outcomes if they lived in a deprived area or were of non-white ethnicity.



### Microvascular complications

- Albuminuria was found in 20.1% of children and young people with Type 2 diabetes who were screened in the audit year, just over double the percentage found in young people with Type 1 diabetes.
- Abnormal eye screening results were found in 5.4% of young people with Type 2 diabetes screened within the audit period, compared to 13.8 % of children and young people with Type 1.



### Macrovascular complications and risk factors

- Hypertension was found in 45.6% of children and young people with Type 2 diabetes, a markedly higher prevalence compared to those with Type 1 diabetes.
- 78.6% of children and young people with Type 2 diabetes were obese.
- 4.5% of young people with Type 2 diabetes aged 12 and above with a recorded smoking status were current smokers.



### Outcomes of psychological assessment

- Over a third (37.4%) of those with Type 2 diabetes required referral and were seen by expert CAMHS/psychology services in 2016/17 for emotional wellbeing support.



### Structured patient education

- Only half (49.4%) of those with Type 2 diabetes were recorded as receiving structured patient education, a reduction of 8.4% since 2015/16.

## 1.11 Summary of recommendations



### Prevalence and incidence

- **Healthcare professionals** caring for children with diabetes and **commissioners of paediatric diabetes services** need to be aware of the gender, ethnic and deprivation differences between Type 1 and Type 2 diabetes.
- **Commissioners** of paediatric diabetes services need to be aware of their local casemix in terms of ethnicity and deprivation and fund care according to healthcare needs.
- **PDU**s should ensure the collection and submission of accurate ethnicity data. The 'not stated' category appears to be over represented in the dataset. This category set out in the Health and Social Care Dataset Change Notice (DSCN) (2008) refers to cases where the patient has been asked, and has either declined or has a genuine inability to choose an ethnic category. It should not be used to define unknown ethnicity status.
- **Healthcare professionals and commissioners** need to be aware of the seasonal variation in presentation of Type 1 diabetes which will cause particular stresses in the winter months, including additional school support.



### Completion of health checks

#### Multidisciplinary paediatric diabetes teams should:

- Ensure children and young people with diabetes are receiving the key essential healthcare 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 healthcare 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 takes place at diagnosis of Type 1 diabetes.
- Caution young people with diabetes against smoking as they have a higher risk of cardiovascular disease. These discussions should be included in their on-going 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.



### Structured education

#### Multidisciplinary paediatric diabetes teams should:

- Ensure that all children and young people with diabetes are provided with an ongoing programme of structured education from diagnosis, tailored to their individual needs.
- Evaluate their structured education programmes and review them regularly to ensure that they are meeting the needs of the children, young people and families they are targeted at.

#### **Commissioners should:**

- Ensure that service providers are delivering suitable structured ongoing education programmes to all stakeholders involved in the care of children and young people with diabetes including parents and other family members, and schools and education providers.

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

- Utilise regional and national structured patient education resources, many of which are already available as part of the National Network's sharing strategy (<http://www.cypdiabetesnetwork.nhs.uk/>) including Goals of Diabetes Education, or SEREN in Wales. Such initiatives should be put into action to avoid wide variability in treatment target outcomes and ensure every child and young person with diabetes and their family receives optimal self-management education that is age and maturity appropriate, delivered by trained educators and provided in a family centred way (Waldron & Campbell, 2014). Programmes should be designed by experienced diabetes educators (Campbell & Waldron, 2013).

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



#### **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.
- Pay particular attention to the care needs of the vulnerable subgroup with persistently high HbA1c levels. Appropriate engagement, education, technology and psychosocial support for this subgroup is paramount so that they are not lost to follow up and are helped as individuals to improve their diabetes management.
- Provide each child with an individualised care plan to achieve the best possible level of HbA1c given the many reasons for the gradual increase of HbA1c with duration of diabetes.
- Be aware of the socioeconomic and patient demographic factors associated with poorer diabetes management, and adapt communications and structured education provision to be able to meet the different needs of vulnerable subgroups.

#### **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 subgroup with an HbA1c >80 mmol/mol.



## Diabetes complications and risk factors



### Multidisciplinary paediatric diabetes teams should:

- Prioritise improving diabetes management 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.
- Submit a complete dataset including admissions data to enable benchmarking and associated QI activity around admission avoidance.

### Commissioners should:

- 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.

Please refer to the NPDA Hospital Admissions Report (RCPCH, 2017) for recommendations for avoidance of diabetes-related admissions.



## Psychological outcomes

### 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 by an expert psychologist and/or CAMHS when necessary.

### 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.



## Treatment regimen

### Multidisciplinary paediatric diabetes teams should:

- Improve the completeness of the recording and submission of treatment regimen 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.

### Regions/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.

## 1.12 Conclusion

The results of this 2016/17 audit provide justification both for celebration and for continuing focus on improving the diabetes care of children and young people with diabetes in England and Wales.

The key successes identified include the continuing downward trend in National HbA1c, and increases in the percentages of children and young people with Type 1 and Type 2 diabetes receiving recommended health checks. However, the audit continues to identify variation in care and outcomes at unit, regional, and national level. Poorer outcomes continue to be associated with non-white ethnicity, adolescence, female gender, and living in a deprived area. Inequalities in treatment deprivation observed previously were also shown to be widening, with children and young people in the least deprived areas being even more likely to be using an insulin pump compared to those in the most deprived areas than in previous audit cycles. Patient and PDU factors responsible for the inequalities identified by the audit must be explored and addressed as part of local and national improvement strategies to improve diabetes management and outcomes.

## 2. Case studies

### 2.1 Teamwork in focus: Applying the learning from improved national HbA1c results in Sweden within England and Wales

In 2012, Hanberger, Samuelsson, Berterö and Ludvigsson published the results of an analysis of team questionnaire data collected from all paediatric diabetes units (PDUs) in Sweden, which compared the responses given by the five PDUs with the best HbA1c outcomes with those from the five least well performing PDUs. Factors associated with better HbA1c outcomes included:

- Clear, consistent messages to children and young people with diabetes and their parents/carers regarding diet, HbA1c target, physical activity, treatment of hypoglycaemia and the importance of structure in everyday life
- Devoted team members
- A positive attitude within the team
- An explicit, lower HbA1c target value
- Perception of a well-functioning team

By contrast, factors associated with higher HbA1c results included:

- Giving vague or inconsistent messages to children and young people with diabetes and their parents/carers
- Lack of staff resources
- Lack of cooperation within the team
- Lack of treatment guidelines

The results of this study fed into an 18-month quality improvement programme: a quality improvement collaborative (QIC) for paediatric diabetes teams (Swediabkids IQ; Peterson, Hanberger, Åkesson, Bojestig, Andersson Gäre & Samuelsson, 2014) involving 12 PDUs caring for 30% of children and young people with diabetes in Sweden. Each team identified treatment targets, areas needing improvement, and action plans, with the main outcome of focus being the PDUs' mean HbA1c level. Analysis showed that PDUs participating in the programme reduced their mean HbA1c value by 3.7 mmol/mol, over double the improvement achieved by non-participating centres over the same period (1.7mmol/mol). Two further rounds of the collaborative were then completed. In the 36 months between the start of the first collaborative and end of the second, the national mean HbA1c decreased by 4.9 mmol/mol to 57.7mmol/mol, with QIC participation associated with significantly decreased mean HbA1c compared to non-participation, and evidence of a spillover effect into non-participating units (Åkesson, Peterson, Hanas & Hanberger, 2016). Change factors identified were improved guidelines, appointment planning, improving patient information, improving teamwork, active use of audit data, and health promotion activities. By 2016, after three rounds of the collaborative including PDUs caring for ~ 90% of all children and young people with diabetes, the national mean was reduced to 56.9 mmol/mol (Swediabkids, 2017).

Representatives from the NPDA, the National Children and Young People's network and RCPCH visited the team behind the Swediabkids IQ in February 2017 to gain a better understanding of the principles and methodology behind the work and to consider whether they could apply in England and Wales.

Inspired and encouraged by the Swedish team's approach and results, the RCPCH is piloting and developing a model for a comprehensive quality improvement programme which, if funded beyond the pilot, will enable every PDU in England and Wales to participate in training and ongoing support, using



proven Quality Improvement methodology, to make tangible improvements in their outcomes for children with diabetes.

This approach, modelled on the Swedish project, aims to:

- Engage with 10-12 PDUs (up to 100 individual participants) in a coordinated, comprehensive 9-month QI training programme
- Equip programme participants with skills needed to design and implement change projects in their units and to sustain them over time
- Develop a collaborative of PDUs working together throughout the project duration to share learning and outcomes and support each other's development
- Develop an online platform for sharing materials and outputs between the units and the RCPCH team
- Evaluate the impact the pilot had on participating teams and establish whether it could be replicated as part of an ongoing programme of work

Whilst applying Quality Improvement methodology, the programme will put special emphasis on training in team development, individual and group leadership and influencing strategies, in recognition of the fact that lasting success depends not on individuals driving a project, but high performing teams supported by management. The programme will include four training and sharing events attended by the entire multidisciplinary team from each participating unit.

The pilot collaborative launched in November 2017 and will complete in July 2018.

## 2.2 Improving health check completion rates

Nearly all patients over the age of 12 with Type 1 diabetes received all seven key care processes at West Middlesex Hospital in 2016/7 and 2015/16, a dramatic improvement compared to the percentage recorded in 2014/15.

We attribute this improvement to the following factors:

1. We obtained more resources with the help of our CCG GP representative Dr Raquel Delgado. This included one full time admin support, another full-time paediatric diabetes nurse specialist, one extra consultant, and increased dietetic and psychology sessions
2. The full-time admin support was the main person who put in all the data into our Twinkle database, which the rest of the team also had training to use
3. Working together as a team from the same office helped in communicating our vision and goal
4. Flexibility of conducting extra clinics opportunistically to accommodate the patients at risk of not completing the care process before the deadline
5. As a group, we review 3 monthly where we are in completing the care processes and this has helped us in focussing our resources

**Dr Jayanti Rangasami**  
Paediatric Consultant  
West Middlesex University Hospital

## 2.3 Improving admission data quality

As a team, we make sure that whoever is the first to hear of an admission emails the entire team. Included on the distribution list is our data manager (he helps pull data for BPT and NPDA). I file these emails in my own separate email folder.

Our data manager pulls admission information from the Twinkle database quarterly. He cross-checks with the coding department for any admissions which have not been brought to our attention, such as those with unrelated illness or emergency surgery, with diabetes as a comorbidity. This list is then sent to me.

The data is never complete the first time as I always identify gaps. We usually go back and forth several times for repeated extractions to build up the full picture. I present the information as an entire dataset to the best of my knowledge, but the process is certainly not seamless, and very time consuming. One of my challenges is to try and raise awareness of how important the issue is, and the implications of the data, to encourage appropriate information sharing. Children's Emergency Department attendances are often missed because they do not count as 'admissions' but capturing these in their entirety could shed light on preventative measures, and safety netting.

I have been looking at lengths of DKA admissions in newly diagnosed patients, and overall length of stays and how an increase in our nursing hours to deliver initial essential education has impacted on bed occupancy. As a Trust we are under pressure to keep length of stay to a minimum, and targets such as carbohydrate counting from diagnosis can delay discharge.

Dissecting accurate admissions data can be a useful way to detect patterns and themes that need addressing. The data can help us see where we need more resource, and when.

**Dr. Dita Aswani**  
Consultant Paediatrician  
Lead for Paediatric Diabetes  
Derbyshire Children's Hospital

## 3. Introduction

The NPDA is delivered by the Royal College of Paediatrics and Child Health (RCPCH) and has been reporting for 14 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 2016/17 audit, capturing information on 29,153 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.

For the seventh year there have been continued improvements in overall blood glucose levels reflected in a reduction in HbA1c. HbA1c is highly associated with risk of acute and chronic complications of the disease. Although it may be early to draw firm conclusions, for the first time, this year, in England and Wales the NPDA is beginning to demonstrate reductions in the prevalence of risk factors associated with the development of macrovascular disease in children and young people with Type 1 diabetes which in the long term will be reflected in a reduction in disease burden on patients, families and the NHS.

### 3.1 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.

## 3.2 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).

## 3.3 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 survey closed in April 2016, and new PREMS are being piloted in selected units in 2018 before wider roll out.
- 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).

## 3.4 Scope of the 2016/17 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 2016/17 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 2016 through to 31st March 2017. 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.

### 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?

## 3.5 Data completeness

Over the seven 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 variability 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 2016/17 audit is the second time that a comprehensive data completeness report was available upon upload of audit data, enabling detection of missing data. It was also the second 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 first time, this report includes analysis of admissions data submitted by PDUs. This has 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 15 of the 173 PDUs submitted admissions data in 2016/17. 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, and to enable comparison with admission trends identified previously using a combined NPDA, HES and PEDW dataset. The NPDA will work with PDUs over the next audit cycle to identify and resolve barriers to the submission of complete and good quality admissions data.

## 4. Patient characteristics, prevalence and incidence

### 4.1 Audit cohort

A total of 29,153 children and young people with diabetes were included in the 2016/17 audit, an increase of 714 since the 2015/16 audit.

**Table 1: Number of children and young people with diabetes included in the audit by age and type of diabetes, 2016/17**

	0 - 4 years	5 - 9 years	10 - 14 years	15 - 19+ years	20 - 24+ years	Total (% of cohort)
Type 1 Insulin-dependent diabetes mellitus	1670	6165	10984	8901	19	27739 (95.1)
Type 2 Non-insulin-dependent diabetes mellitus	*	11	269	429	*	715 (2.5)
Cystic fibrosis-related diabetes	21**		91	67	0	179 (0.6)
Monogenic types of diabetes	22	35	48	56	0	161 (0.6)
Other specified diabetes mellitus	22	29	60	61**		172 (0.6)
Not specified diabetes mellitus	16	33	58	62	0	169 (0.6)
Missing type of diabetes	*	*	*	13	0	18 (0.1)

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

\*\*Column has been combined to mask a number < 5 that could be identifiable from the total.

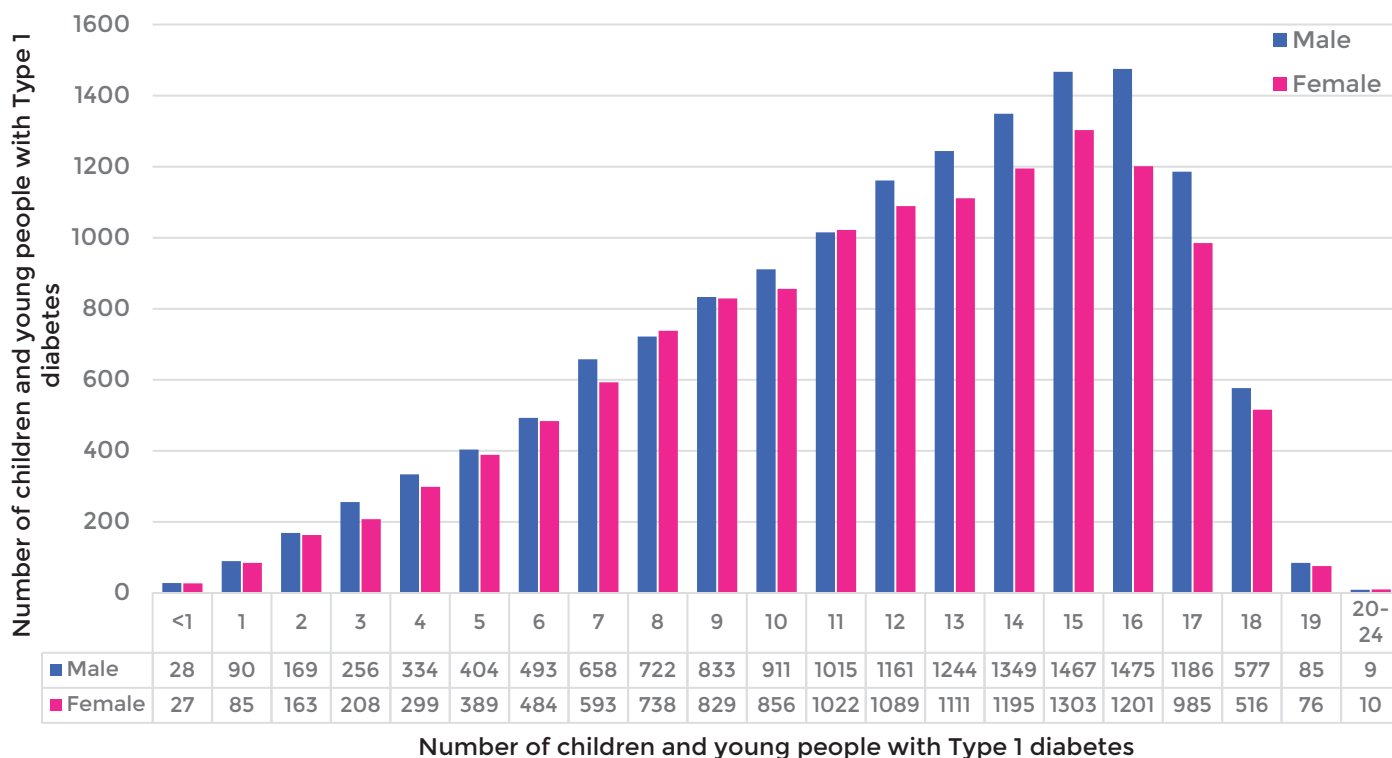
+ The NPDA recognises that transition to adult diabetes services usually starts in a patient's late teenage years. The numbers presented in these columns represents the number still receiving care from a PDU and may not necessarily represent the total number of young people with diabetes in these age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

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

### 4.2.1 Age and gender

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, 2016-17



## 4.2.2 Location

Table 2 shows the distribution of children and young people with Type 1 diabetes by country, regional network and age category.

**Table 2: Number of children and young people included in the audit with Type 1 diabetes by country, region and age, 2016/17 (based on PDU location)**

	0-4 years	5-9 years	10-14 years	15-19 years	20-24 years	Total aged <20 (% of total <20)
England and Wales	1670	6165	10984	8901	19	27720 (100%)
England	1590	5843	10399	8439	19	26271 (94.8%)
Wales	80	322	585	462	0	1449 (5.2%)
East of England	186	713	1190	1001	*	3090 (11.1%)
East Midlands	111	422	829	496	0	1858 (6.7%)
London and South East	408	1450	2438	1984	*	6280 (22.7%)
North East and North Cumbria	93	318	625	513	*	1549 (5.6%)
North West	205	781	1327	1145	0	3458 (12.5)
South Central	158	511	975	764	0	2408 (8.7%)
South West	126	458	867	688	6	2139 (7.7%)
West Midlands	149	610	1086	972	*	2817 (10.2%)
Yorkshire and the Humber	154	580	1062	876	*	2672 (9.6%)

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



## 4.2.3 Ethnicity

Prevalence of disease per ethnic group can be calculated using denominators from 2011 census data.

Table 3 shows the ethnicity of the children and young people with Type 1 diabetes. Since 11.8% of patients do not have a stated ethnicity recorded, percentages have also been calculated excluding this category to allow comparison of ethnic category percentages to the 2011 census data, which does not contain a 'not stated' category. There is no difference in the ethnicity of children with Type 1 diabetes compared to the background population.

**Table 3: Ethnic group of children and young people with Type 1 diabetes England and Wales, 2016/17**

Ethnic category	Number	Percentage of total sample	Percentage of total with stated ethnicity*	Percentage of population in 2011 England and Wales Census
White	20838	75.1%	85.6%	86.0%
Mixed	699	2.5%	2.9%	2.2%
Asian	1417	5.1%	5.8%	7.5%
Black	956	3.4%	3.9%	3.3%
Other	421	1.5%	1.7%	1.0%
Not stated	3262	11.8%	-	-
Unallocated ethnic group	146	0.5%	-	-

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

## 4.2.4 Deprivation

Table 4 shows the breakdown of children and young people with Type 1 diabetes by deprivation quintile, derived from patient postcode using multiple indices of deprivation data for England (IMD, 2016) and Wales (WIMD, 2015). There is similar prevalence across all quintiles.

**Table 4: Number of children and young people with Type 1 diabetes by deprivation quintile, 2016/17**

Deprivation quintile	Number	Percentage of total sample
Most deprived	6049	21.8%
2nd most deprived	5506	19.8%
3rd most deprived	5264	19.0%
2nd least deprived	5286	19.1%
Least deprived	5325	19.2%
Missing deprivation data	309	1.1%

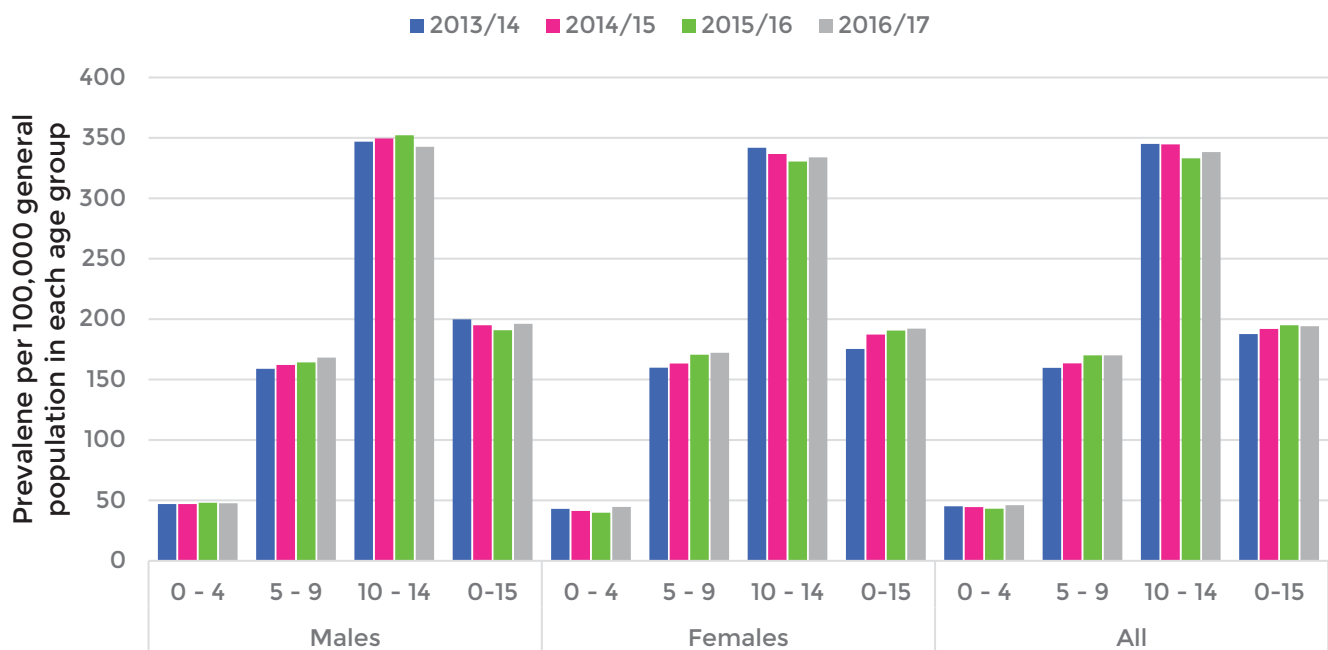
## 4.3 Prevalence and incidence of Type 1 diabetes

### 4.3.1 Prevalence

Prevalence is calculated for children and young people aged 15 and below since transition to adult services typically occurs from this age onwards. In 2016/17 the prevalence of Type 1 diabetes in children and young people aged 0 to 15 years old in England and Wales was 194.2 per 100,000 of the general population; slightly higher among males (196.1 per 100,000) compared to females (192.2 per 100,000).

Figure 2 shows the prevalence rates across the last four audit years.

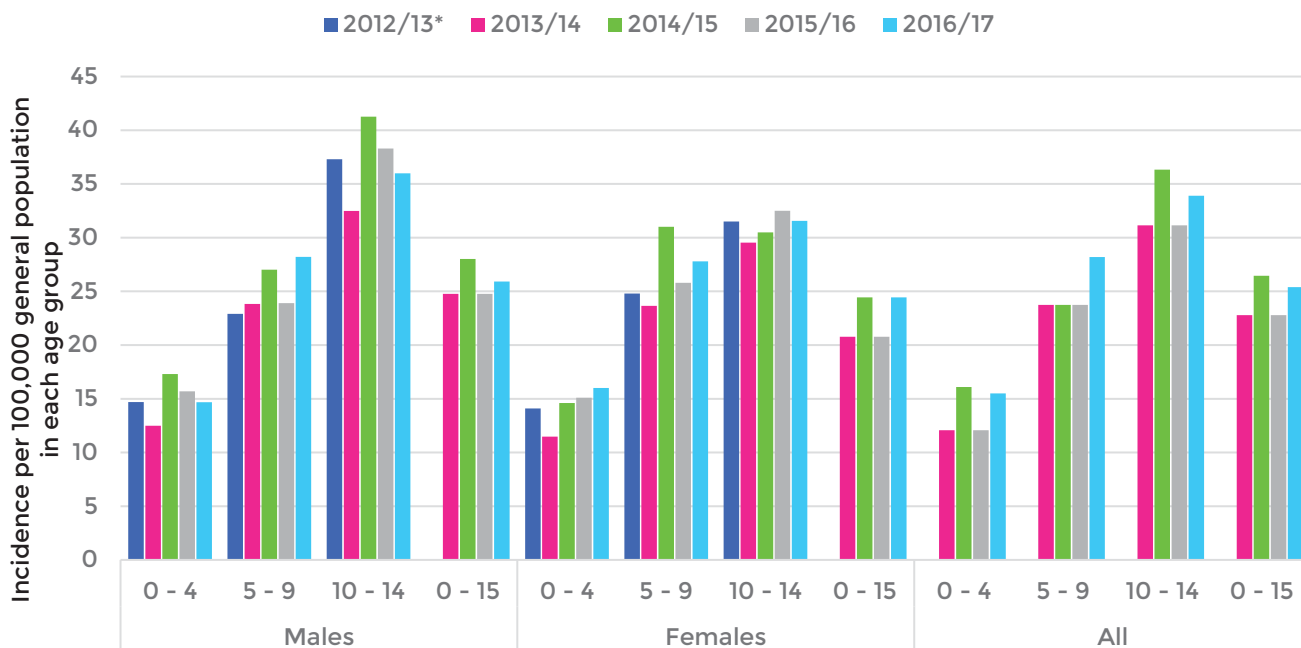
**Figure 2: Prevalence of Type 1 diabetes per 100,000 general population by age and gender in England and Wales, 2013/14 to 2016/17**



### 4.3.2 Incidence

In 2016/17 there were 2807 children and young people aged 0 to 15 years old newly diagnosed with Type 1 diabetes in England and Wales, giving an incidence of 25.4 per 100,000 general population within this age group. Figure 3 shows that overall, incidence rates have varied since 2012/13, with increasing incidence amongst males and females aged 5-9.

Figure 3: Incidence of Type 1 diabetes per 100,000 general population by age group and gender, 2012/13-2016/17



\* Overall incidence was not reported in the 2012/13 audit year

### 4.3.3 Month of diagnosis

Figure 4 shows the number and percentage, respectively, of children and young people of all ages diagnosed with Type 1 diabetes within each month, for those diagnosed within and prior to the 2016/17 audit year. The red line indicates the percentage that would be diagnosed each month if new cases were distributed equally throughout the year (8.3%).

Figure 4: Percentage of children and young people diagnosed in 2016/17 or within previous audit years by month of diagnosis

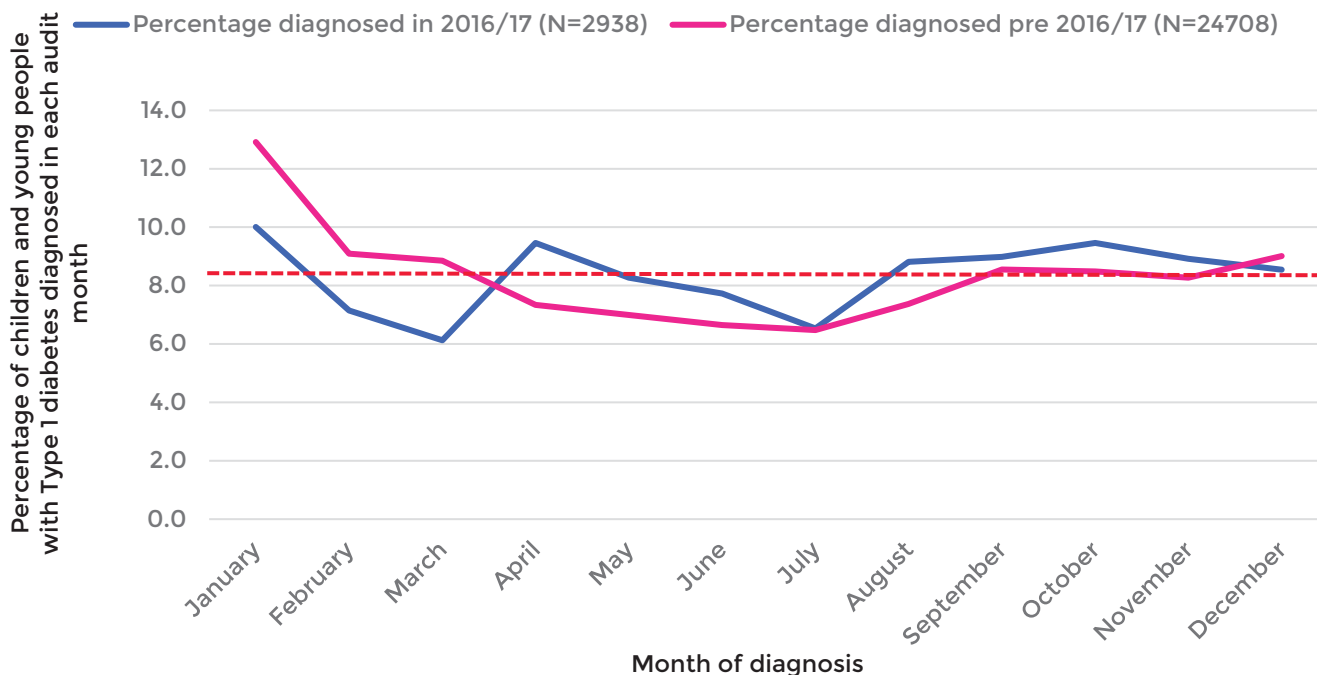
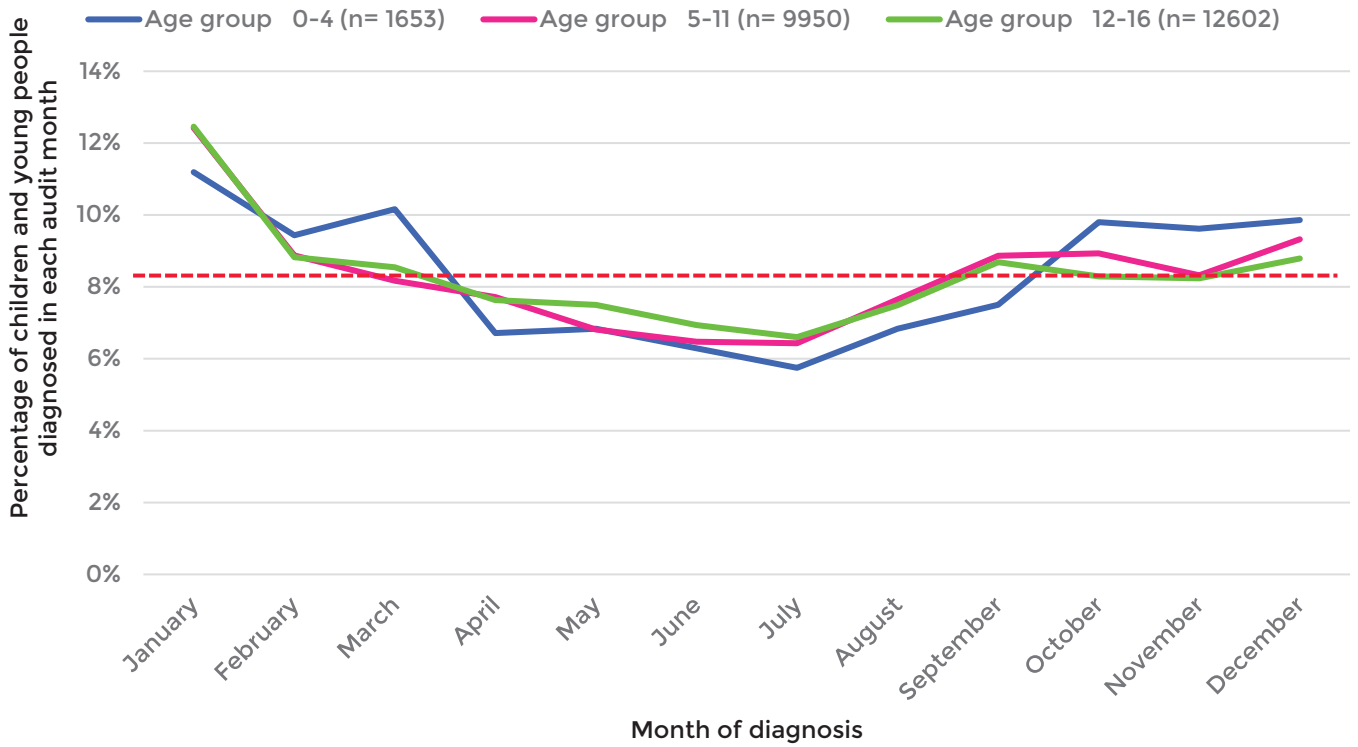


Figure 5 shows the number and percentages of all children and young people with Type 1 diabetes included in the 2016/17 audit diagnosed within each month by school age. The red line indicates the percentage that would be diagnosed each month if new cases were distributed equally throughout the year (8.3%).

**Figure 5: Percentage of children and young people with Type 1 diabetes included in the 2016/17 audit diagnosed within each month**



Figures 4 and 5 show a trend for increased rates of diagnosis of Type 1 diabetes in January and lower rates in the summer months.

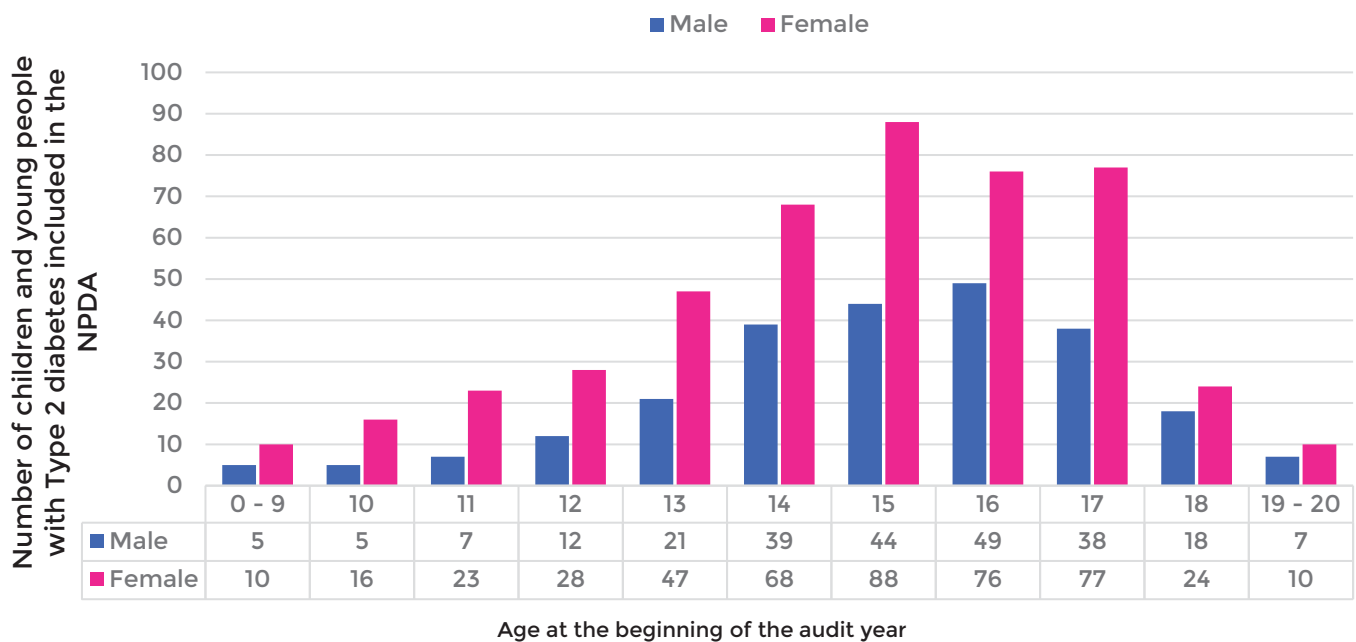
## 4.4 Characteristics of children and young people with Type 2 diabetes

In 2016/17, there were 715 children and young people under the age of 25 with Type 2 diabetes cared for in a paediatric centre in England and Wales reported to the audit, of whom 172 were newly diagnosed within the audit year. This is an increase of 77 from 2015/16. However, 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.

### 4.4.1 Age and gender

Figure 6 shows the numbers of children and young people with Type 2 diabetes being cared for by PDUs 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 6: Numbers of children and young people with Type 2 diabetes included in the NPDA by age and gender, 2016-17



## 4.4.2 Location

**Table 5: Number of children and young people included in the audit with Type 2 diabetes by country and region, 2016/17 (based on PDU location)**

	Total	% of total sample
England and Wales	715	100%
England	687	96.1%
Wales	28	3.9%
East of England	37	5.2%
East Midlands	38	5.3%
London and South East	234	32.7%
North East and North Cumbria	28	3.9%
North West	77	10.8%
South Central	41	5.7%
South West	43	6.0%
West Midlands	123	17.2%
Yorkshire and Humber	66	9.2%

### 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 by ethnic category. The results show that those of non-white ethnicity have a disproportionately higher prevalence of Type 2 diabetes.

**Table 6: Ethnic group of children and young people with Type 2 diabetes England and Wales, 2016/17**

	Number	Percentage of total sample	Percentage of total with stated ethnicity*	Percentage of population in 2011 England and Wales Census
White	246	34.4%	42.1%	86.0%
Asian	212	29.7%	36.3%	2.2%
Black	79	11.0%	13.5%	7.5%
Mixed	29	4.1%	5.0%	3.3%
Other	18	2.5%	3.1%	1.0%
Not stated	126	17.6%		
Unallocated ethnic group	5	0.7%		

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

### 4.4.4 Deprivation

Table 7 shows there is 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, 2016/17**

Deprivation quintile	Number	Percentage of total sample
Most deprived	336	47.0%
2nd most deprived	166	23.2%
3rd most deprived	101	14.1%
2nd least deprived	63	8.8%
Least deprived	38	5.3%
Missing deprivation data	11	1.5%

## 4.5 Key findings

- A total of 29,153 children and young people with diabetes were included in the 2016/17 audit, an increase of 714 since the 2015/16 audit.
- There were more male than female children and young people with Type 1 diabetes included within the audit.
- Prevalence rates of Type 1 diabetes remained stable since 2013/14, however there have been consistent increases in prevalence amongst children aged 5-9 since 2012/13.
- There were 2807 children and young people aged 0 to 15 years old newly diagnosed with Type 1 diabetes in 2016/17, giving an incidence of 25.4 per 100,000 general population.
- Incidence was similar amongst males (25.9 per 100,000) compared to females (24.4 per 100,000).
- Seasonal variation in rates of diagnosis of Type 1 diabetes was found, with higher rates in January compared to rates in the summer months.
- 715 children and young people under the age of 25 with Type 2 diabetes in England and Wales were reported to the audit of whom 172 were diagnosed in the audit year, an increase of 77 from 2015/16
- There were proportionally more females, 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 the gender, ethnic and deprivation differences between Type 1 and Type 2 diabetes.
- Commissioners of paediatric diabetes services need to be aware of their local casemix in terms of ethnicity and deprivation and fund care according to healthcare needs.
- PDUs should ensure the collection and submission of accurate ethnicity data. The 'not stated' category appears to be over represented in the dataset. This category set out in the Health and Social Care Dataset Change Notice (DSCN) (2008) refers to cases where the patient has been asked, and has either declined or has a genuine inability to choose an ethnic category. It should not be used to define unknown ethnicity status.
- Healthcare professionals and commissioners need to be aware of the seasonal variation in presentation of Type 1 diabetes which will cause particular stresses in the winter months, including additional school support.



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

### 5.1 The key health checks for children and young people with Type 1 diabetes

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.

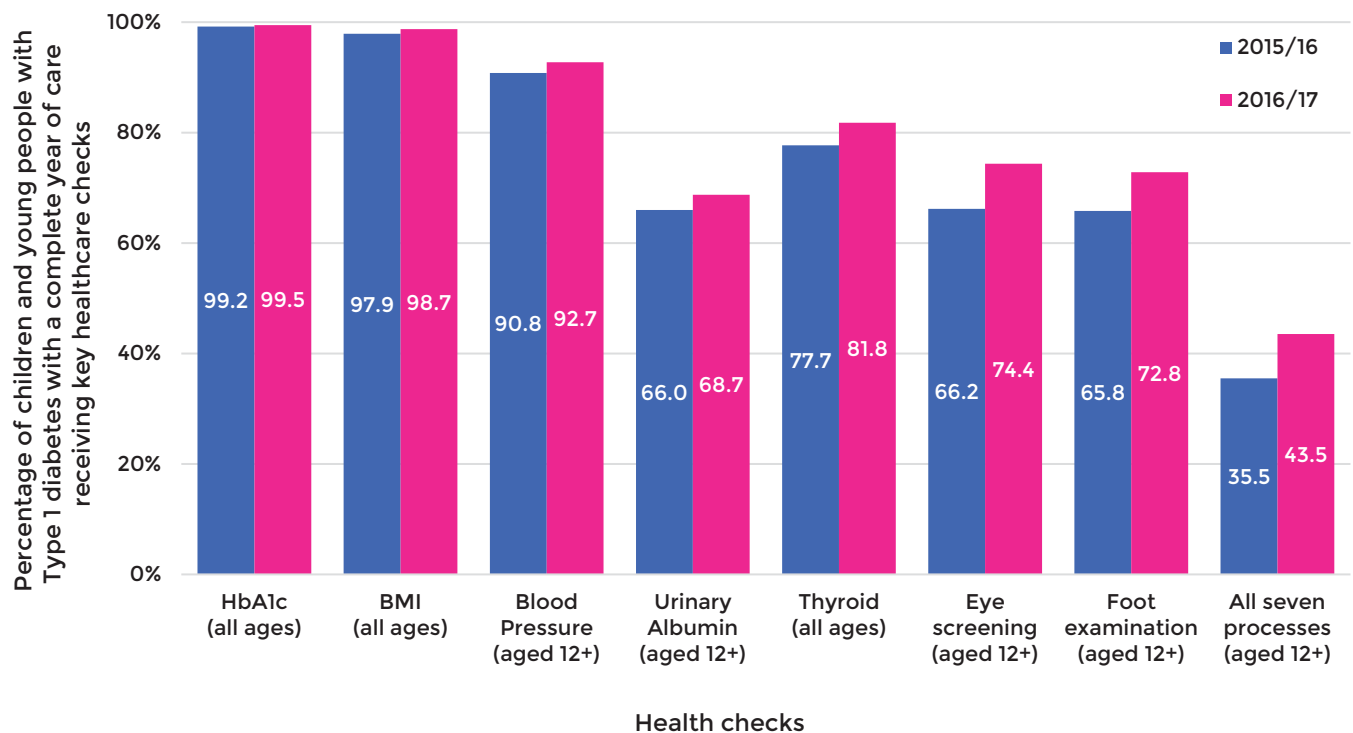
### 5.2 The healthcare checks for children and young people with Type 2 diabetes

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.

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

Figure 7. shows improvements in the completion rates for all seven individual essential health checks from 2015/16 to 2016/17, for children and young people with a complete year of care in the audit year (n= 22,933, all ages; n=13437 aged 12+). The overall completion rate of all seven has improved from 35.5% to 43.5%.

**Figure 7: Percentage of children and young people with Type 1 diabetes who completed a full year of care receiving key healthcare checks during the audit year, 2015/16-2016/17**



## 5.3.1 Variation in key care process completion

There was considerable variation in completion rates regionally and across PDUs. Table 8 provides 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 2016/17 by country, region and overall in England and Wales.

**Table 8: Percentage of children and young people with Type 1 recorded as receiving the seven healthcare checks in 2016/17, by country and region**

	HbA1c (all ages)	BMI (all ages)	Blood Pressure (aged 12+)	Urinary Albumin (aged 12+)	Thyroid (all ages)	Eye screening (aged 12+)	Foot examination (aged 12+)	All seven processes (aged 12+)
<b>England and Wales</b>	99.5%	98.7%	92.7%	68.7%	81.8%	74.4%	72.8%	43.5%
<b>England</b>	99.5%	98.7%	92.9%	68.0%	81.4%	74.0%	72.2%	42.5%
<b>Wales</b>	99.3%	98.9%	90.5%	83.1%	89.3%	82.3%	84.5%	63.5%
<b>East of England</b>	99.3%	98.5%	93.9%	60.8%	75.2%	72.1%	70.8%	35.6%
<b>East Midlands</b>	99.9%	99.0%	87.4%	71.4%	87.1%	73.4%	80.9%	49.6%
<b>London and South East</b>	99.3%	98.7%	94.1%	63.5%	75.3%	71.6%	58.8%	32.9%
<b>North East and North Cumbria</b>	99.8%	98.9%	89.9%	82.3%	90.5%	80.7%	76.9%	53.2%
<b>North West</b>	99.7%	99.4%	92.9%	69.7%	86.8%	75.4%	78.9%	46.6%
<b>South Central</b>	99.3%	98.6%	90.8%	77.7%	86.4%	76.1%	76.0%	50.2%
<b>South West</b>	99.8%	97.4%	92.7%	65.1%	83.3%	80.4%	77.9%	45.6%
<b>West Midlands</b>	99.4%	99.2%	96.3%	68.8%	83.0%	68.2%	79.4%	47.2%
<b>Yorkshire and Humber</b>	99.2%	98.5%	92.4%	67.3%	79.0%	75.7%	71.4%	42.0%

Figure 8 shows the variation by unit in the percentage of young people aged 12 years and older who had a record of all seven healthcare checks completed. The horizontal black 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. Units below the bottom dotted or dashed lines performed significantly worse than those above on this measure, and those above the top dotted or dashed lines performed significantly better.<sup>1</sup>

**Figure 8: Percentage of young people aged 12 years and older with Type 1 diabetes receiving a complete year of care who received all seven essential healthcare checks by unit, 2016/17**

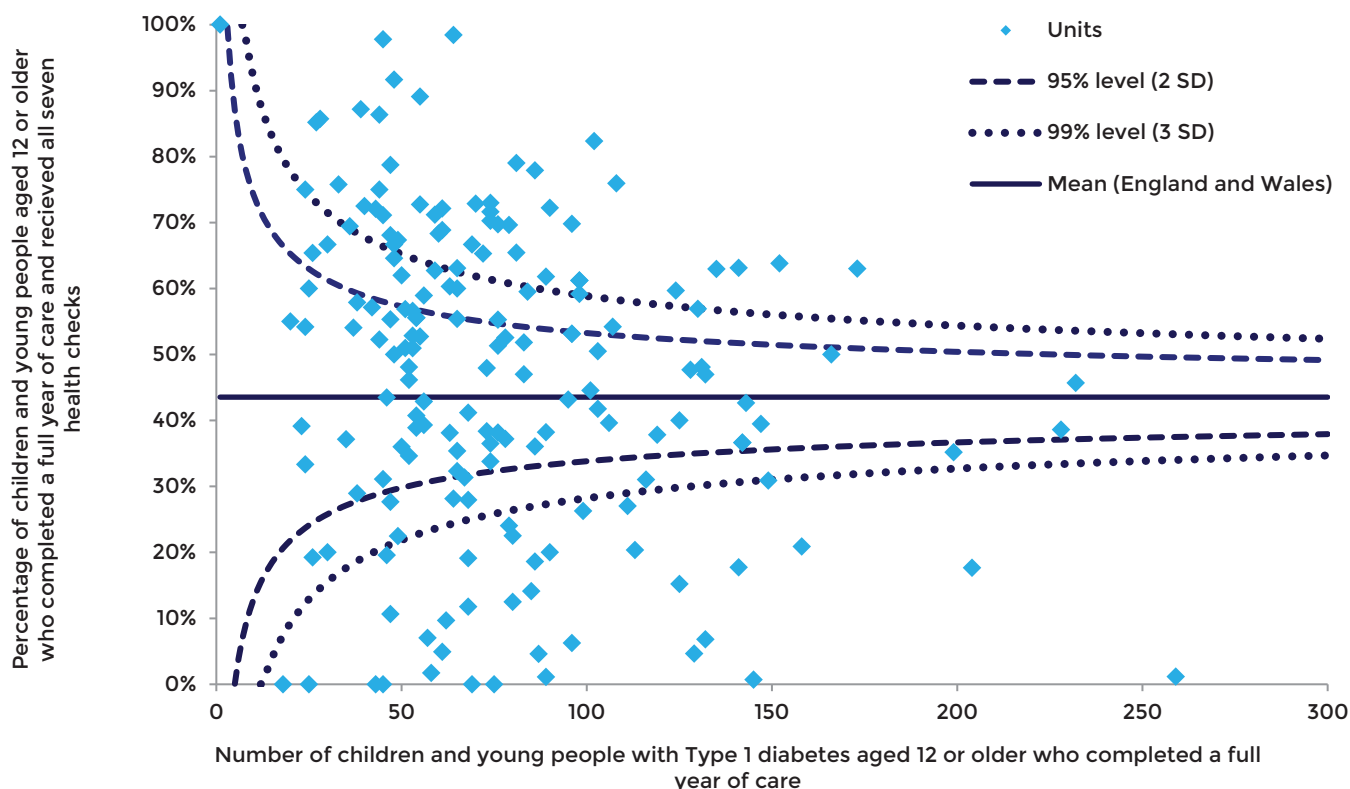
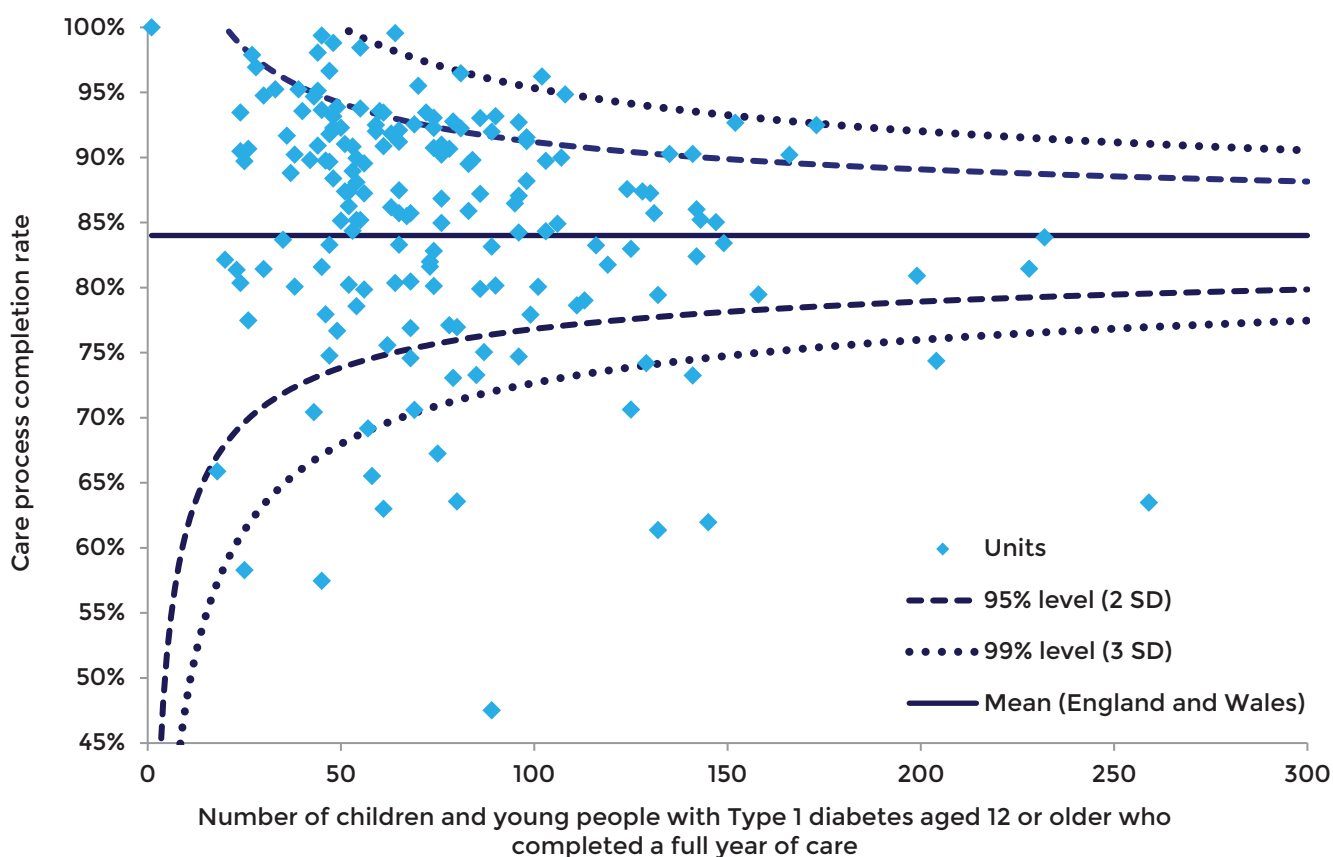


Figure 9 plots PDU care process completions rate against the total number of children and young people with Type 1 diabetes aged 12 or older who completed a full year of care in each unit.

The care process completion rate is calculated by dividing the total number of health checks completed in each unit by the total expected number of health checks (which is equal to the number of children and young people with Type 1 diabetes aged 12 or older who completed a full year of care multiplied by 7 - the number of health checks they should have received).

<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 9: Care completion rate for young people aged 12 years and older with Type 1 diabetes receiving a complete year of care by unit, 2016/17**

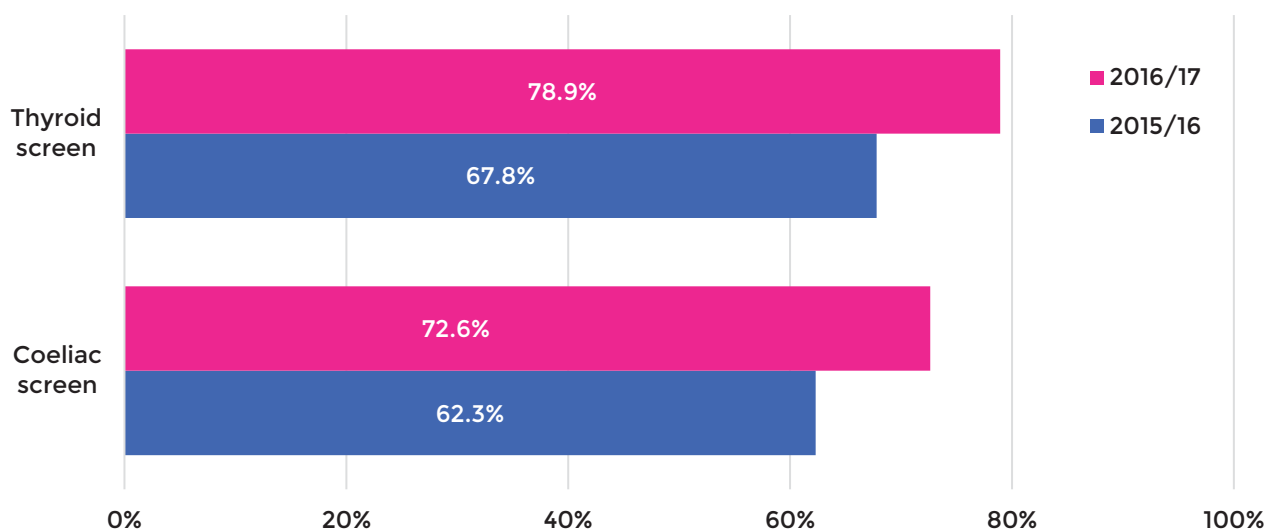


### 5.3.2 Screening for coeliac and thyroid disease at diagnosis of Type 1 diabetes

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

Figure 10 shows the percentage of children and young people diagnosed more than 90 days before the end of the audit year (n= 2,251), who received screening for coeliac and thyroid disease within 90 days of diagnosis. There was improvement in the rates of completion of both of healthcare checks at diagnosis between 2015/16 and 2016/17.

**Figure 10: Percentage of children and young people with Type 1 diabetes who received screening for thyroid or coeliac disease within 90 days of diagnosis in 2015/16 and 2016/17**

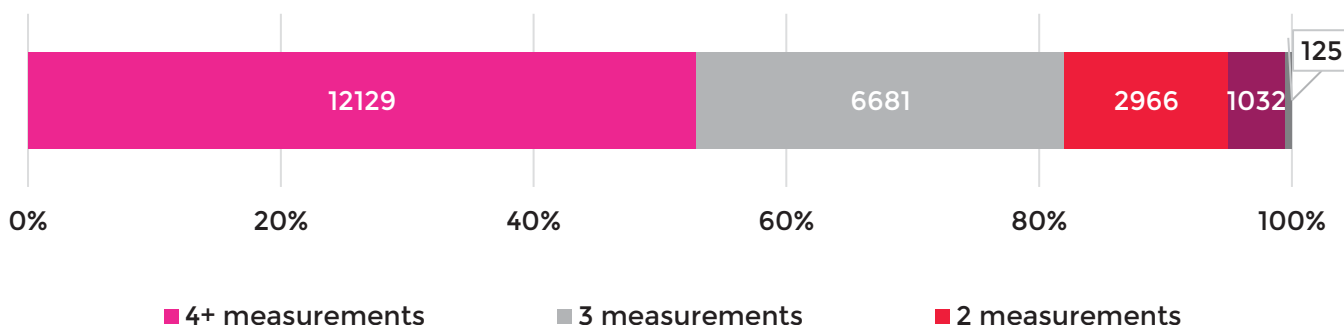


Percentage of children and young people with Type 1 diabetes who received screening for thyroid or coeliac disease within 90 days of diagnosis

### 5.3.3 Number of HbA1c measurements for children and young people with Type 1 diabetes

The Paediatric Diabetes Best Practice Tariff Criteria (Department of Health, 2012; Randell, 2012) require that four HbA1c measurements are offered per year per patient. Figure 11 shows the number and percentage of children and young people with Type 1 diabetes receiving a full year of care by number of HbA1c measurements per patient in the audit year. It shows that 52.9% had four or more measurements recorded in the audit year.

**Figure 11: Number and percentages of children and young people with Type 1 diabetes with a complete year of care by number of HbA1cs recorded per patient, 2016/17**



## 5.3.4 Psychological assessment and smoking status checks for children and young people with Type 1 diabetes

The NPDA also collects data on two additional health checks for children and young people with Type 1 diabetes:

- Smoking status for those aged 12 years and older (an indication of greater cardiovascular risk)
- Psychological assessment (assessment for need of psychological support)

Results are shown in Table 9 for all children and young people with a complete year of care.

**Table 9: Percentage of children and young people with Type 1 diabetes receiving the individual checks of smoking status and psychological assessment by country and region, 2016/17**

	Smoking status recorded (aged 12+ years, n=13,437)	Psychological assessment (all ages, n=22,933)
England and Wales	69.7%	74.1%
England	68.9%	74.3%
Wales	86.1%	71.1%
East of England	51.5%	65.3%
East Midlands	68.3%	94.7%
London and South East	71.9%	66.3%
North East and North Cumbria	64.2%	91.3%
North West	83.0%	79.5%
South Central	56.4%	73.0%
South West	69.6%	77.3%
West Midlands	81.2%	76.3%
Yorkshire and the Humber	64.4%	69.2%

## 5.4 Completion of health checks for children and young people with Type 2 diabetes

Figure 12 shows the percentage of children and young people with Type 2 diabetes completing a full year of care between 2015/16 and 2016/17 who were reported to have received each of the seven recommended healthcare checks. In 2016/17, there were 473 children and young people recorded as having Type 2 diabetes with a complete year of care, of which 436 were aged 12 years and above.

**Figure 12: Percentage of children and young people with Type 2 diabetes with a complete year of care receiving key healthcare checks, 2015/16-2016/17**

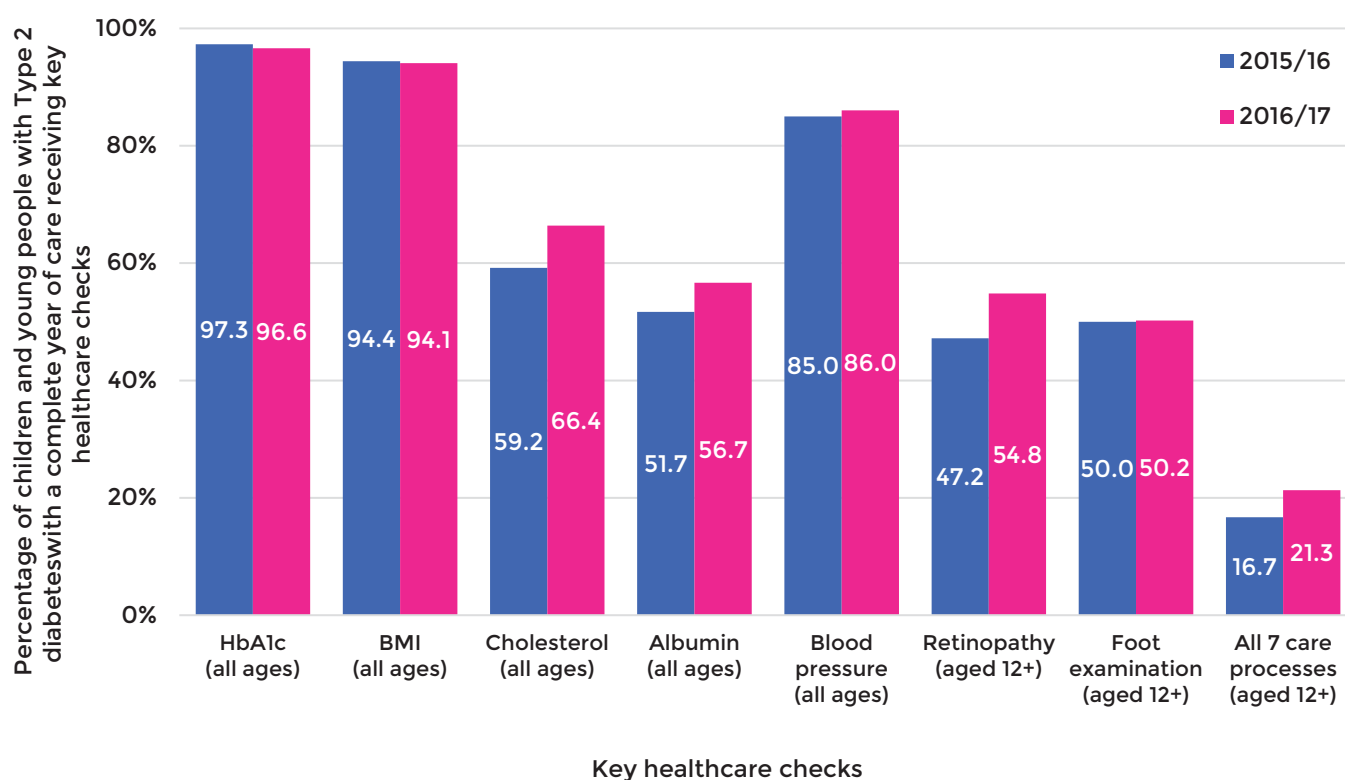
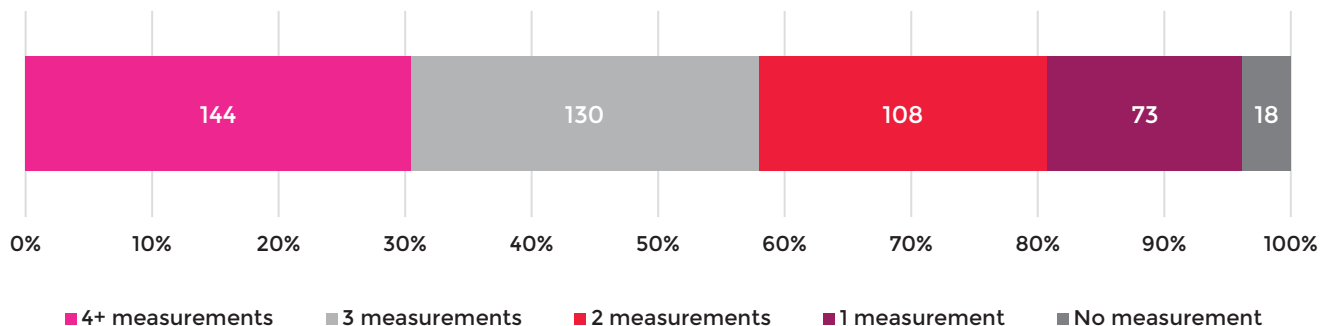




Figure 13 shows the number and percentage of children and young people with Type 2 diabetes receiving a full year of care over the audit period by number of HbA1c measurements recorded per patient. Of these, 30.4% met the Paediatric Diabetes Best Practice Tariff criteria requiring a minimum of four HbA1c measurements per year.

**Figure 13: Number of HbA1c measurements recorded for children and young people with Type 2 diabetes receiving a full year of care, 2016/17**



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

- smoking status ascertainment for those aged 12 years and older (as indication of greater cardiovascular risk)
- psychological assessment (assessment for need of psychological support)

Results are shown in Table 10.

**Table 10: Percentage of children and young people with Type 2 diabetes receiving the healthcare checks of psychological assessment and smoking status check by country, 2016/17**

	Smoking status recorded (aged 12+ years, n=436)	Psychological assessment (all ages, n=454)
England and Wales	65.8%	61.3%
England	64.6%	61.9%
Wales	100%	47.4%

## 5.5 Key findings

- The proportion of children and young people, aged 12 and above, with Type 1 diabetes completing a year of care receiving all seven key healthcare checks has increased from 35.5% in 2015/16 to 43.5% in 2016/17. This is in comparison to 21.3% of those with Type 2 diabetes.
- Most children and young people with Type 1 diabetes had an HbA1c measurement (99.5%), a BMI recorded (98.7%) and a blood pressure measurement (92.7%, 12 years and over only) during the audit year. Almost three-quarters of young people aged 12 and above had a foot check (72.8%) and a retinopathy screen (74.4%) recorded, whilst two thirds had a urinary albumin screen performed (68.7%). Rates were lower in those with Type 2 diabetes.
- There was wide variation in the percentage of children and young people with Type 1 diabetes within each PDU receiving all seven essential healthcare checks, ranging from 0% to nearly 100%.
- Just over half (52.9%) of children and young people with Type 1 diabetes completing a full year of care over the audit period had four or more HbA1c measurements recorded. Less than one third of young people with Type 2 diabetes had four HbA1c's recorded.
- Three quarters of children and young people newly diagnosed with Type 1 diabetes had been screened for coeliac and thyroid disease.
- Almost three-quarters (74.1%) of children and young people with Type 1 diabetes received a psychological assessment compared to 61.3% of children and young people with Type 2 diabetes.

## 5.6 Recommendations

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

- Ensure children and young people with diabetes are receiving the key essential healthcare 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 healthcare 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 takes place at diagnosis of Type 1 diabetes.
- Caution young people with diabetes 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.

## 6. Outcomes of care

The collection of annual audit data on outcomes of care in paediatric diabetes is important to monitor the health and wellbeing of children and young people with the condition. Outcomes can be benchmarked year on year to monitor quality improvement. Treatment targets can be viewed as part of the process of care or as an 'intermediate outcome' i.e. intermediary steps between a care process of the patient and a 'hard' endpoint such as the development of a complication. This section covers:

- HbA1c measurements (recommended as the best indicator of long term diabetes management)
- indicators of small vessel (microvascular) disease
- large vessel (macrovascular) disease including cardiovascular risk, and
- autoimmune disease

### 6.1 HbA1c

HbA1c is a marker of overall diabetes blood glucose management over the preceding six to eight weeks and provides a measure of long term 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 published new guidance (NG18, 2015) which introduced stricter HbA1c targets to indicate excellent diabetes management for both Type 1 and 2 diabetes with a 'cut-off' of 48mmol/mol or below. It also requested providers to report those achieving a level of 53 mmol/mol or below. Given the low numbers of children and young people achieving this new target and to allow historical benchmarking, the NPDA will continue to include the numbers achieving the previous NICE (2004) target of 58 mmol/mol or below. An HbA1c level above 80mmol/mol carries considerable increased risk of both microvascular diabetic complications (eye disease and kidney disease) and cardiovascular disease, and so the numbers of children and young people exceeding this upper limit is also reported.

HbA1c values were included in the outcome analysis if they were within the acceptable range (20-195mmol/mol), dated within the audit period, and were 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 for.

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

The mean and median HbA1c of children and young people with all types of diabetes in England and Wales receiving care in a PDU in 2016/17 were 66.9 and 64.0 mmol/mol respectively (Table 11). This is a reduction in the national mean of 0.9 mmol/mol and the national median of 0.5 mmol/mol, compared to those recorded in 2015/16 of 67.8 and 64.5 mmol/mol. This means that for the seventh consecutive year there has been a fall in the HbA1c levels for England and Wales (Figure 12).

Figure 14: Median HbA1c for children and young people with all types of diabetes in England and Wales 2007/08 to 2016/17 with associated NHS policy and/or paediatric diabetes delivery structural changes

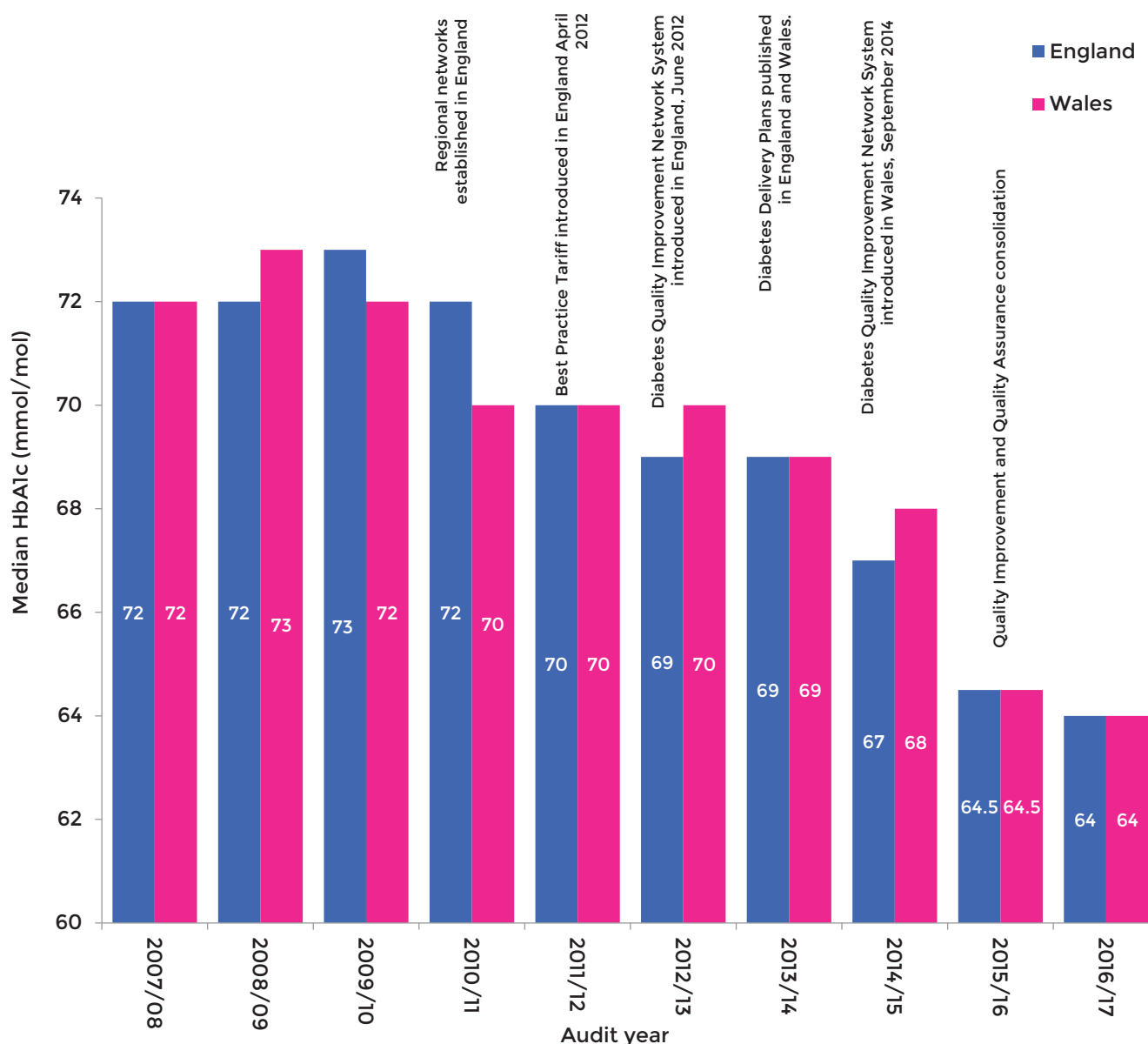


Table 11 provides a breakdown of the unadjusted mean and median HbA1c results achieved by each region and country, and the level of variation within them.

**Table 11: HbA1c for all children and young people with all types of diabetes and one or more valid HbA1c measurements by country and regional network, 2016/17**

	No. of children & young people	Mean mmol/mol	Standard deviation mmol/mol	Median mmol/mol	IQR mmol/mol
England and Wales	27,420	66.9	17.3	64.0	18.0
England	26,034	66.9	17.4	64.0	18.0
Wales	1,385	66.9	16.8	64.0	18.0
East of England	2,984	66.5	17.1	63.0	18.5
East Midlands	1,847	62.6	14.9	60.5	16.5
London and South East	6,283	67.9	18.2	64.5	19.5
North East and North Cumbria	1,502	66.6	16.7	64.0	17.5
North West	3,445	68.4	18.2	65.0	18.5
South Central	2353	63.9	15.4	61.5	15.0
South West	2126	66.0	17.0	63.0	18.0
West Midlands	2,838	67.9	17.8	65.0	18.0
Yorkshire and the Humber	2,657	68.1	16.8	65.0	18.0

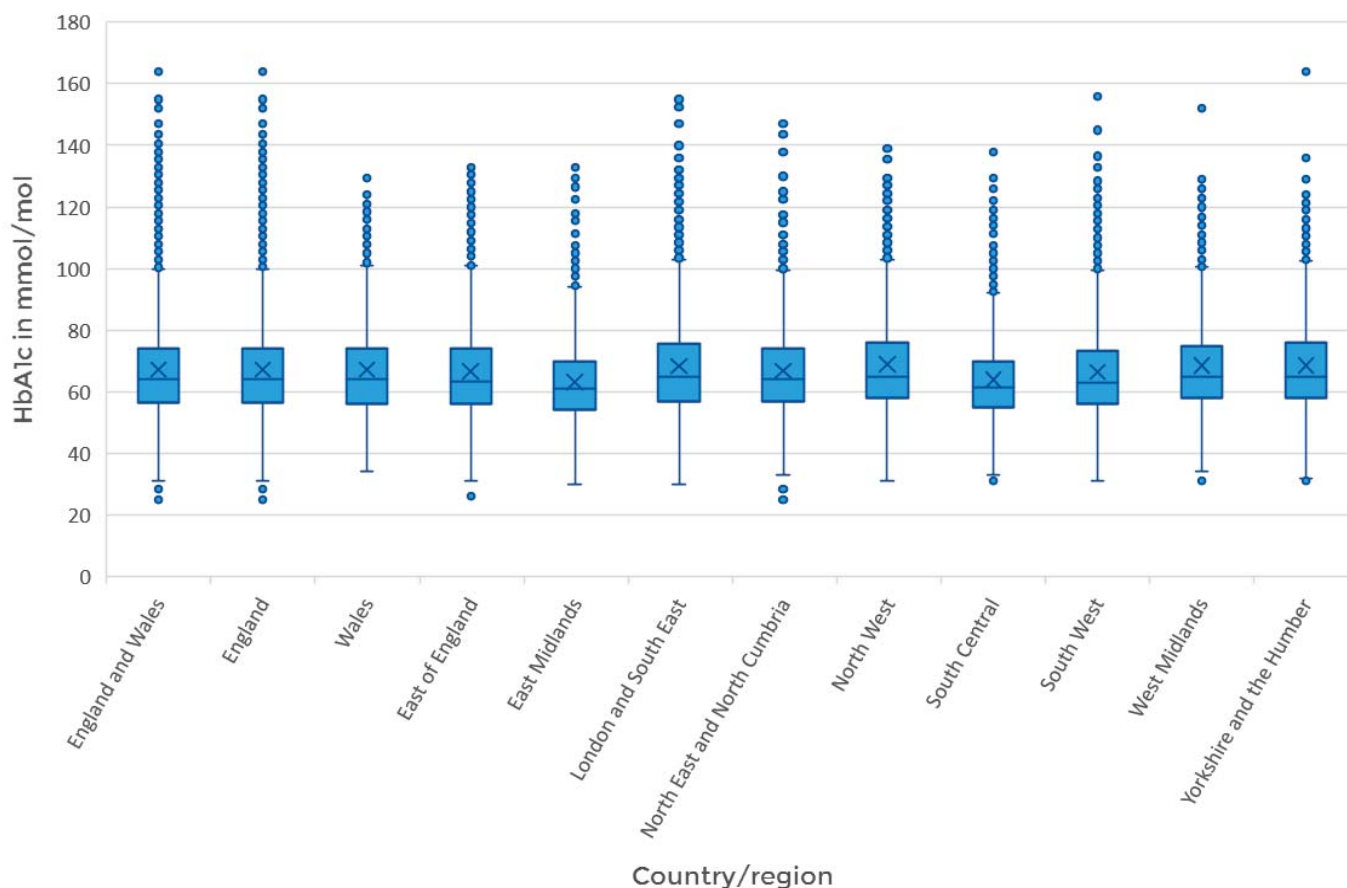
## 6.1.2 HbA1c outcomes of children and young people with Type 1 diabetes

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 across key confounders.

### 6.1.2.1 National and regional variation in HbA1c outcomes

The national unadjusted mean HbA1c for children and young people with Type 1 diabetes was 67.3 mmol/mol, and the median was 64.0 mmol/mol. Both these figures represent a decrease of 1 mmol/mol compared to 2015/16 results. Figure 15 shows the unadjusted mean and median HbA1c results for children and young people with Type 1 diabetes achieved by each region and country. Although there is little difference between means and medians by region, there is considerable variation within each region and country.

Figure 15: Unadjusted mean and median HbA1c for all children and young people with Type 1 diabetes and one or more valid HbA1c measurements by country and regional network with outliers, 2016/17

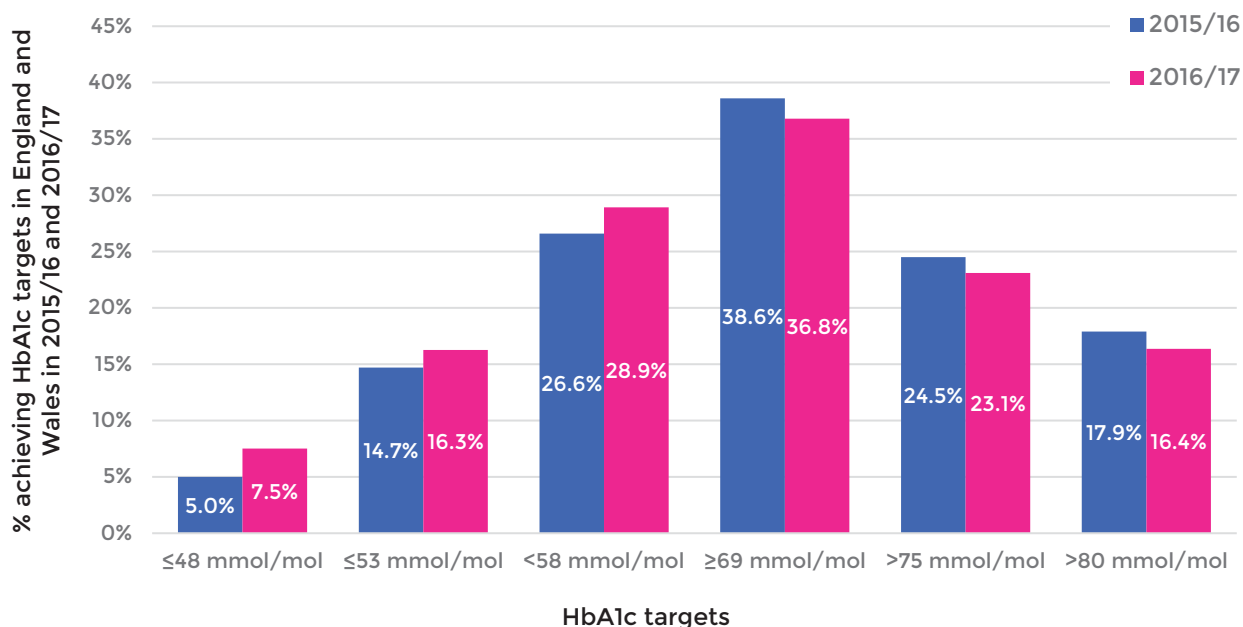


#### Interpreting the box and whisker plot

The X shows the mean HbA1c result for children and young people with Type 1 diabetes within each country or region. The box component indicates the HbA1c results at the 25th, 50th (median) and 75th percentiles. The whiskers extending upwards from the top of the box include all values that are less than or equal to 1.5 times the interquartile range and the whiskers extending down from the bottom of the box include all values that are less than 1.5 times the interquartile range in the opposite direction. Individual patient median values outside this range within each country/region are categorised as outliers and are represented by the blue dots. PDUs, regions and countries should be aiming for low mean and median HbA1c, with a small interquartile range indicating a low variation in HbA1cs recorded for children and young people using their service.

Figure 16 shows the percentages of children and young people who achieved NICE (2004, 2015) treatment targets in 2015/16 and 2016/17 and Figure 17 shows the percentage of children and young people with Type 1 diabetes with a HbA1c result below 58 mmol/mol, between 58 and 80 mmol, and above 80 mmol/mol from 2011/12 to 2016/17. Both graphs show an increase in the percentage of children and young people achieving lower HbA1c targets and a decrease in the percentage of children and young people with HbA1c exceeding 80 mmol/mol.

**Figure 16: Percentage of children and young people with Type 1 diabetes achieving HbA1c targets in England and Wales in 2015/16 and 2016/17**



**Figure 17: Percentage of children and young people with Type 1 diabetes with an HbA1c result below 58 mmol/mol, between 58 and 80 mmol, and above 80 mmol/mol, 2011/12 - 2016/17**

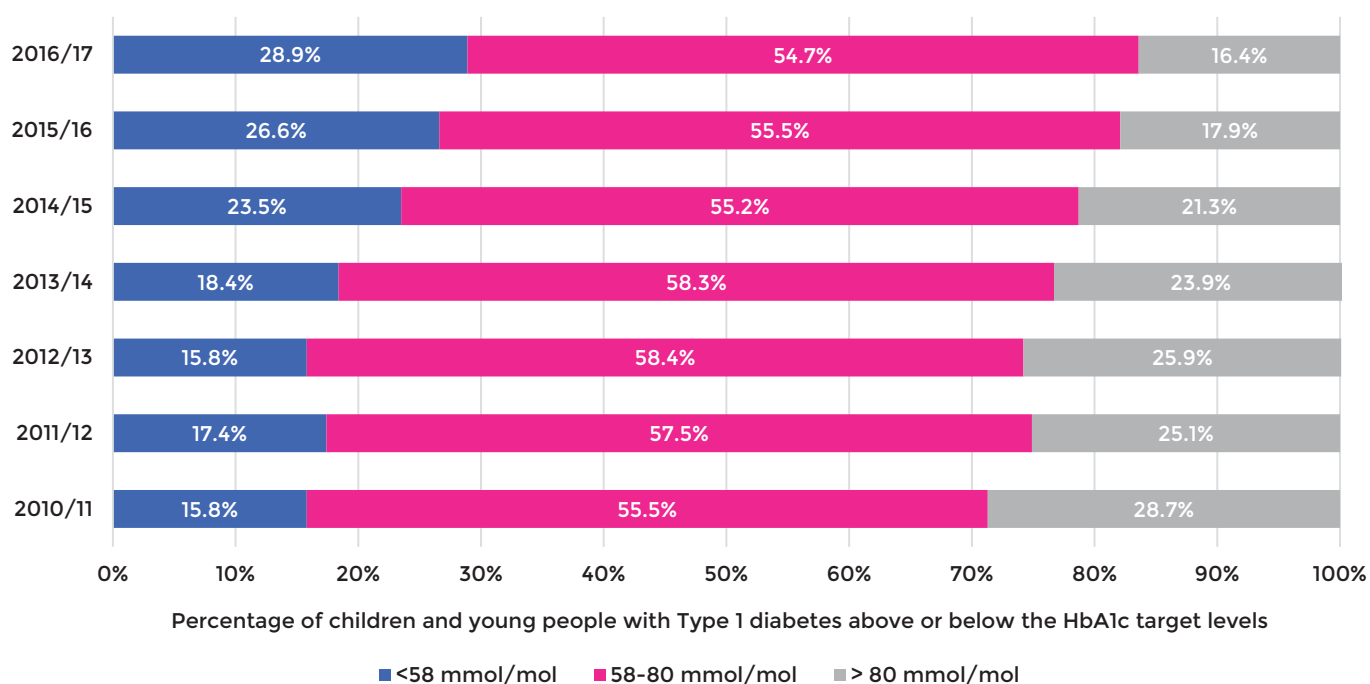


Table 12 shows the percentages of children and young people who achieved these targets by country and by region.

**Table 12: Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by country and regional network, 2016/17**

	≤48 mmol/mol	≤53 mmol/mol	<58 mmol/mol	≥69 mmol/mol	>75 mmol/mol	>80 mmol/mol
England and Wales	7.5%	16.3%	28.9%	36.8%	23.1%	16.4%
England	7.6%	16.2%	28.9%	36.8%	23.1%	16.4%
Wales	6.5%	16.6%	29.7%	37.6%	22.7%	15.0%
East of England	8.4%	17.6%	31.3%	35.3%	23.0%	16.3%
East Midlands	10.6%	22.8%	38.6%	27.7%	15.1%	10.2%
London and South East	7.1%	15.7%	28.1%	40.0%	25.4%	18.3%
North East and North Cumbria	8.0%	16.2%	28.1%	36.5%	22.6%	15.0%
North West	6.5%	14.0%	24.6%	40.5%	25.6%	18.6%
South Central	8.9%	19.3%	34.2%	28.3%	16.5%	11.7%
South West	9.0%	18.7%	32.1%	34.8%	22.3%	16.1%
West Midlands	6.1%	13.4%	24.9%	38.9%	24.9%	17.6%
Yorkshire and the Humber	5.8%	12.5%	24.3%	39.5%	25.3%	18.0%



### 6.1.2.2 HbA1c outcomes of children and young people with Type 1 diabetes associated with patient characteristics

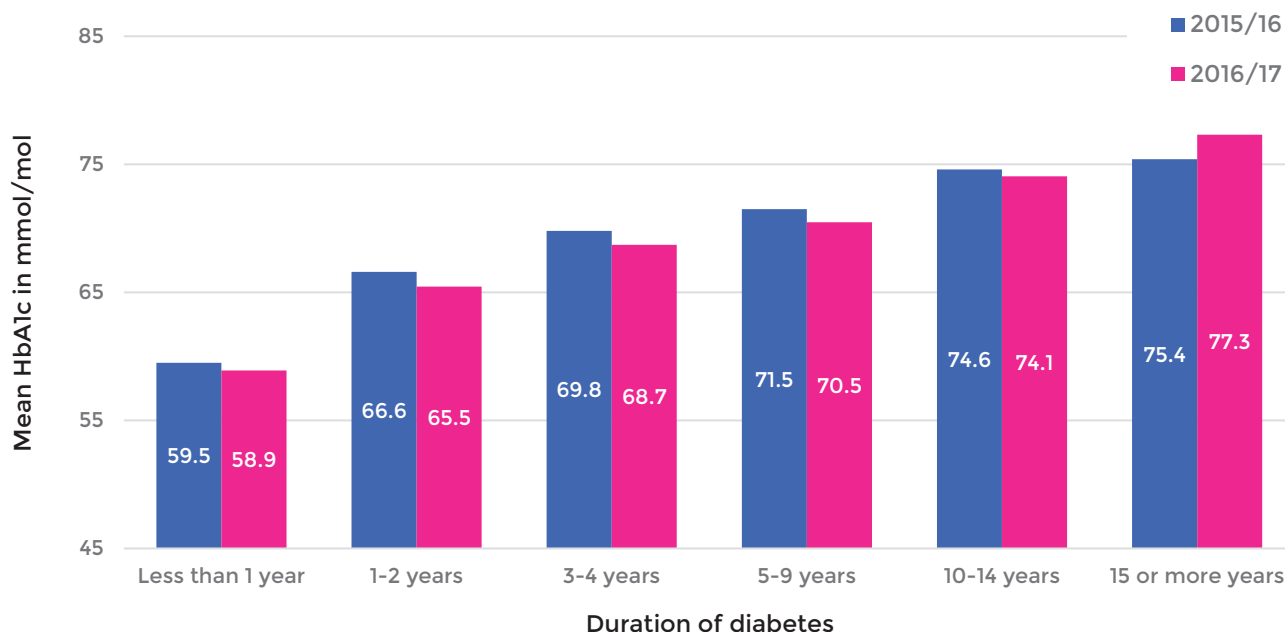
Figure 18 shows that older children and young people tend to have higher HbA1c levels compared to younger children. It also shows that males tend to have lower HbA1c levels compared to females at all ages apart from at age two.

Figure 18: Mean HbA1c for children and young people with Type 1 diabetes by age and sex, 2016/17



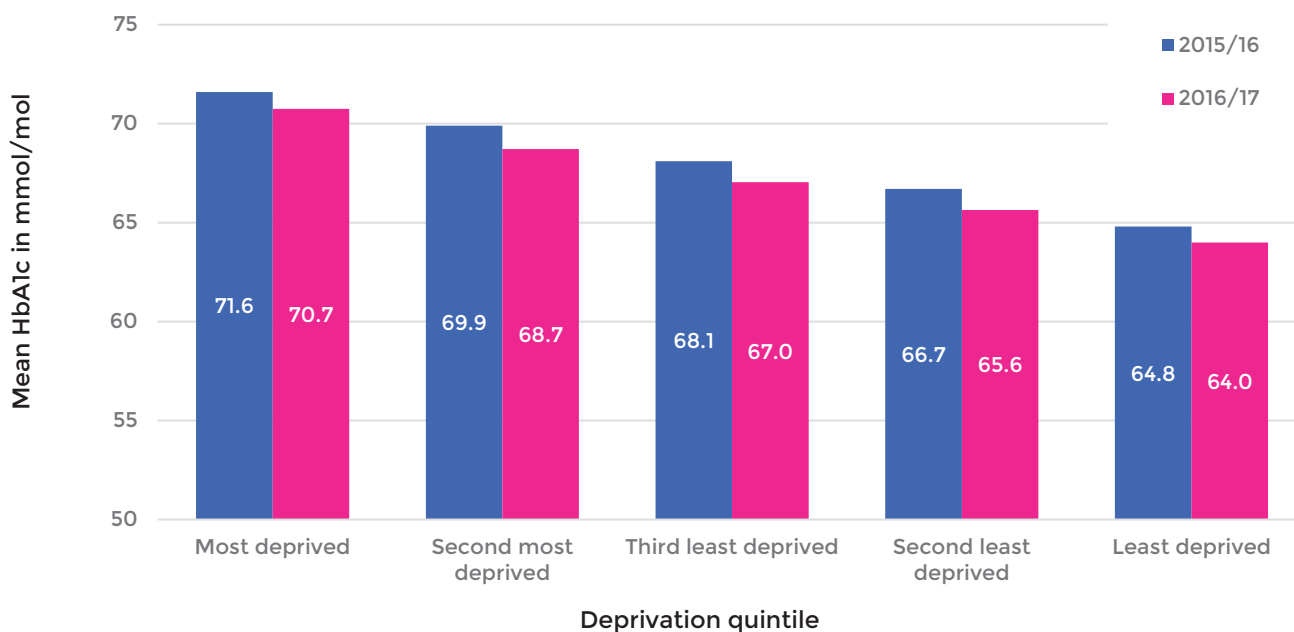
In line with findings from previous years, mean HbA1c tends to increase as duration of diabetes increases (Figure 19). This may well reflect increasing age as shown in Figure 5 above.

**Figure 19: Mean HbA1c for children and young people with Type 1 diabetes by duration of diabetes for England and Wales, 2015/16 and 2016/17**



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 20). Figure 20 also shows an improvement in HbA1c levels within each deprivation quintile compared to 2015/16.

**Figure 20: Mean HbA1c for children and young people with Type 1 diabetes in England and Wales by deprivation quintile, 2015/16 and 2016/17**



Children and young people with Type 1 diabetes from Black and ethnic minority groups had higher HbA1c levels than White children and young people (Table 13).

**Table 13: Mean HbA1c and percentage of children and young people with Type 1 diabetes in England and Wales achieving HbA1c targets by ethnic group, 2016/17**

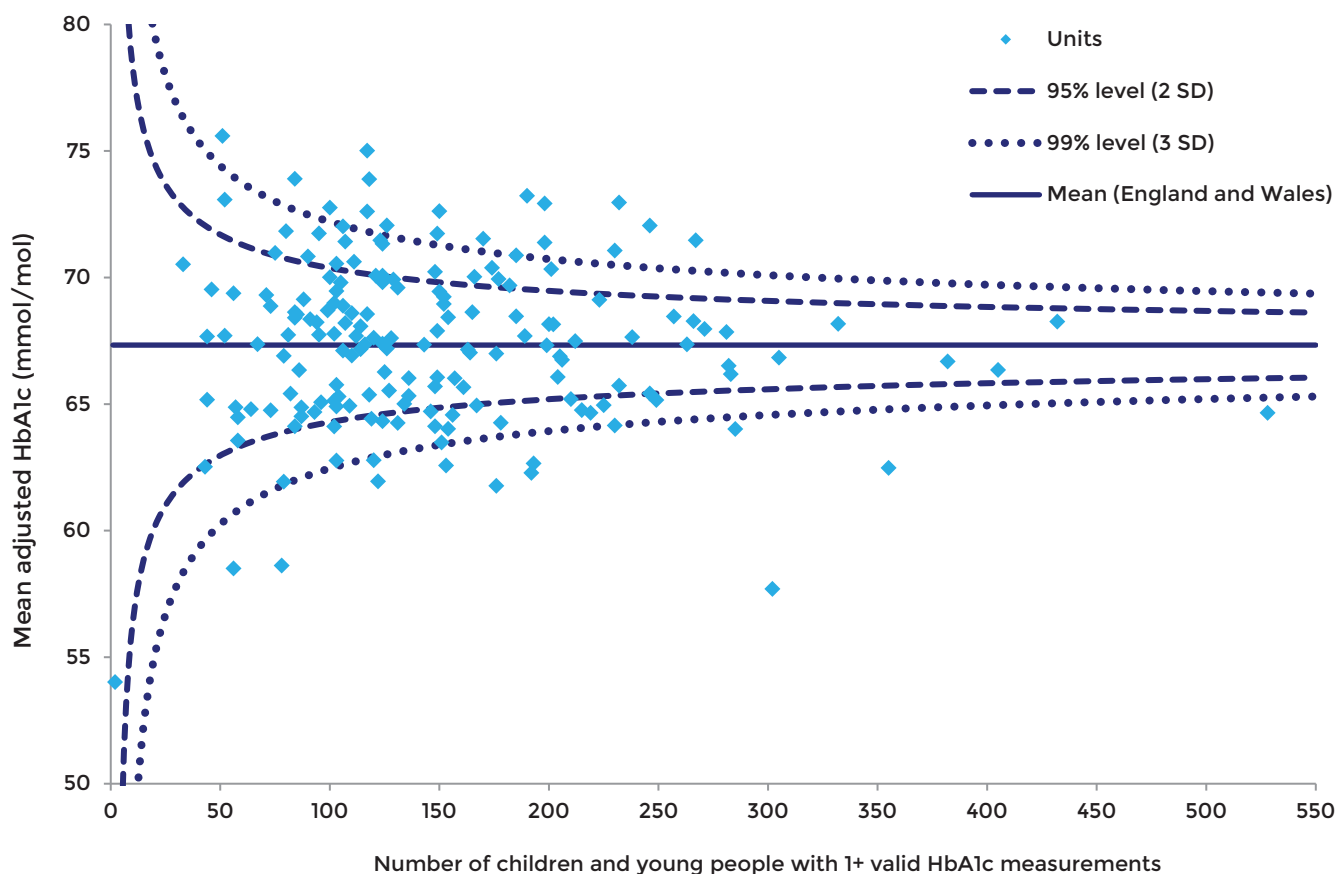
Ethnic group	Mean in mmol/mol	% of children and young people achieving HbA1c targets					
		≤48 mmol/mol	≤53 mmol/mol	<58 mmol/mol	≥69 mmol/mol	> 75 mmol/mol	> 80 mmol/mol
White	66.9	7.4%	16.6%	29.8%	35.5%	22.0%	15.6%
Mixed	69.2	7.0%	14.8%	24.5%	43.9%	26.8%	18.8%
Asian	69.1	6.3%	12.2%	22.7%	42.5%	27.9%	19.3%
Black	74.5	5.4%	8.7%	16.1%	54.4%	37.8%	28.9%
Other	67.4	9.1%	19.7%	32.8%	36.6%	23.0%	18.4%
Not stated	66.7	9.3%	18.3%	30.8%	36.4%	23.0%	16.0%

### 6.1.2.3 Adjusted HbA1c outcomes for HbA1c for children and young people with Type 1 diabetes achieved by PDUs

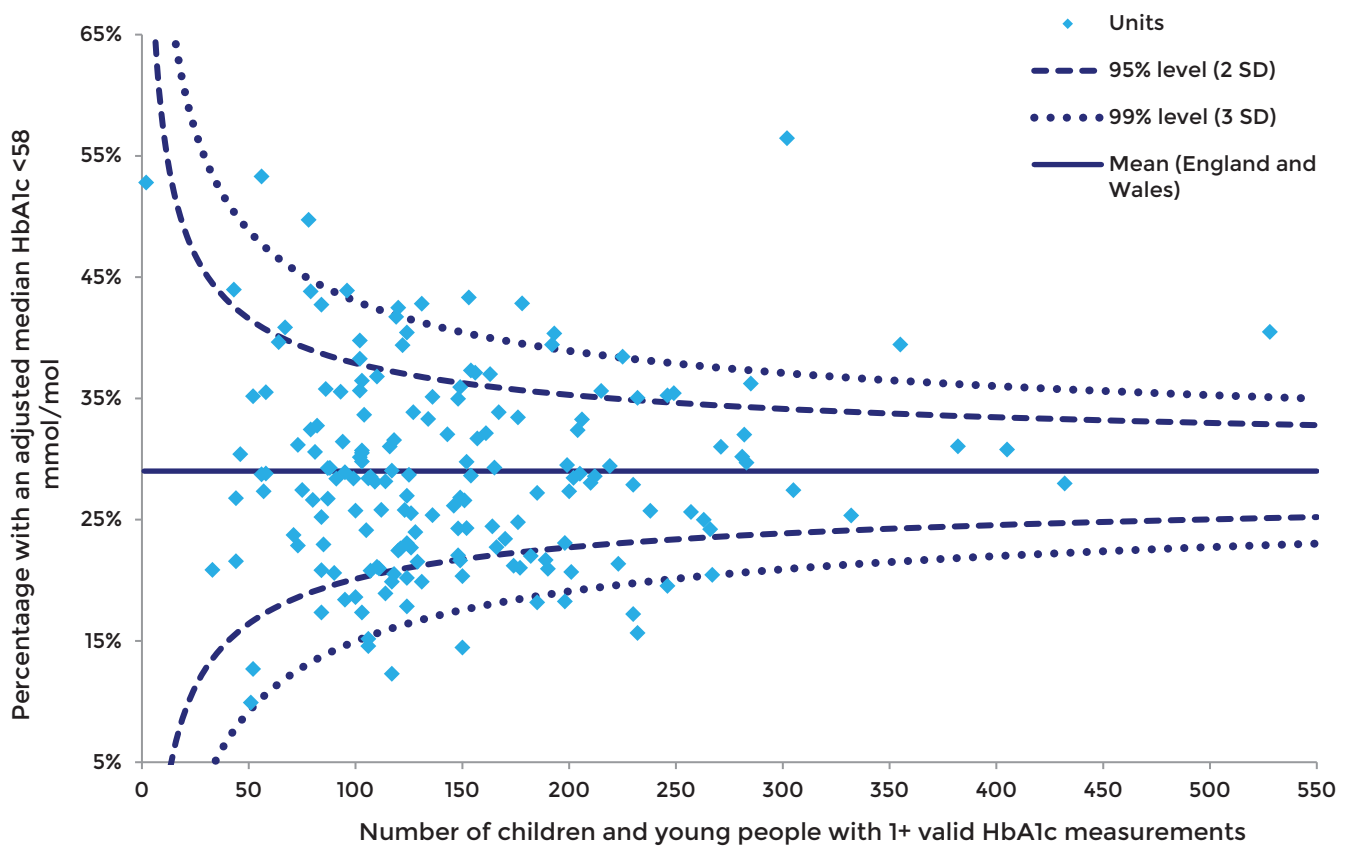
Given the variations in HbA1c associated with different demographic and social characteristics, it is appropriate to adjust HbA1c figures to take account of the characteristics of their patients or case-mix when comparing the performance of individual PDUs. The case-mix adjustments applied to the 2016/17 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.

There remains considerable variability across England and Wales in the mean HbA1c for children and young people with Type 1 diabetes achieved by PDUs after adjustment for case-mix. Figure 21 shows the mean adjusted HbA1c for each PDU in England and Wales, and Figures 22 and 23 show the case-mix adjusted percentage of children and young people per clinic with an HbA1c result below 58 mmol/mol and above 80 mmol/mol, respectively.

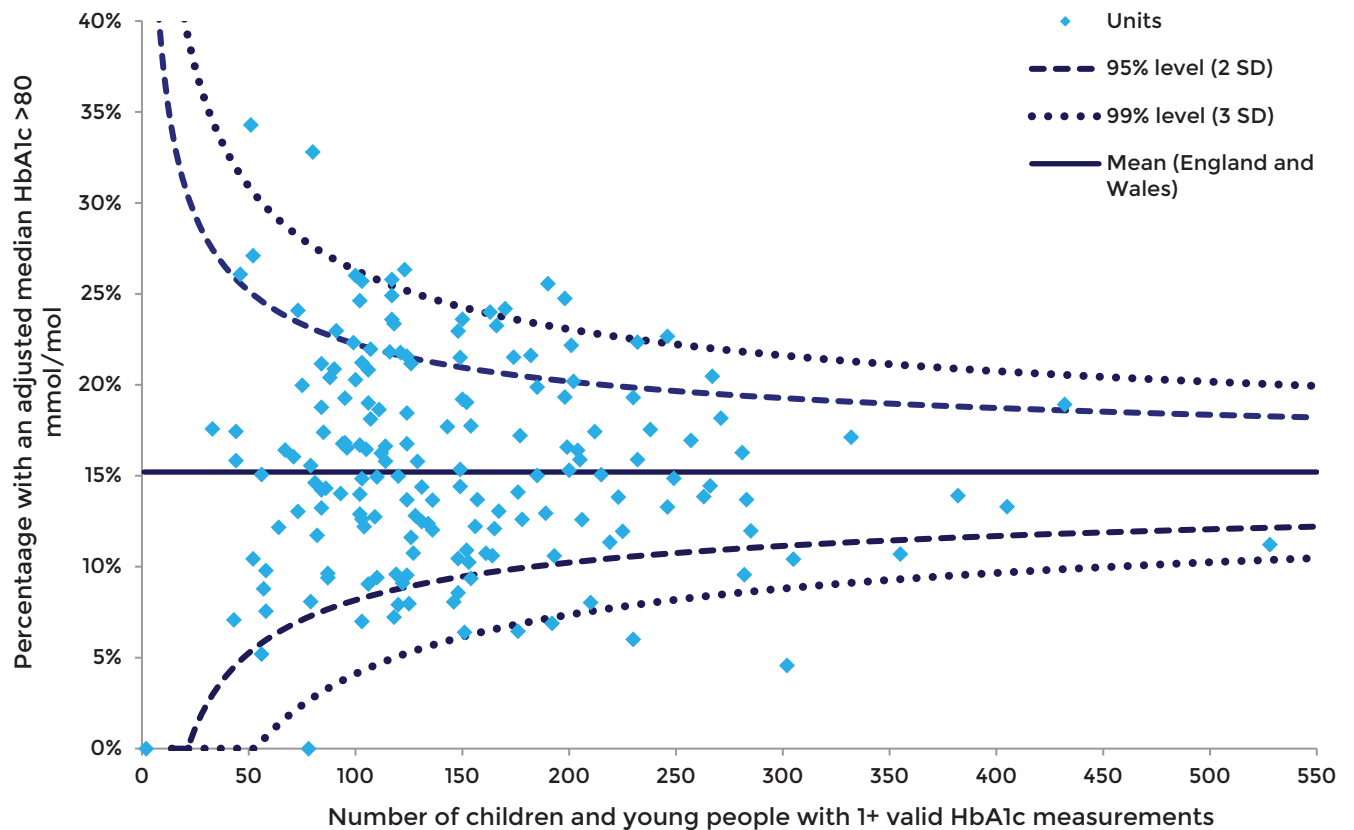
Figure 21: Funnel plot of mean adjusted HbA1c for children and young people with Type 1 diabetes in England and Wales by PDU, 2016/17



**Figure 22: Funnel plot of percentage of children and young people with Type 1 diabetes in England and Wales with an adjusted HbA1c <58 mmol/mol by PDU, 2016/17**



**Figure 23: Funnel plot of percentage of children and young people with Type 1 diabetes in England and Wales with an adjusted HbA1c >80 mmol/mol by PDU, 2016/17**



## 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 2016/17 were 60.2 and 52.0 mmol/mol, respectively (Table 14).

**Table 14: HbA1c for all children and young people with Type 2 diabetes and one or more valid HbA1c measurements in England and Wales, 2016/17**

	No. of children & young people with a recorded HbA1c	Mean mmol/mol	Standard deviation mmol/mol	Median mmol/mol	IQR mmol/mol
2016/17	605	60.2	24.6	52.0	33.5
2015/16	539	59.7	25.4	51.0	30.5

Figure 24 shows an association between level of deprivation and mean HbA1c. In 2016/17, the mean HbA1c in the most and least deprived areas were lower compared to 2015/16. In contrast, the mean HbA1c of those living in three middle deprivation quintiles increased over the year.

**Figure 24: Mean HbA1c for children and young people with Type 2 diabetes in England and Wales by deprivation quintile, 2016/17**

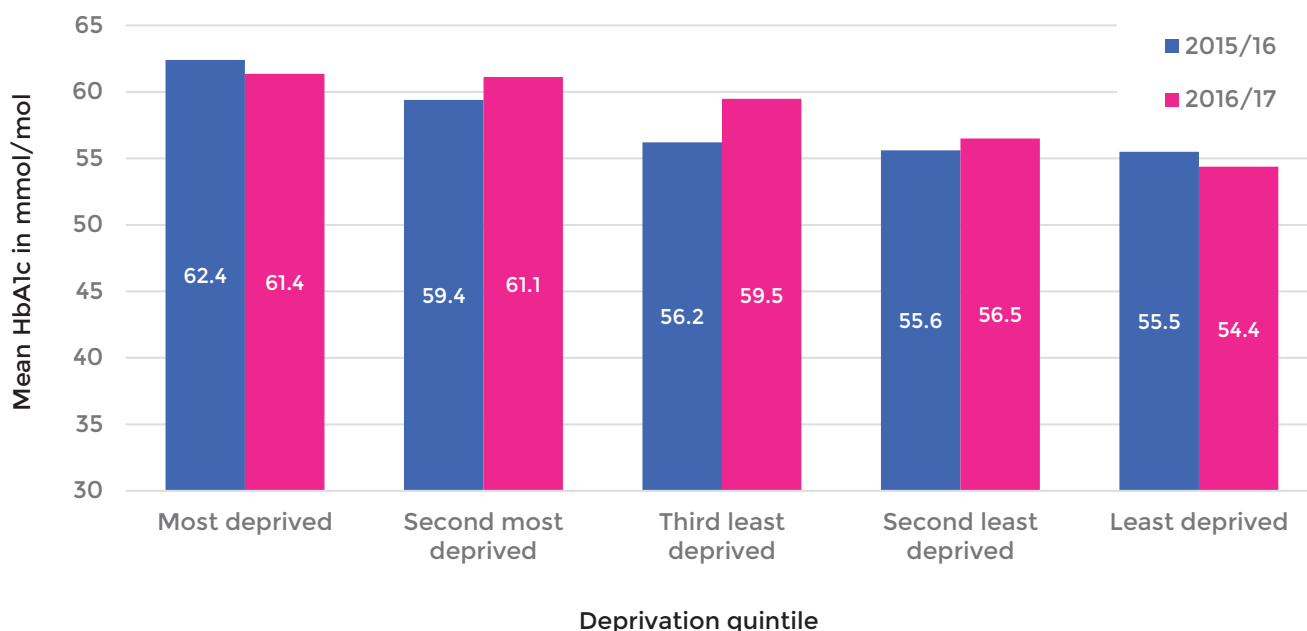
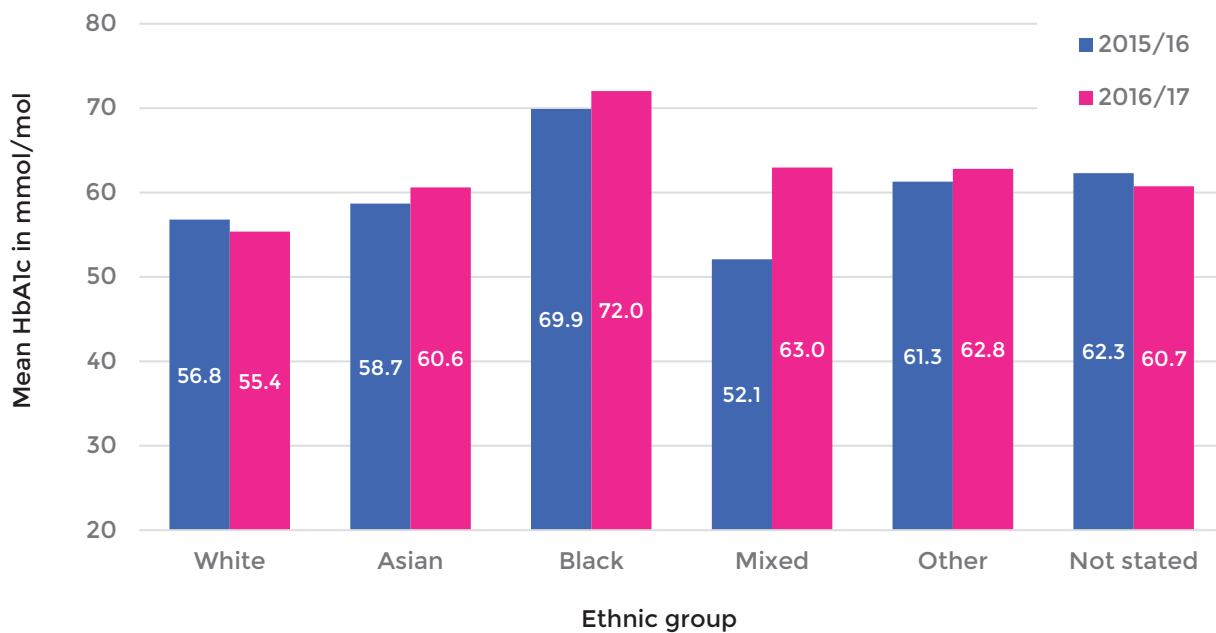


Figure 25 shows variation in mean HbA1c in those with Type 2 diabetes by ethnic group, with Black children and young people having a higher HbA1c level compared to those of other ethnic backgrounds.

**Figure 25: Mean HbA1c for children and young people with Type 2 diabetes in England and Wales by ethnic group, 2016/17**



## 6.1.4 Key findings

- There have been reductions of 0.9 and 0.5 mmol/mol respectively in the national mean and median HbA1c for all children and young people being treated within a PDU in England and Wales since 2015/16. The national mean in 2016/17 was 66.9 and the median was 64.0 mmol/mol.
- There has been a 9 mmol/mol reduction in median HbA1c in England and Wales for all children and young people with diabetes over the last 7 years from 73 mmol/mol in 2009/10 to 64 mmol/mol in 2016/17.
- The national unadjusted mean HbA1c for children and young people with Type 1 diabetes was 67.3 mmol/mol, and the median was 64.0 mmol/mol. Both represent a decrease of 1 mmol/mol compared to 2015/16.
- There has been an increase in the percentage of children and young people with Type 1 diabetes achieving good HbA1c levels (<58 mmol/mol) over the last year from 26.6% in 2015/16 to 28.9% in 2016/17. Over the last 7 years the percentage achieving an HbA1c <58 mmol/mol has almost doubled from 15.8% in 2010/11.
- There has been a reduction in the percentage of children and young people with Type 1 diabetes with poor HbA1c (>80mmol/mol) from 17.9% in 2015/16 to 16.4% in 2016/17. Over the last 7 years the percentage achieving an HbA1c >80 mmol/mol has almost halved from 28.7% in 2010/11.
- Older children and young people with Type 1 diabetes had poorer HbA1c levels compared to younger children.
- Considerable variability in HbA1c target outcomes persists between PDUs even after case-mix adjustment.
- In both Type 1 and Type 2 diabetes there were differences in HbA1c target outcomes associated with deprivation and ethnicity. In general, for both type of diabetes children and young people had poorer outcomes if they lived in a deprived area or were of non-white ethnicity.

## 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.
- Pay particular attention to the care needs of the vulnerable subgroup with persistently high HbA1c levels. Appropriate engagement, education, technology and psychosocial support for this subgroup is paramount so that they are not lost to follow up and are helped as individuals to improve their diabetes management.
- Provide each child with an individualised care plan to achieve the best possible level of HbA1c given the many reasons for the gradual increase of HbA1c with duration of diabetes.
- Be aware of the socioeconomic and patient demographic factors associated with poorer diabetes management, and adapt communications and structured education provision to be able to meet the different needs of vulnerable subgroups.

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 subgroup



## 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 diabetes-related complications. Research in adults with Type 1 diabetes has shown that a 1 percentage point (11 mmol/mol) 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).

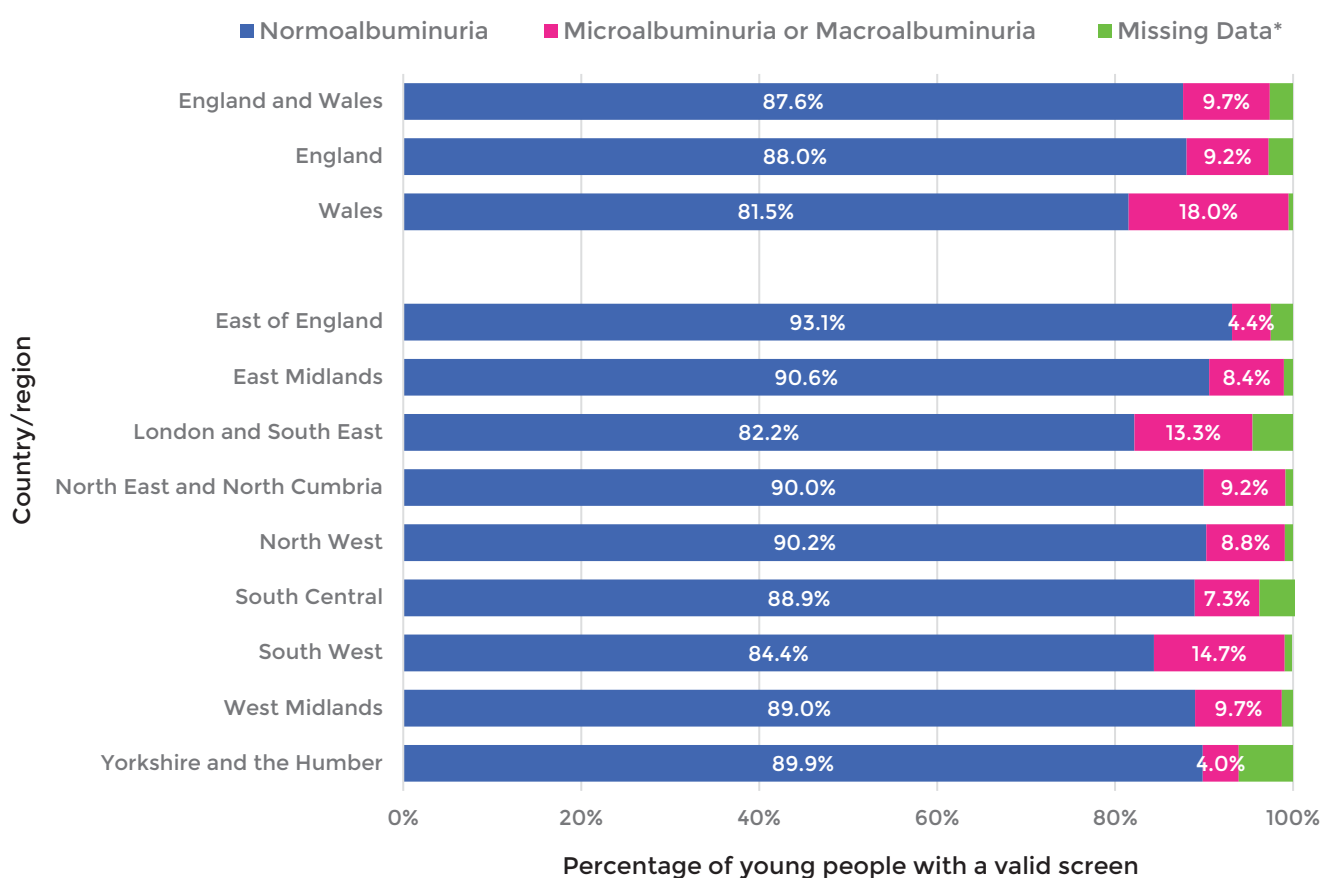
### 6.2.1 Kidney disease

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

Increased risk of kidney disease is indicated by the presence of either micro- or macro-albuminuria. Figure 1 shows the results of 10,214 young people with Type 1 diabetes aged 12 years and above with an albuminuria screen dated during the audit period which equates to 63.5% of the total potential cohort of 16,085.

The percentage of young people with Type 1 diabetes in England and Wales aged 12 years and above with micro- or macro-albuminuria was 9.7%, the same result as was found in 2015/16. However, the percentage varied according to country and region (Figure 26).

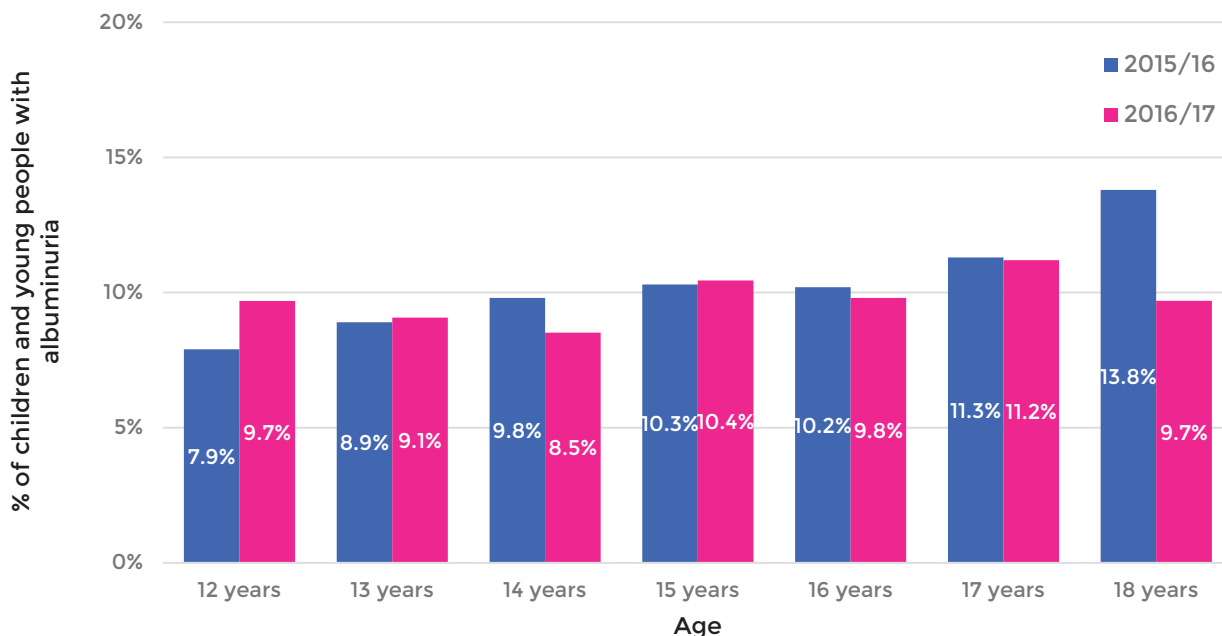
**Figure 26: Percentage of young people with Type 1 diabetes aged 12 years and older with albuminuria by country and region, 2016/17**



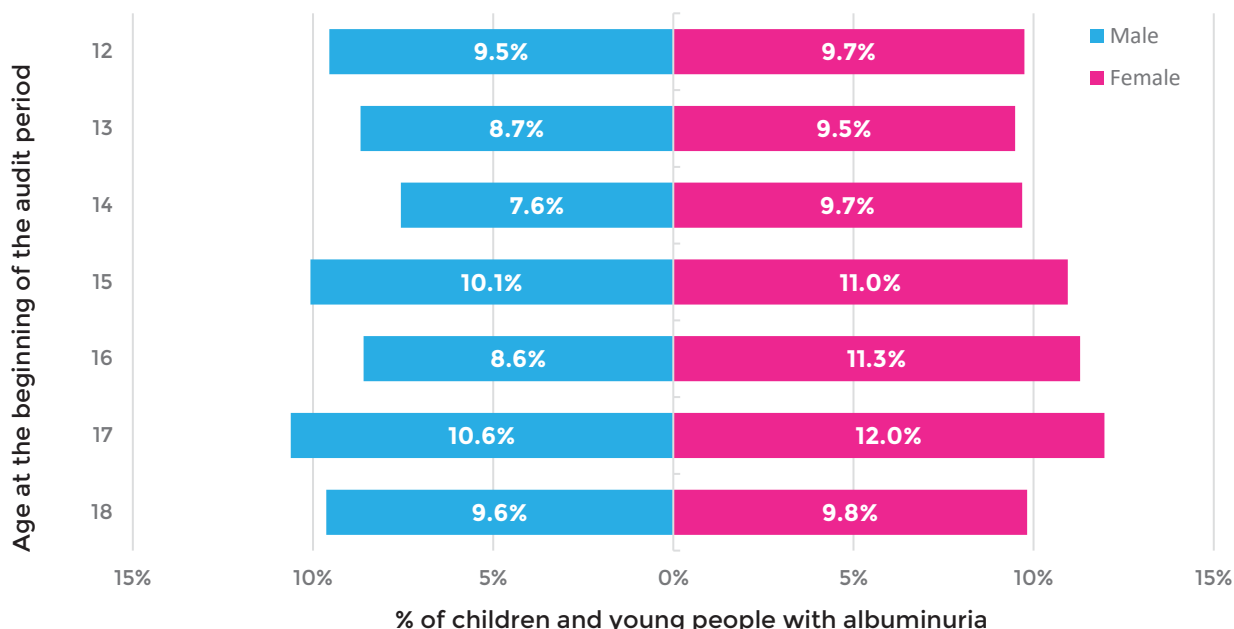
\*Missing data relates to patients with a valid recorded albuminuria level but no interpretation of this result.

In 2016/17, the occurrence of albuminuria was similar across all age groups and differed only slightly compared to 2015/16 (Figure 27). When broken down by gender, females tend to be at greater risk of having albuminuria than males (Figure 28).

**Figure 27: Percentage of children and young people with Type 1 diabetes aged 12 years and older with albuminuria by age, 2015/16 and 2016/17**

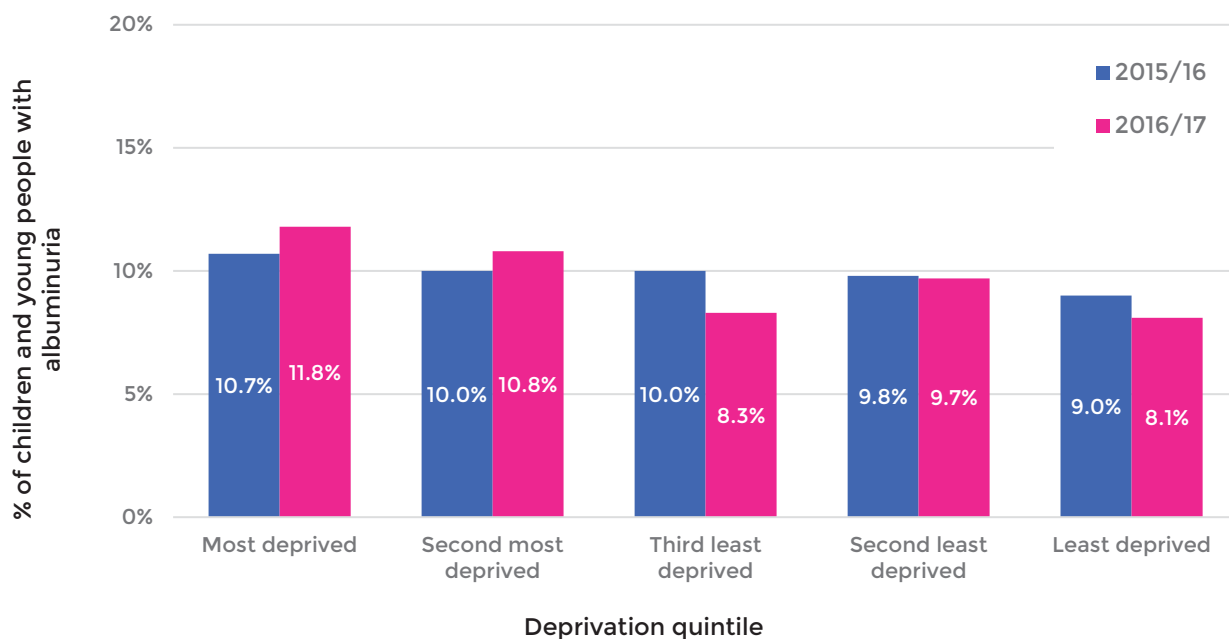


**Figure 28: Percentage of children and young people with Type 1 diabetes aged 12 years and older with albuminuria by age and gender, 2016/17**



Albuminuria prevalence was higher amongst those living in more deprived areas and has increased in the most and second most deprived areas since 2015/16 (Figure 29).

**Figure 29: Percentage of children and young people with Type 1 diabetes aged 12 years and older with albuminuria by deprivation quintile, 2015/16 and 2016/17**



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

Albuminuria was present in 20.1% of young people with Type 2 diabetes with a valid screen (n= 343), an increase from 14.5% in 2015/16. This prevalence is higher than for that recorded for young people with Type 1 diabetes (9.7%) - putting young people with Type 2 diabetes at a higher risk of kidney disease.

**Table 15: Percentage of children and young people with Type 2 diabetes with albuminuria in England and Wales, 2015/16 and 2016/17**

	Normo-albuminuria	Micro- or Macro-albuminuria	Missing Data*
2016/17	75.5%	20.1%	4.4%
2015/16	84.4%	14.5%	1.2%

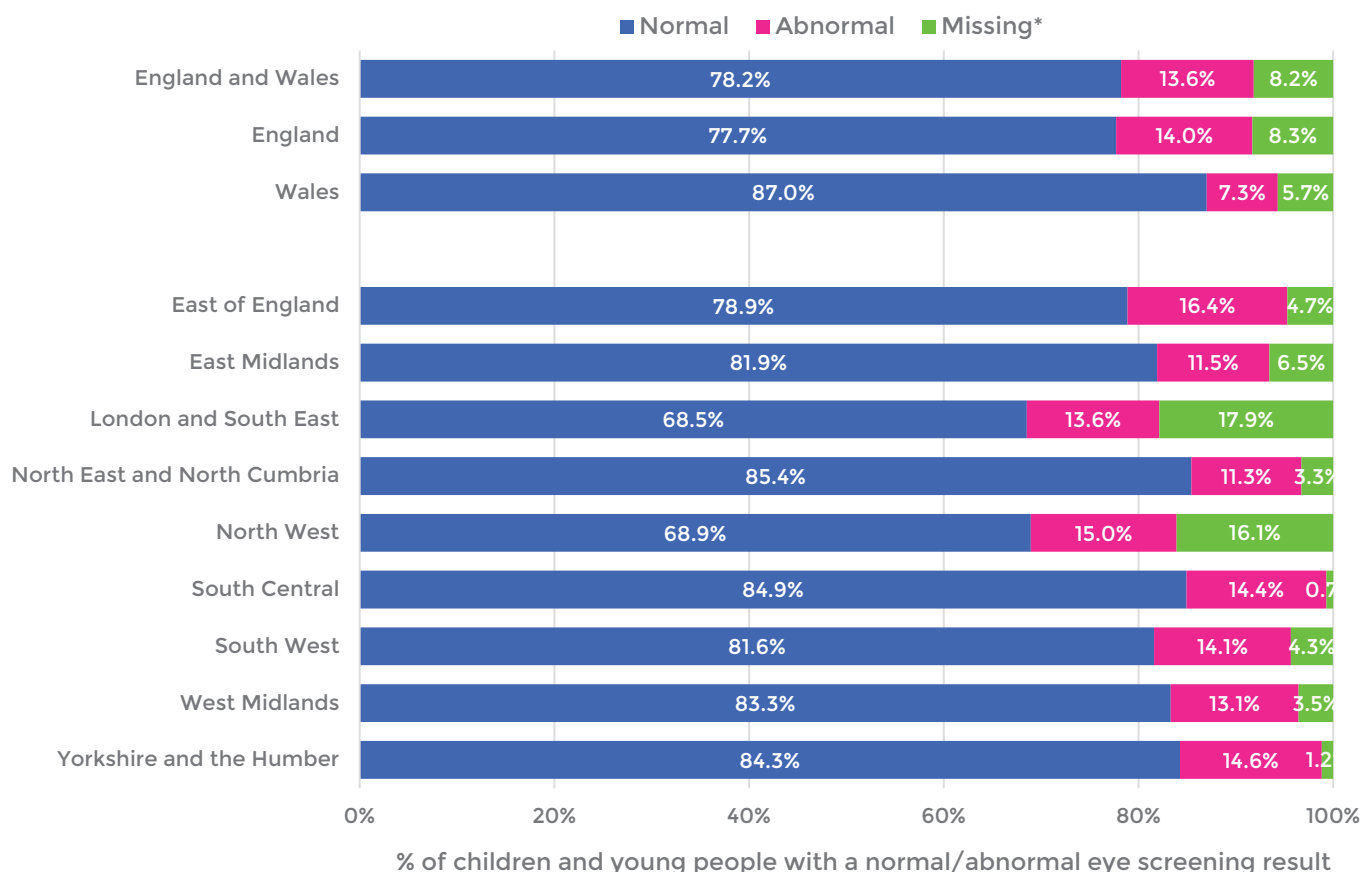
\*Missing data relates to patients with a valid recorded albuminuria level but no interpretation of this result.

## 6.2.2 Eye Disease

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

Figure 30 shows the outcome results of the 11,336 children and young people with Type 1 diabetes aged 12 years or older who underwent retinopathy screening during the audit period. In England and Wales, 13.6% had an abnormal screen result in 2016/17 compared to 13.8% in 2015/16; the percentage varies by county and by region.

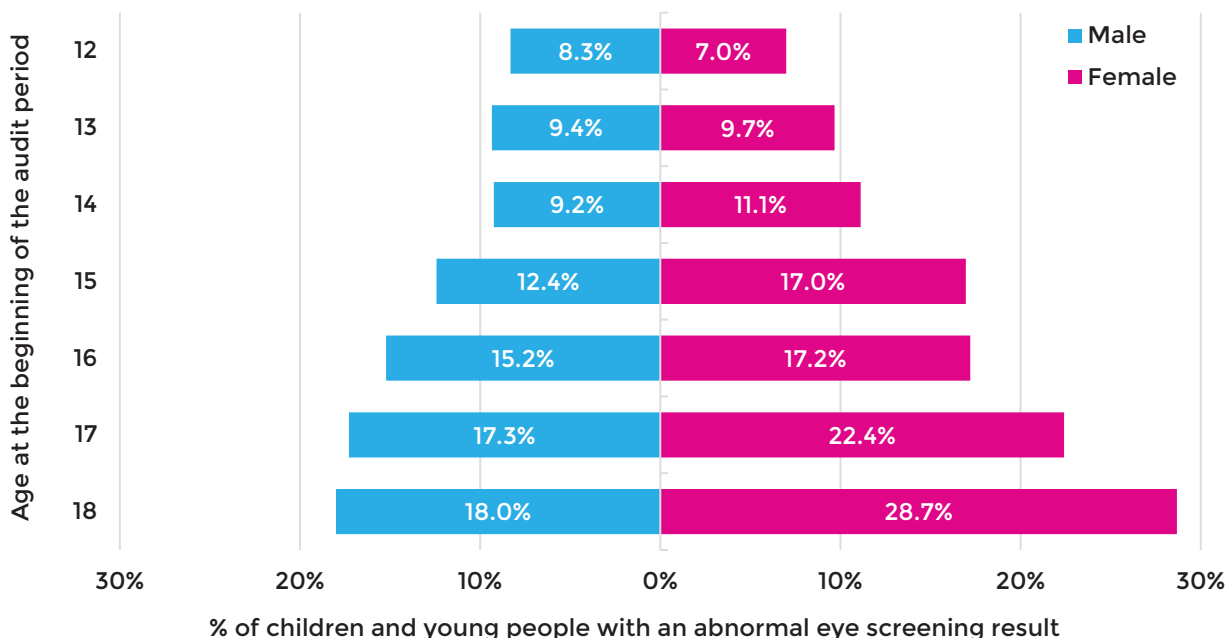
**Figure 30: Percentage of young people with Type 1 diabetes aged 12 years and older with a normal/abnormal retinopathy screening result by country and region, 2016/17**



\*missing refers to results that were recorded as either unknown or no result was recorded

There were 1,545 children and young people with Type 1 diabetes aged 12 or older who had an abnormal eye screen result recorded within the audit period. The risk of retinopathy increased with age and it was highest amongst adolescent females (Figure 31). The risk also tends to increase as duration of diabetes increases (Figure 32); this may well reflect increasing age as shown in Figure 31.

**Figure 31: Percentage of children and young people with Type 1 diabetes aged 12 years and older with albuminuria by age and gender, 2016/17**



**Figure 32: Percentage of children and young people with Type 1 diabetes aged 12 years and older with albuminuria by duration of diabetes, 2016/17**

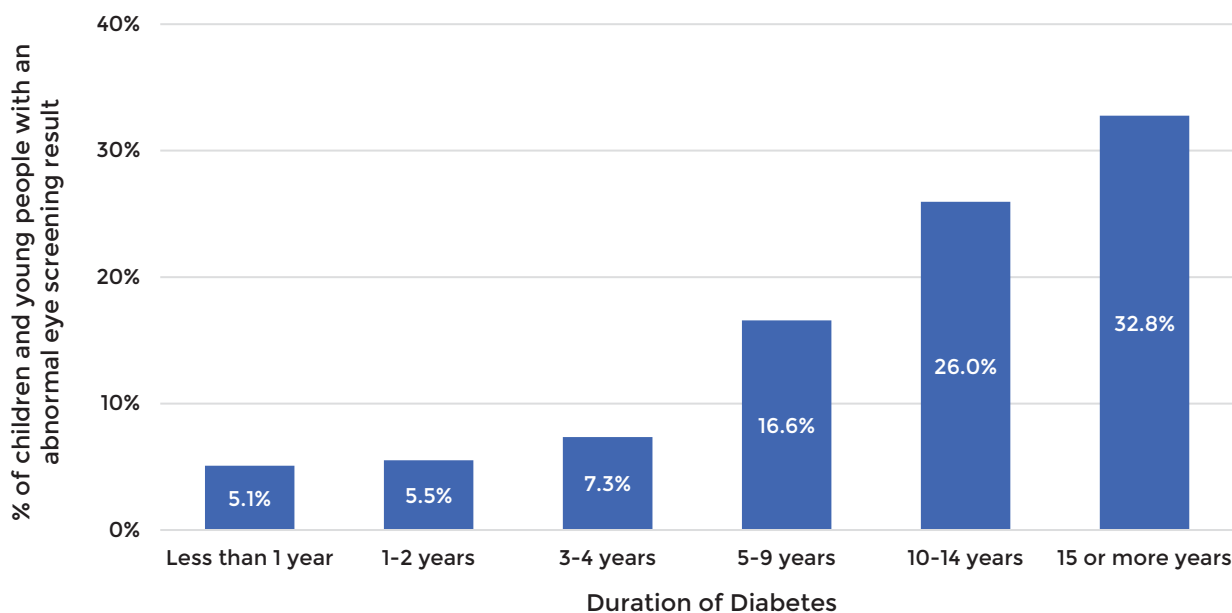
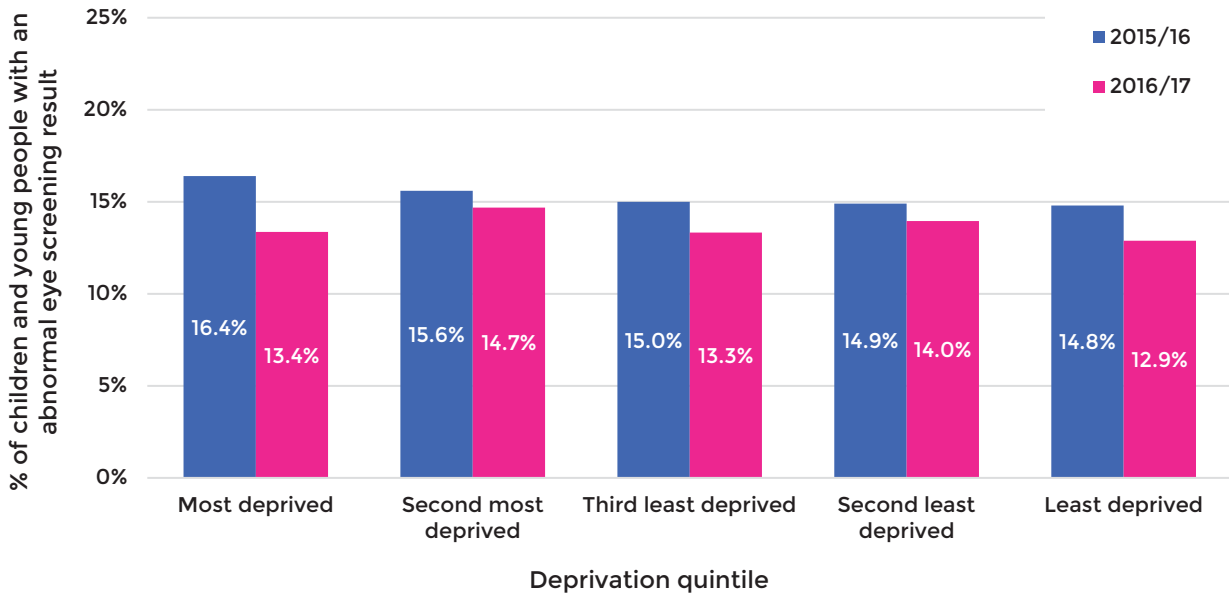


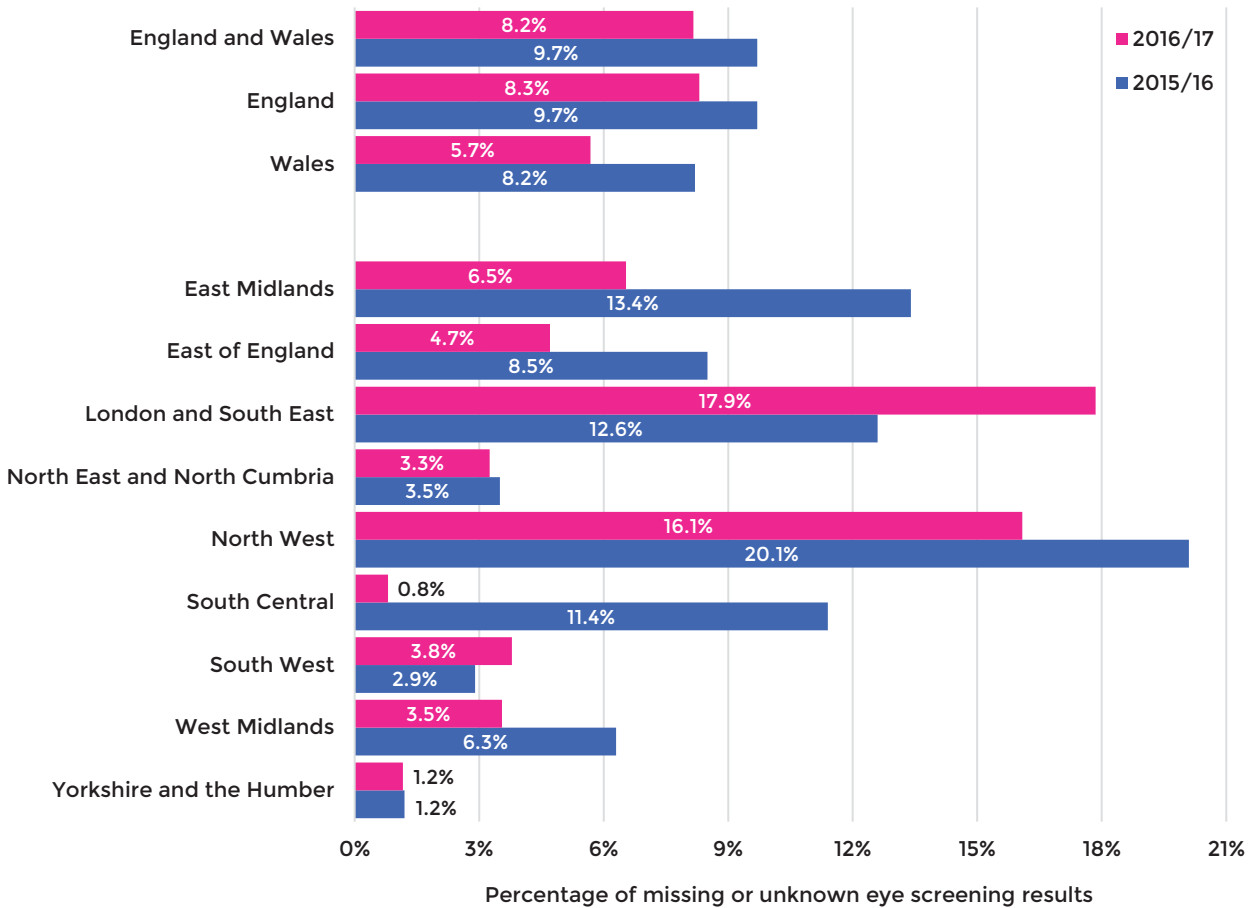
Figure 33 shows little or no variation in the risk of retinopathy by deprivation quintile.

**Figure 33: Percentage of children and young people with Type 1 diabetes aged 12 years and older with abnormal eye screening by deprivation quintile in England and Wales, 2016/17**



There has been a reduction in the number of eye screening results recorded as unknown or missing. Despite improvements however there is significant variation, particularly by region (Figure 34).

**Figure 34: Percentage of missing or unknown eye screening results by country and region, 2015/16 and 2016/17**



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

Table 16 shows the retinopathy screen outcome results for 320 young people with Type 2 diabetes aged 12 years or older. Five percent had an abnormal screen.

**Table 16: Eye screening results for children and young people aged 12 years and above with Type 2 diabetes, 2015/16-2016/17**

	Normal	Abnormal	Missing
2015/16	81.7%	5.4%	12.9%
2016/17	87.5%	4.4%	8.1%

*\*missing refers to results that were recorded as either unknown or no result was recorded*

## **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, high body mass index and smoking.

### **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 total cholesterol levels are 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 has 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 children and young people with Type 1 diabetes

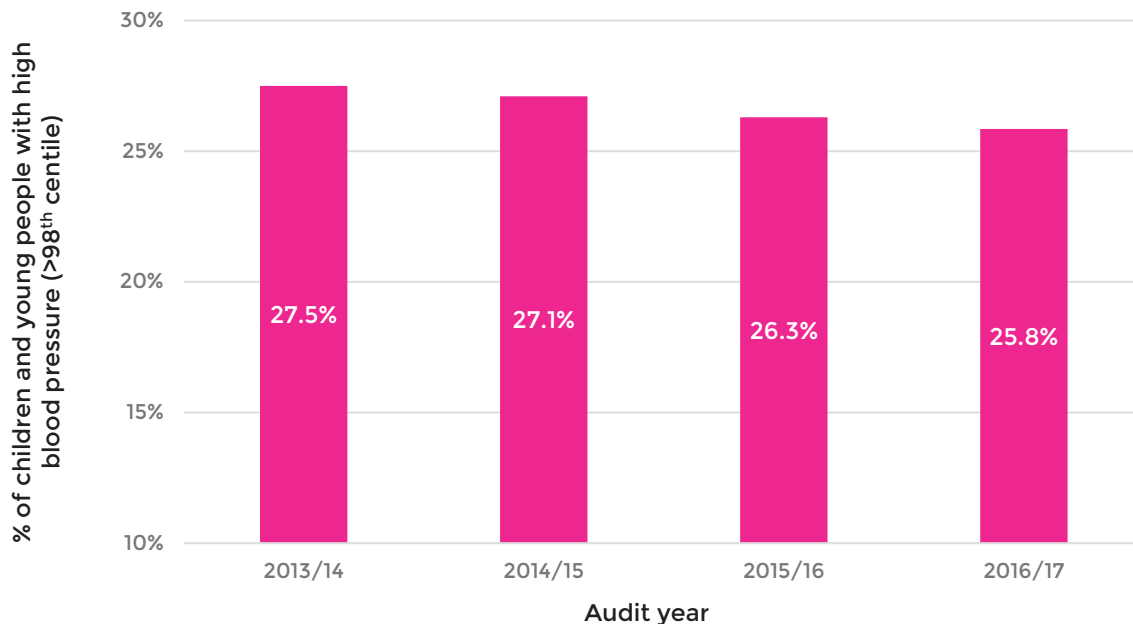
Table 17 shows the percentages of young people aged 12 or older with Type 1 diabetes with a recorded blood pressure in the audit period (n=14,415) classified as 'high normal' (91<sup>st</sup> -98<sup>th</sup> centile) or 'high' blood pressure (>98<sup>th</sup> centile), and those with a recorded cholesterol screen (n=10,308) within the target for total blood cholesterol. It shows that over a quarter of young people (25.8%) with Type 1 diabetes had high blood pressure (hypertension), and that 23.0% exceeded the target for total blood cholesterol.

**Table 17: Percentage of children and young people with Type 1 diabetes aged 12 years and over falling within blood pressure and total cholesterol targets by country and region, 2016/17**

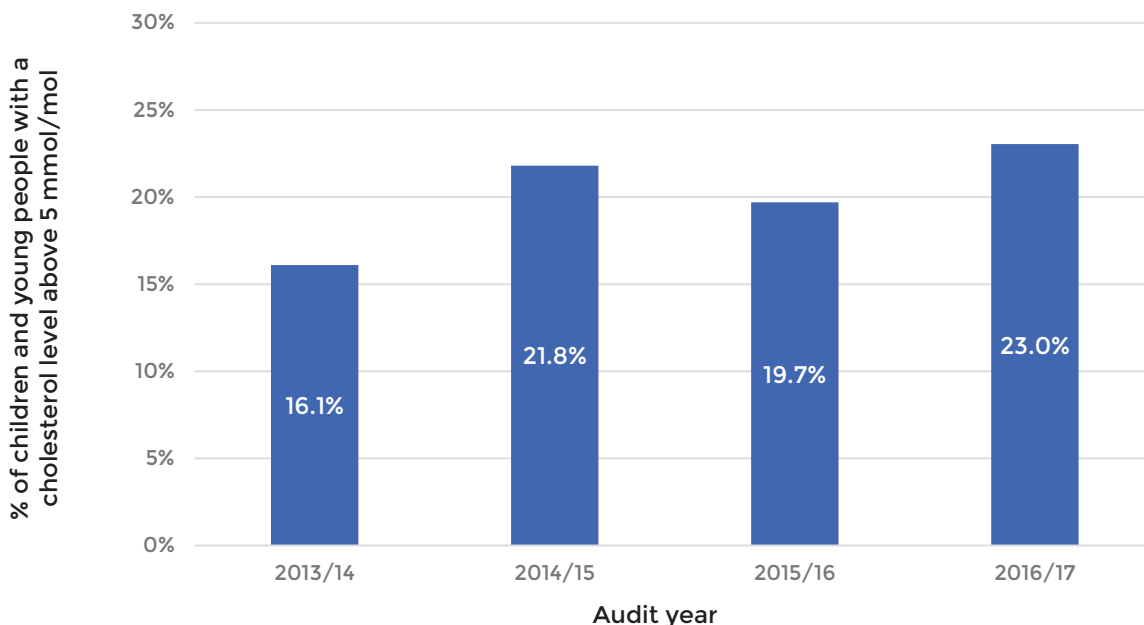
	'High normal' blood pressure (91 <sup>st</sup> -98 <sup>th</sup> centile)			'High' blood pressure (>98 <sup>th</sup> centile)			Total blood cholesterol	
	Diastolic	Systolic	Diastolic and/or systolic	Diastolic	Systolic	Diastolic and/or systolic	4 mmol/l or more	5 mmol/l or more
England and Wales	27.2%	9.6%	34.2%	24.4%	4.1%	25.8%	65.8%	23.0%
England	27.1%	9.7%	34.1%	24.4%	4.1%	25.9%	65.8%	23.1%
Wales	30.4%	9.1%	36.7%	23.6%	3.4%	24.9%	64.8%	21.8%
East of England	27.7%	8.6%	32.2%	26.5%	4.9%	27.9%	62.7%	21.8%
East Midlands	25.4%	11.4%	36.2%	24.9%	3.8%	26.6%	66.2%	23.5%
London and South East	27.7%	9.4%	34.2%	22.6%	2.7%	23.6%	69.7%	26.0%
North East and North Cumbria	26.6%	5.0%	30.1%	23.1%	1.5%	23.5%	60.3%	22.0%
North West	28.9%	9.1%	35.6%	23.6%	3.1%	24.8%	65.4%	23.6%
South Central	27.4%	11.0%	34.9%	23.4%	4.8%	25.7%	62.2%	19.8%
South West	28.4%	11.0%	36.8%	28.6%	6.1%	30.8%	64.9%	21.5%
West Midlands	25.5%	10.5%	33.4%	25.6%	5.2%	27.3%	68.0%	23.7%
Yorkshire and the Humber	25.4%	10.4%	32.8%	24.9%	5.8%	26.4%	64.3%	21.4%

There has been a gradual fall in the percentage of young people with Type 1 diabetes with 'high' blood pressure (>98<sup>th</sup> centile) over the last four audit cycles, decreasing by 1 percentage point each year (Figure 35). On the other hand, the percentage of young people with Type 1 diabetes with high cholesterol has varied over the same period (Figure 36).

**Figure 35: Percentage of young people aged 12 years and older with Type 1 diabetes with high blood pressure in England and Wales, 2013/14-2016/17**



**Figure 36: Percentage of young people aged 12 years and older with Type 1 diabetes above the target for total blood cholesterol in England and Wales, 2013/14-2016/17**



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

Table 18 shows the percentages of children and young people with Type 2 diabetes with a recorded blood pressure in the audit period (n=531) classified as ‘high normal’ (91<sup>st</sup> -98<sup>th</sup> centile) or ‘high’ blood pressure (>98<sup>th</sup> centile), and those with a recorded cholesterol screen (n=378) within the target for total blood cholesterol. It shows that 45.6% of children and young people with Type 2 diabetes have high blood pressure, and 36.2% are exceeding the target for total blood cholesterol.

**Table 18: Percentage of children and young people with Type 2 diabetes falling within blood pressure and total cholesterol targets by country, 2016/17**

	‘High normal’ blood pressure (91 <sup>st</sup> -98 <sup>th</sup> centile)			‘High’ blood pressure (>98 <sup>th</sup> centile)			Total blood cholesterol	
	Diastolic	Systolic	Diastolic and/or systolic	Diastolic	Systolic	Diastolic and/or systolic	4 mmol/l or more	5 mmol/l or more
England and Wales	24.5%	15.8%	36.2%	42.2%	13.6%	45.6%	75.9%	36.2%
England	24.6%	15.4%	35.9%	41.2%	13.7%	44.7%	75.6%	36.2%
Wales	*	*	42.1%	68.4%	*	68.4%	84.6%	38.5%

\* indicates a percentage that has been suppressed due to it being derived from a number <=5.

### 6.3.2 Body Mass Index

Higher Body Mass Index (BMI, weight/height<sup>2</sup>) is associated with increased cardiovascular risk. To allow

- Underweight: below the 5th centile
- Healthy weight: between the 5th and 85th centile
- Overweight: between the 85th and 95th centile
- Obese: above the 95th centile

direct comparisons across different ages and genders BMI requires standardisation using centile charts.

The following categories of BMI are shown based on the UK 1990 standards (Pan & Cole, 2012).

Comparisons can be made with the National Child Measurement Programme in England 2016/17 (NHS Digital, 2017) and the Child Measurement Programme in Wales (2015/16). 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.

For 2016/17, in England 33.4% of children aged 4 to 5 years old with Type 1 diabetes are overweight or obese (a decrease from 33.7% in 2015/16) compared to 22.6% in the National Child Measurement Programme for England.

A similar pattern is found in Wales where 39.4% of children with Type 1 diabetes aged 4 to 5 years are overweight or obese (a decrease from 45.4% in 2015/16) compared to 26.2% within the Child Measurement Programme for Wales.

Amongst children aged 10 to 11 years old with Type 1 diabetes in England the prevalence of overweight and obesity was 35.3% (an increase from 33.7% in 2015/16) compared to 34.3% in the National Child Measurement Programme in England.

Therefore, despite the secular trends in body mass index since 1990, comparisons with the National Child Measurement Programmes clearly demonstrate a higher prevalence of obesity among young children with Type 1 diabetes.

### 6.3.2.1 Body Mass Index and Type 1 diabetes

Figures 37 and 38 show the percentage of children and young people with Type 1 diabetes included in the 2016/17 audit within each BMI category. It shows that a higher percentage of those aged 0-11 years had a healthy weight (63.9%) compared to those aged 12 years and older (56.7%), and that higher percentages of children and young people with Type 1 diabetes were overweight or obese than were underweight.

**Figure 37: Percentage of children aged 0-11 years with Type 1 diabetes within BMI categories by country and region, 2016/17**



**Figure 38: Percentage of children and young people 12 years and older with Type 1 diabetes within BMI categories by country and region, 2016/17**



*\*Missing refers to records which had a BMI recorded but the result was missing or recorded incorrectly*

Figure 39 shows the distribution of body mass index of children and young people with Type 1 diabetes between 2014/15 and 2016/17 in comparison to the 1990 standards. It shows that overall, children and young people with Type 1 diabetes have a higher BMI than the general population.

**Figure 39: Distribution of body mass index of children and young people with Type 1 diabetes in 2014/15, 2015/16 and 2016/17 compared to the 1990 reference population**

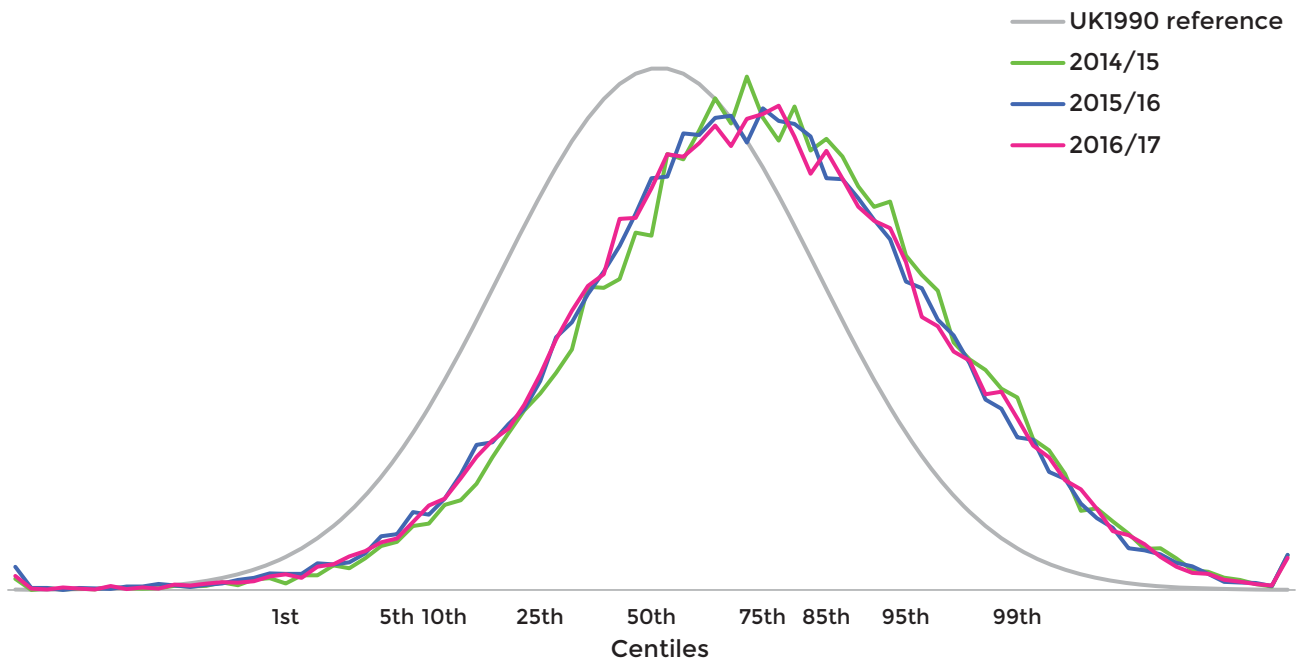
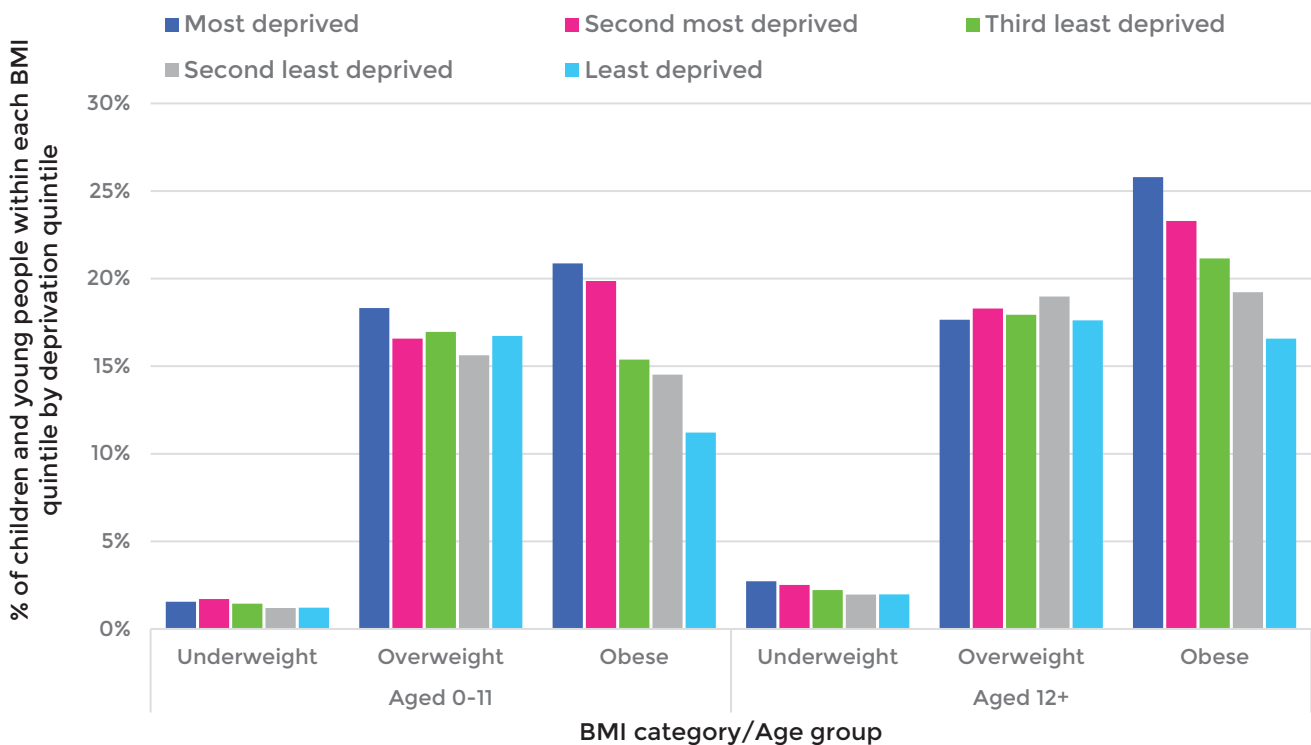


Figure 40 shows the percentage of children and young people with Type 1 diabetes who are categorised as underweight, overweight or obese by deprivation quintile. It shows that children and young people with Type 1 diabetes who are recorded as being obese are more likely to live in more deprived areas than in least deprived areas.

**Figure 40: Percentage of children and young people with Type 1 diabetes within each body mass index category by deprivation quintile, 2016/17**



### 6.3.2.2 Body Mass Index and Type 2 diabetes

Table 19 shows the percentage of children and young people with Type 2 diabetes in each BMI category for England and Wales in 2015/16 and 2016/17.

**Table 19: Body mass index categories for children and young people with Type 2 diabetes, 2015/16 and 2016/17**

	Percentage of children and young people with Type 2 diabetes in the following categories				
	Underweight	Healthy weight	Overweight	Obese	Missing data
2016/17	0.3%*	5.7%	7.4%	78.6%	8.0%
2015/16	*	6.9%	7.3%	78.5%	7.3%

*\*indicates a percentage derived from a number <5*

### 6.3.3 Smoking

Smoking has adverse effects in any population, and in young people with diabetes is detrimental to outcomes and raises the risk of future complications.

Table 20 shows the percentages of children and young people age 12 and over with Type 1 and Type 2 diabetes with a recorded smoking result in the audit period classified as 'current smoker'. It shows that just under one in 30 patients were smoking at the time of audit. It shows that young people with Type 2 diabetes were more likely to be smoking than those with Type 1.

**Table 20: Percentage of young people aged 12 years and older with Type 1 diabetes and Type 2 diabetes who were smoking by country and regional network, 2016/17**

	Type 1 diabetes (n= 11,039)	Type 2 diabetes (n= 419)
England and Wales	3.2%	4.5%
England	3.3%	4.3%
Wales	2.8%	9.1%
East of England	5.0%	-
East Midlands	3.0%	-
London and South East	2.1%	-
North East and North Cumbria	2.8%	-
North West	4.1%	-
South Central	4.9%	-
South West	4.0%	-
West Midlands	2.5%	-
Yorkshire and the Humber	2.9%	-



## 6.3.4 Micro and macrovascular outcomes key findings

### Microvascular disease and risk factors

- Consistent with results of the 2015/16 audit, Albuminuria was found in 9.7% of young people aged 12 years and above with Type 1 diabetes screened in the audit year.
- The prevalence of albuminuria in Type 1 diabetes was higher amongst those living in the most deprived areas.
- Albuminuria was found in 20.1% of children and young people with Type 2 diabetes screened in the audit year.
- Retinopathy was found in 13.6% of young people aged 12 and above with Type 1 diabetes who received screening in the audit year.
- The risk of retinopathy increased with age and was highest amongst adolescent females. There was little or no variation in the prevalence of abnormal eye screening results by deprivation quintile.
- Abnormal eye screening results were found in 5.4% of young people with Type 2 diabetes screened within the audit period.

### Macrovascular disease and risk factors:

- High blood pressure (hypertension) was found in 25.8% of young people aged 12 years and older with Type 1 diabetes screened in the audit year.
- 23.0% 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 or less.
- Hypertension was found in 45.6% of children and young people with Type 2 diabetes, a markedly higher prevalence compared to those with Type 1 diabetes.
- 16.8% of children aged 0 to 11 years with Type 1 diabetes were overweight, and 16.7% were obese. These figures rose to 18.1% and 21.3%, respectively, for young people aged 12 years and above.
- 78.6% of children and young people with Type 2 diabetes were obese.
- 3.2% of young people with Type 1 diabetes aged 12 and above with a recorded smoking status were current smokers, as were 4.5% of young people with Type 2 diabetes aged 12 and above.

## 6.3.5 Micro and macrovascular recommendations

### Multidisciplinary paediatric diabetes teams should:

- Prioritise improving diabetes management to reduce the lifetime risk of developing complications.

### Commissioners should:

- 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.

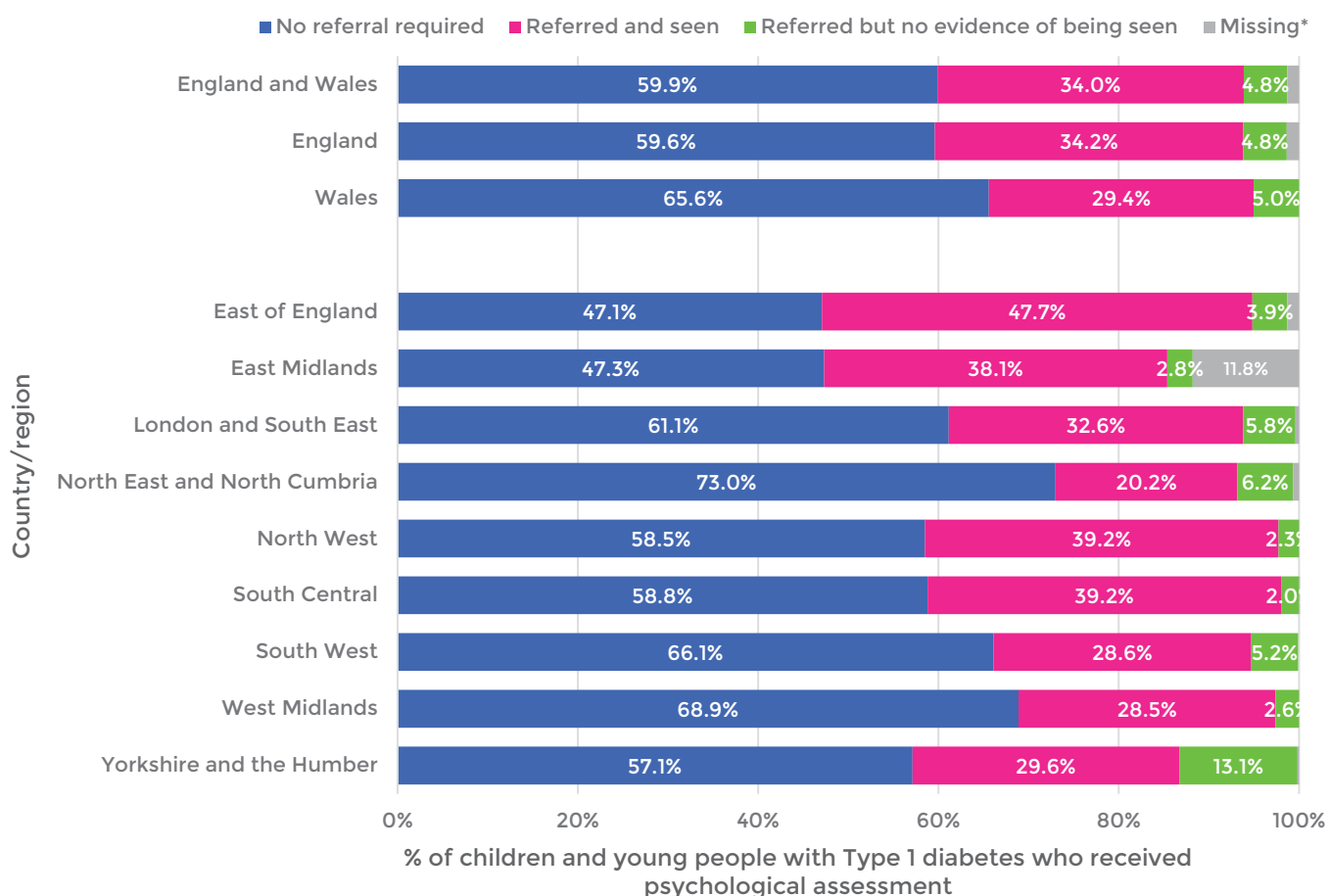
## 6.4 Psychological assessment

Psychological assessment and access to psychology services should be available to all children and young people and their families with diabetes.

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

Of the children and young people with Type 1 diabetes recorded as having psychological assessment within the audit period (n=19,694), one-third (34%) were recorded as having a referral and being seen at least once within the audit period, and a further 5% were recorded as having a referral however there was no evidence that they were seen.

**Figure 41: Outcome of assessment for need of Child and Adolescent Mental Health Services/psychological support of children and young people with Type 1 diabetes by country and region, 2016/17**



\*missing indicates those who were recorded as being in need of psychological assessment but there was no evidence to indicate whether or not a referral was made

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

Table 21 shows the latest outcome recorded in the audit year for the children and young people with Type 2 diabetes who had a psychological assessment dated within the audit period (n=390). As this only represents 54.5% of the Type 2 cohort, these figures should be interpreted with caution.

**Table 21: 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 referral required	Referred and seen	Referred but no evidence of being seen	Missing data
England and Wales	55.6%	37.4%	5.6%	1.3%

## 6.4.3 Key findings

- 34.0% of children and young people with Type 1 diabetes and 37.4% of those with Type 2 diabetes required referral and were seen by expert CAMHS/psychology services in 2016/17.

## 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 by an expert psychologist and/or CAMHS when necessary.

### 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.

## 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 the Hospital Episode Statistics in England (HES), and Patient Episode Database for Wales (PEDW). (RCPCH 2014 & 2017), hence rates are not directly comparable.

In 2016/17, 158 out of 173 PDUs submitted admission data to the audit from 25,589 children and young people with Type 1 diabetes. Results are presented for children and young people with Type 1 diabetes only due to small numbers with other types of diabetes (Table 22).

**Table 22: Percentage of children and young people with Type 1 diabetes (n= 25,589) admitted at least once in 2016/17 for diabetes-related reasons**

	DKA not at diagnosis	Hypoglycaemia	Ketosis without acidosis	Other
England and Wales	3.0%	1.5%	1.6%	6.9%
England	3.0%	1.5%	1.6%	6.8%
Wales	3.6%	2.0%	1.9%	8.4%
East of England	3.4%	2.1%	2.2%	10.2%
East Midlands	1.3%	1.1%	1.1%	4.1%
London and South East	2.3%	1.1%	0.9%	5.2%
North East and North Cumbria	3.1%	2.3%	1.2%	6.1%
North West	3.7%	1.3%	1.6%	6.8%
South Central	2.0%	2.0%	1.1%	6.6%
South West	3.5%	1.1%	2.2%	7.1%
West Midlands	2.9%	1.1%	1.9%	6.9%
Yorkshire and the Humber	4.4%	1.5%	2.8%	8.1%

The results from PDU submitted data alone (Table 22) show a lower prevalence of DKA not at diagnosis (3.0% vs 5.2%), hypoglycaemia (1.5% vs 2.3%) and 'other causes' (6.9% vs 18.8%) compared to the combined PDU and HES/PEDW data published in 2017. This could be the result of successful avoidance of admissions in the interim period, incomplete data submission, or incomplete linkage of admissions recorded in both HES/PEDW databases and the NPDA dataset.

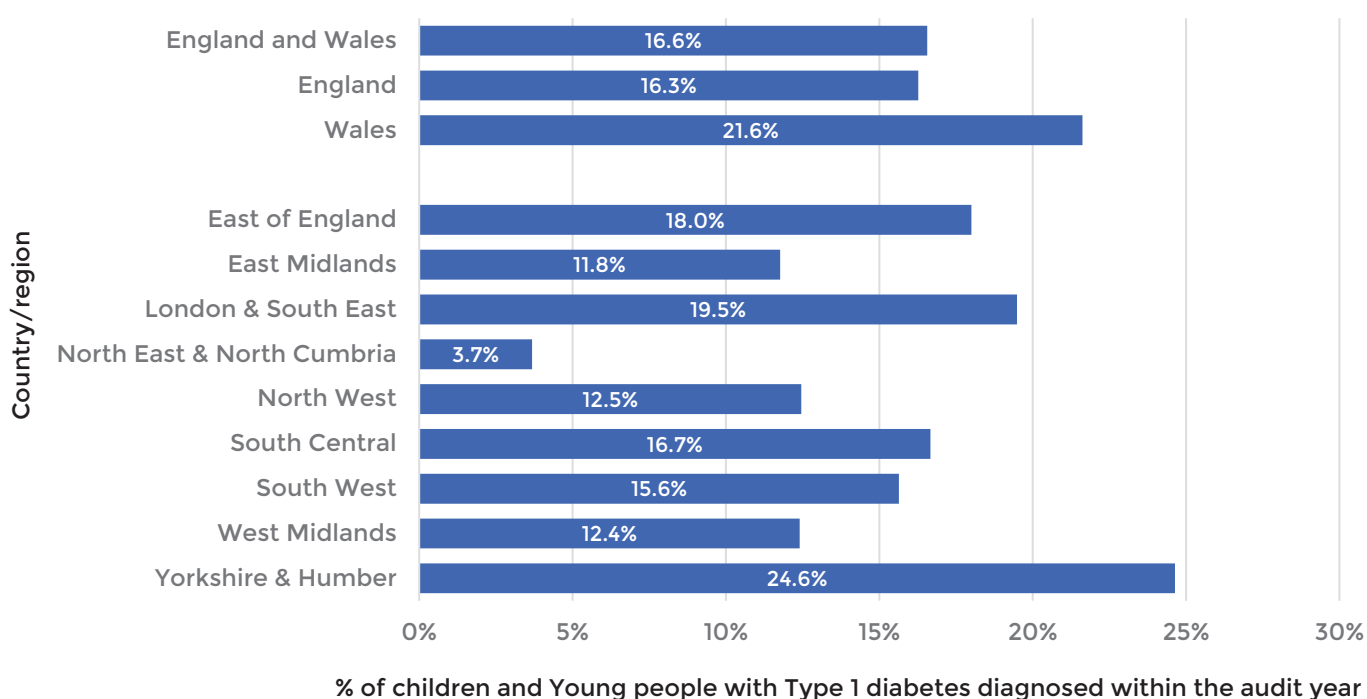
Analysis showed that 18 children and young people were admitted for stabilisation of diabetes at least once subsequent to the diagnostic period.

## 6.5.1 DKA at diagnosis

Figure 42 shows that for England and Wales combined, 16.6% of all newly diagnosed patients in 2016/17 (n= 2711) had DKA at diagnosis of Type 1 diabetes. This finding is lower than the 23% incidence rate reported in the previous NPDA Hospital Admissions Report (RCPCH, 2017). 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 2016/17 audit alone.

A 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 42: Percentage of children and young people with Type 1 diabetes who had DKA at diagnosis in 2016/17, by region and country**



## 6.5.2 Key findings

- Not all PDUs participating in the NPDA submitted admissions data.
- Incidence of diabetes-related admissions was lower than reported in the NPDA Admissions Report (NPDA, 2017) which combined PDU-submitted data with data from the HES and PEDW databases.
- 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 before PDU submitted admission data can be considered representative of admission trends in England and Wales.

## 6.5.3 Recommendations

- All PDUs participating in the NPDA should submit a complete dataset to 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

The NPDA collects information on individual treatment regimen for both Type 1 and Type 2 diabetes. Data is collected to observe trends in usage of different regimens rather than ascribing outcomes related to different treatments. Where a treatment regimen changes throughout the audit year the latest regimen is used for the analysis.

### 7.1 Type 1 diabetes

Table 23 provides a breakdown of the treatment regimens recorded by nation and region for children with Type 1 diabetes (n= 27,739).

**Table 23: Percentage of children and young people with Type 1 diabetes on each treatment regimen by country and region in England and Wales, 2016/17**

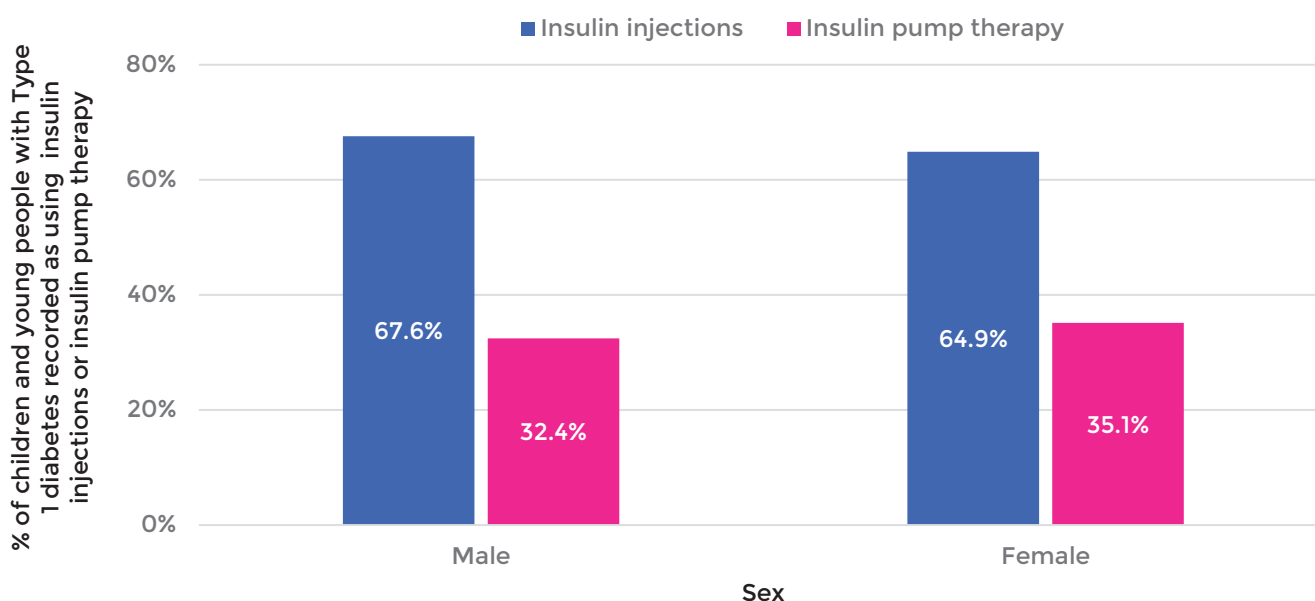
	No insulin	1-2 insulin injections per day	3 insulin injections per day	4 or more insulin injections per day	Insulin pump therapy	Oral hypoglycaemic agents +/- insulin	Missing data
England and Wales	1.3%	1.7%	1.7%	60.1%	32.2%	0.5%	2.5%
England	1.2%	1.8%	1.7%	60.0%	32.4%	0.5%	2.5%
Wales	2.3%	1.2%	2.0%	61.3%	29.2%	0.1%	3.9%
East of England	0.7%	1.4%	1.9%	64.7%	29.0%	0.7%	1.7%
East Midlands	3.2%	0.8%	0.4%	58.8%	35.6%	0.4%	0.8%
London and South East	1.2%	2.4%	1.1%	59.5%	32.2%	0.5%	3.2%
North East and North Cumbria	0.8%	3.3%	4.8%	52.6%	36.6%	0.3%	1.6%
North West	1.7%	3.1%	1.9%	57.6%	31.4%	0.5%	3.8%
South Central	1.1%	1.0%	1.9%	61.0%	32.4%	0.2%	2.5%
South West	0.7%	0.8%	1.1%	62.7%	31.0%	0.4%	3.3%
West Midlands	1.2%	1.0%	2.7%	64.5%	29.0%	0.6%	1.0%
Yorkshire and the Humber	0.6%	0.9%	0.7%	56.6%	38.2%	0.5%	2.5%

Although most children and young people with Type 1 diabetes were recorded as being on insulin in some form, 1.3% were recorded as being on 'no insulin'. Care should be taken in interpreting this result as children and young people with a diagnosis of Type 1 diabetes clearly require insulin as part of their ongoing treatment.

However, there has been an improvement in the quality of treatment data submitted for children and young people with Type 1 diabetes since 2015/16, when 8.7% had no treatment regimen data submitted.

Figure 43 shows the breakdown of insulin regimens amongst those with a recorded gender and regimen (n= 26,468).

**Figure 43: Percentage of children and young people with Type 1 diabetes recorded as using insulin injections or insulin pump therapy by gender, 2016/17**



It shows that pump usage is more prevalent in females.

Table 24 provides a breakdown of insulin therapy into injections and pump therapy by age group amongst those with a recorded insulin regimen (n= 26,557). Younger children were more likely to be using insulin pump therapy in keeping with the trend seen in some other European and transatlantic cohorts (Sherr et al., 2016).

**Table 24: Percentage of children and young people with Type 1 diabetes on insulin injections or pump therapy by age category in England and Wales, 2016/17**

	1-4 + daily injections	Insulin pump therapy
0 - 4 years	51.0%	45.7%
5 - 9 years	59.1%	38.6%
10 - 14 years	63.5%	34.4%
15 - 19 years	68.9%	27.0%

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 44).

**Figure 44: Percentage of children and young people either on daily insulin injections or pump therapy by age group for England and Wales, 2014/15 -2016/17**

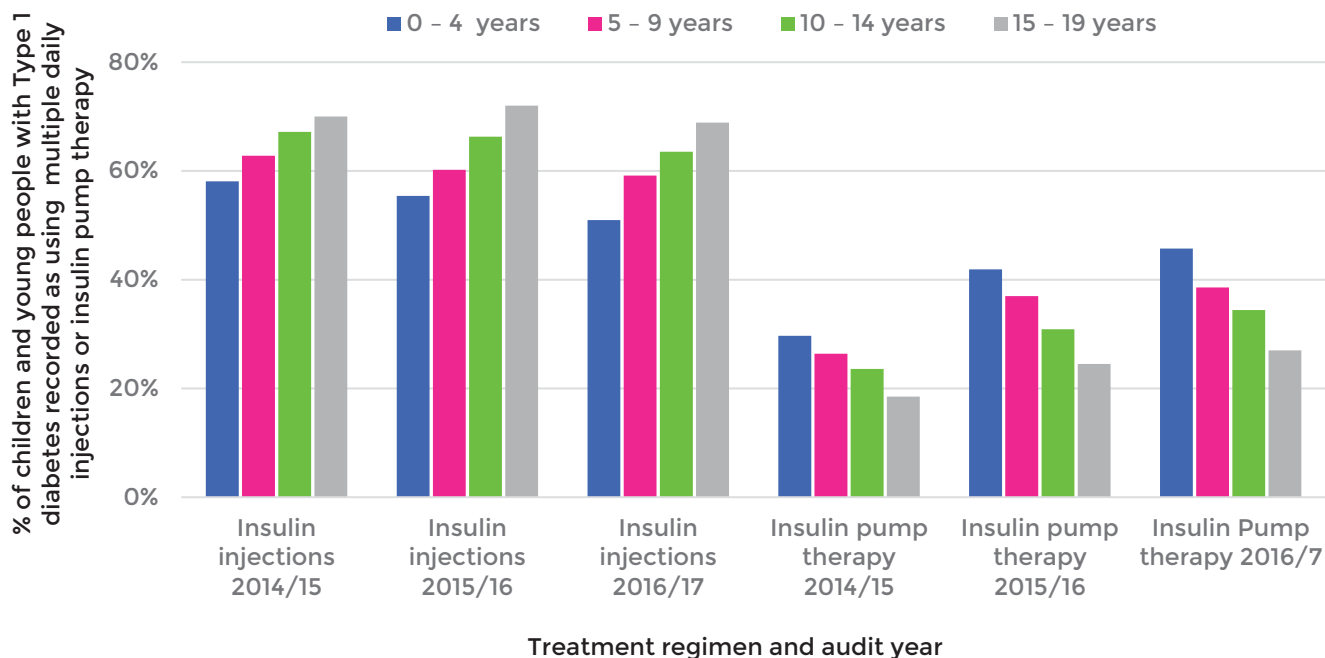


Figure 45 shows variability in the proportion of children and young people using insulin injections or pump therapy associated with duration of diabetes. Data is presented from all those with a recorded regimen and date of diagnosis (n= 26,479). Those in their first year of diagnosis of Type 1 diabetes were more likely to be using insulin injections, whereas those who had been diagnosed between 5-9 years had the highest percentage of insulin pump usage.

**Figure 45: Percentage of children and young people either on daily insulin injections or pump therapy by duration of diabetes for England and Wales, 2016/17**

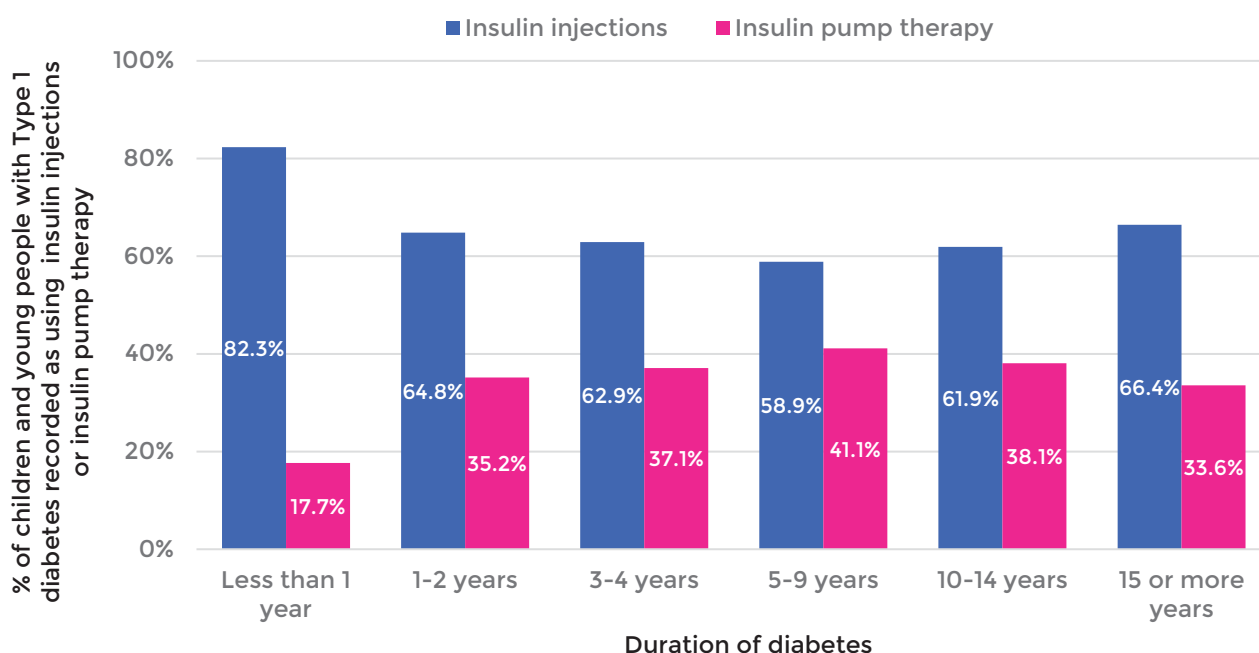
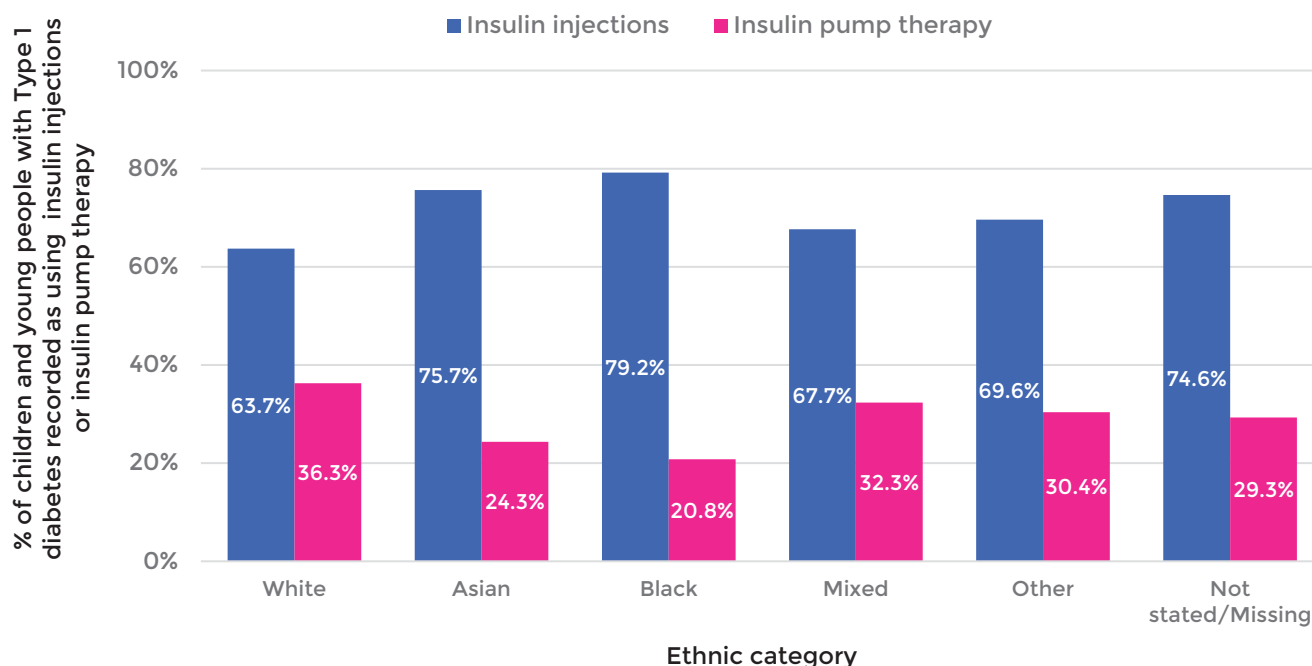




Figure 46 shows that White ethnicity was associated with a higher relative pump usage compared to insulin injections, compared to ethnic minority groups (n=26,557).

**Figure 46: Percentage of children and young people either on daily insulin injections or pump therapy by ethnic category for England and Wales, 2016/17**



Insulin pump therapy is more prevalent in those living in the least deprived areas using postcode as a measure of deprivation (n= 27,430, Table 25). Use of insulin injections was more prevalent amongst those living in the most deprived areas.

**Table 25: Percentage of children and young people with Type 1 diabetes using insulin injections or pump therapy by deprivation quintile, 2016/17**

	Insulin injections	Insulin pump therapy
Most deprived	70.1%	25.6%
2 <sup>nd</sup> most deprived	66.2%	29.0%
3 <sup>rd</sup> most deprived	62.1%	33.7%
2 <sup>nd</sup> least deprived	59.1%	36.8%
Least deprived	59.0%	37.5%

Figure 47 shows that 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. In 2014/15 the percentage on insulin pump therapy for the most and least deprived areas was 18.4% versus 26.3%, whereas in 2016/17 the gap has widened respectively to 25.6% versus 37.5%.

**Figure 47: Percentage of children and young people with Type 1 diabetes using insulin injections or insulin pump therapy by deprivation quintile and audit year 2014/15 - 2016/17**

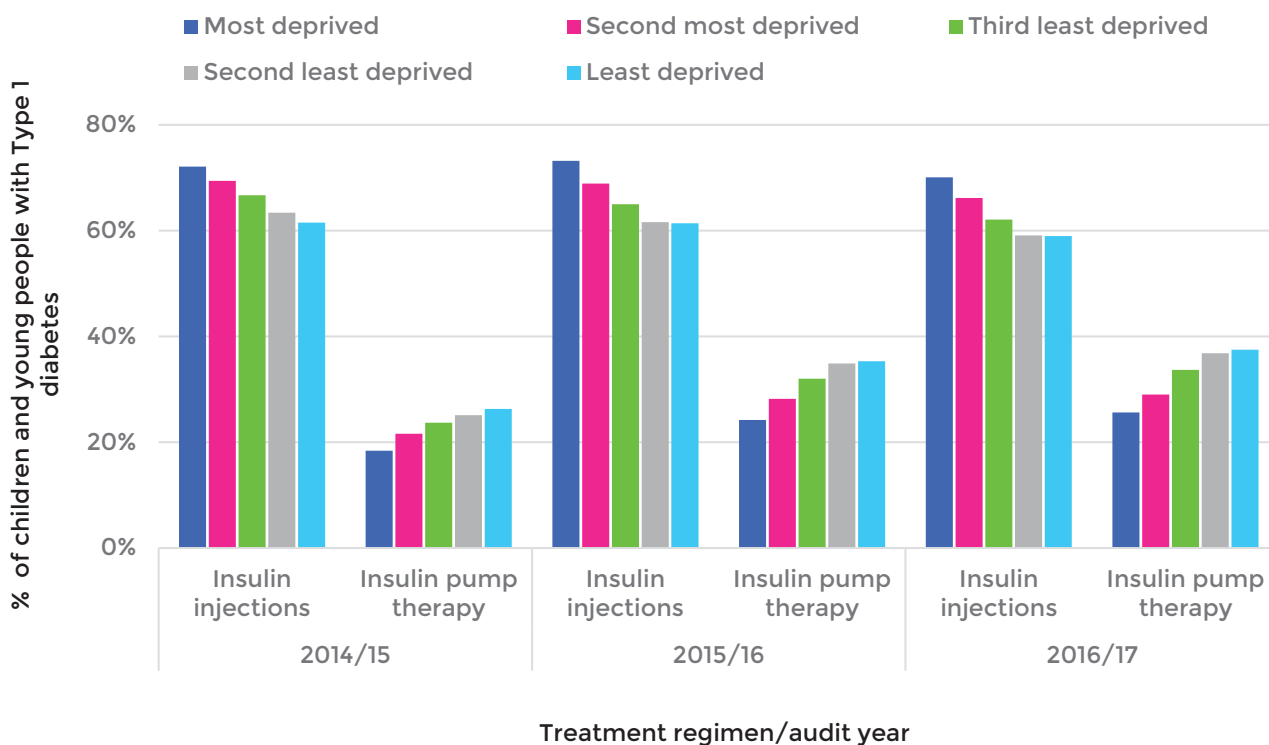
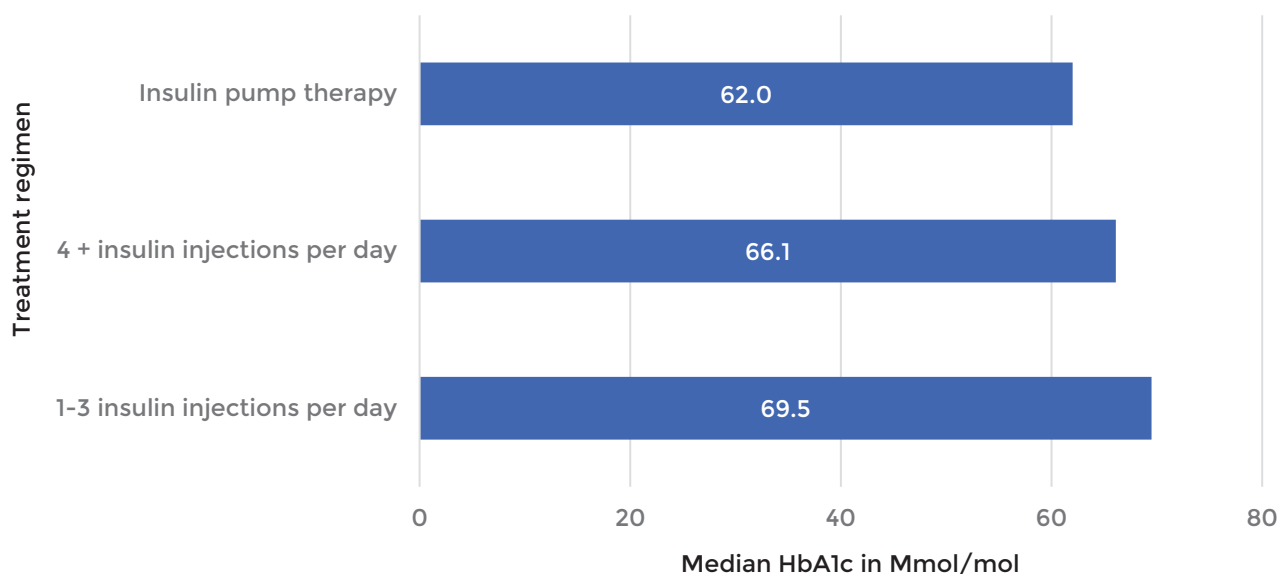


Figure 48 shows the median HbA1c by treatment regimen. This data does not take into account the influence of deprivation, age, duration of diabetes or other factors which may influence the choice of insulin regimen and have been shown to impact upon diabetes control, and so these results should be interpreted with caution.

**Figure 48: Median HbA1c of children and young people by treatment regimen in mmol/mol**



## 7.2 Type 2 diabetes

Table 26 shows the breakdown of diabetes treatment regimen for children and young people with Type 2 diabetes.

**Table 26: Percentage of children and young people with Type 2 diabetes on each treatment regimen, 2016/17**

	No insulin (dietary treatment only)	1-3 insulin injections per day	4 or more insulin injections per day	Insulin pump therapy	Oral hypoglycaemic agents	Oral hypoglycaemic agents and insulin	Missing data
England and Wales	16.9%	2.6%	9.8%	0.8%	42.5%	18.5%	8.8%

Although the majority of those with Type 2 diabetes were either managing their diabetes with diet alone (no insulin) or oral hypoglycaemic medication (alone or in combination with insulin), there was a small cohort on insulin alone and some missing data. Caution should therefore be taken when interpreting these results.

## 7.3 Key findings

- Usage of insulin pumps to deliver insulin therapy in Type 1 diabetes is increasing in all age groups since 2014/15.
- Younger children with Type 1 diabetes, females, those living in the least deprived areas and those with White ethnicity were more likely to be using pump therapy.
- Pump usage amongst children and young people with Type 1 diabetes was associated with lower median HbA1c. 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 patients with these characteristics within the cohort of pump users.
- Most young people with Type 2 diabetes are controlled with diet and oral hypoglycaemic agents.

## 7.4 Recommendations

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

- Improve the completeness of the recording and submission of treatment regimen 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.

### **Regions/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. 'Structured patient education' for self-management

Structured education is important to support children and young people with diabetes and their families to understand the optimal management of their treatment regimen, blood glucose monitoring, the effects of diet, physical activity and illness, and how to detect and manage hypoglycaemia, hyperglycaemia and ketosis.

NICE (NG18, 2015) recommends:

Children and young people with Type 1 diabetes and their family members or carers (as appropriate) should be offered a continuing programme of education from diagnosis.

The programme should include the following core topics:

- insulin therapy, including its aims, how it works, its mode of delivery and dosage adjustment
- blood glucose monitoring, including targets for blood glucose control (blood glucose and HbA1c levels)
- the effects of diet, physical activity and intercurrent illness on blood glucose control
- managing intercurrent illness ('sick-day rules', including monitoring of blood ketones [beta-hydroxybutyrate])
- detecting and managing hypoglycaemia, hyperglycaemia and ketosis

Children and young people with Type 2 diabetes and their family members or carers (as appropriate) should be offered a continuing programme of education from diagnosis.

The programme should include the following core topics:

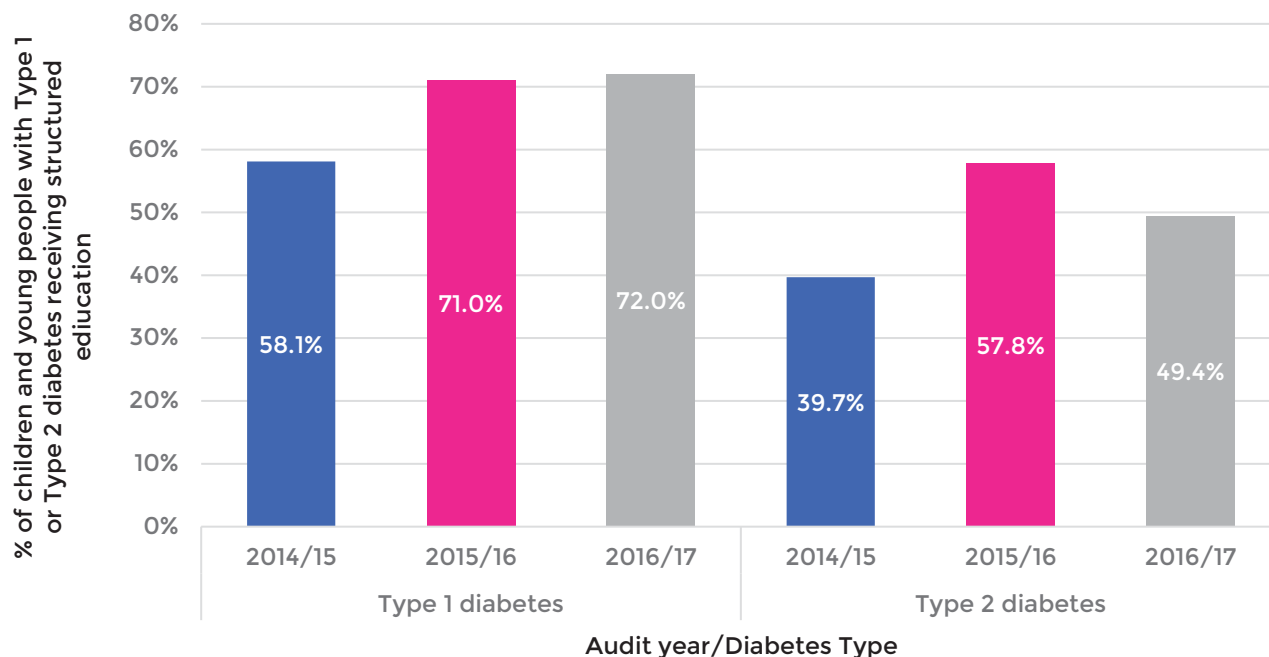
- HbA1c monitoring and targets
- the effects of diet, physical activity, body weight and intercurrent illness on blood glucose control
- the aims of metformin therapy and possible adverse effects
- the complications of type 2 diabetes and how to prevent them

For the purposes of audit, the NPDA has defined a structured patient education programme for paediatric diabetes as:

*'A programme of self-management education, tailored to the needs of the child or young person and their family, both at the time of initial diagnosis and on an ongoing basis throughout the child or young person's attendance at the paediatric diabetes service. This is a programme offered in addition to the education provided at routine outpatient consultations.'*

Figure 49 shows an improvement in the percentage of children and young people with Type 1 diabetes receiving structured patient education between 2014/15 and 2016/17 but a decline in provision to those with Type 2 diabetes between 2015/16 and 2016/17.

**Figure 49: Percentage of children and young people with Type 1 and 2 diabetes included in the 2014- 2016/17 audits for England and Wales receiving structured education by audit year\***



*\*(Please note: The 2014/15 figures exclude patients without a full year of care, whereas the 2015/16 and 2016/17 results include those from all children and young people with Type 1 or 2 diabetes included in the audit).*

There is considerable variability in the provision of structured education across the two nations. Table 27 gives a breakdown of the percentage of children receiving structured education for self-management in the audit period by country and region.

**Table 27: Percentage of children and young people with Type 1 and 2 diabetes recorded as receiving structured patient education in the audit period by country and regional network, 2016/17**

	Type 1 diabetes	Type 2 diabetes
England and Wales	72.0%	49.4%
England	73.9%	50.2%
Wales	38.0%	28.6%
East of England	75.8%	75.7%
East Midlands	73.6%	57.9%
London and South East	68.4%	43.6%
North East and North Cumbria	85.2%	53.6%
North West	79.3%	75.3%
South Central	74.5%	61.0%
South West	73.5%	48.8%
West Midlands	67.3%	40.7%
Yorkshire and the Humber	77.7%	36.4%

## 8.1 Key findings

- Just over two thirds (72%) of children and young people with Type 1 diabetes were recorded as receiving structured patient education in 2016/17, similarly to the previous audit year.
- Only half (49.1%) of those with Type 2 diabetes were recorded as receiving structured patient education, a reduction of 8.4% since 2015/16.
- There was considerable variation in the percentages recorded as receiving structured patient education between regions and between England and Wales, with twice as many children and young people in England receiving it compared to Wales.

## 8.2 Recommendations

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

- Ensure that all children and young people with diabetes are provided with an ongoing programme of structured education from diagnosis, tailored to their individual needs.
- Evaluate their structured education programmes and review them regularly to ensure that they are meeting the needs of the children, young people and families that they are targeted at.

### **Commissioners should:**

- Ensure that service providers are delivering suitable structured ongoing education programmes to all stakeholders involved in the care of children and young people with diabetes including parents and other family members, schools and education providers.

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

- Explore options for developing and utilising regional and national structured patient education resources, many of which are already available as part of the National Network's sharing strategy ([www.cypdiabetesnetwork.nhs.uk/](http://www.cypdiabetesnetwork.nhs.uk/)). Such initiatives should be put into action to avoid wide variability in treatment target outcomes and ensure every child and young person with diabetes and their family receives optimal self-management education that is age and maturity appropriate, delivered by trained educators and provided in a family centred way (Waldron & Campbell, 2014). Programmes should be designed by experienced diabetes educators (Campbell & Waldron, 2013).



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

Table 28 shows that of the 27, 739 children and young people with Type 1 diabetes included in the audit, 2.6% were being treated for thyroid disease, and 4.4% were following a gluten-free diet indicative of coeliac disease. For coeliac disease, this is a similar finding to a large international collaborative study that found a prevalence rate of 3.5% across three continents (Craig et al., 2017).

**Table 28: Percentage of children and young people with Type 1 diabetes with thyroid or coeliac disease by country and region in England and Wales, 2016/17**

	Percentage on thyroxine for hypothyroidism or anti-thyroid medication for hyperthyroidism	Percentage on gluten free diet
England and Wales	2.6%	4.4%
England	2.6%	4.3%
Wales	3.2%	5.7%
East of England	2.5%	3.6%
East Midlands	3.9%	5.8%
London and South East	2.1%	3.5%
North East and North Cumbria and Cumbria	3.0%	4.2%
North West	2.2%	4.2%
South Central	2.3%	5.3%
South West	3.3%	4.7%
West Midlands	2.3%	4.6%
Yorkshire and the Humber	2.7%	4.7%

Figure 50 shows year on year variation in prevalence of thyroid and coeliac disease.

**Figure 50: Percentage of children and young people with Type 1 diabetes with thyroid or coeliac disease by country and in England and Wales, 2014/2015-2016/17**

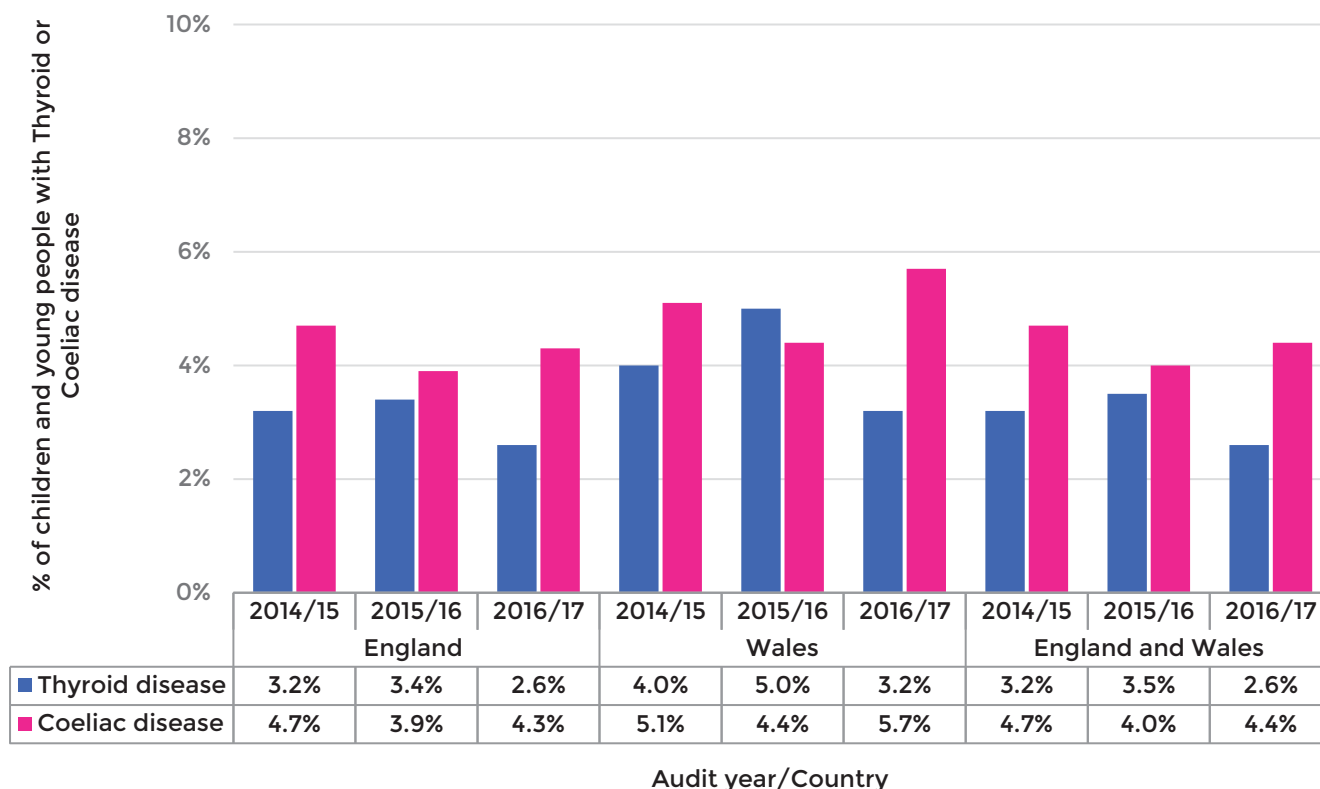


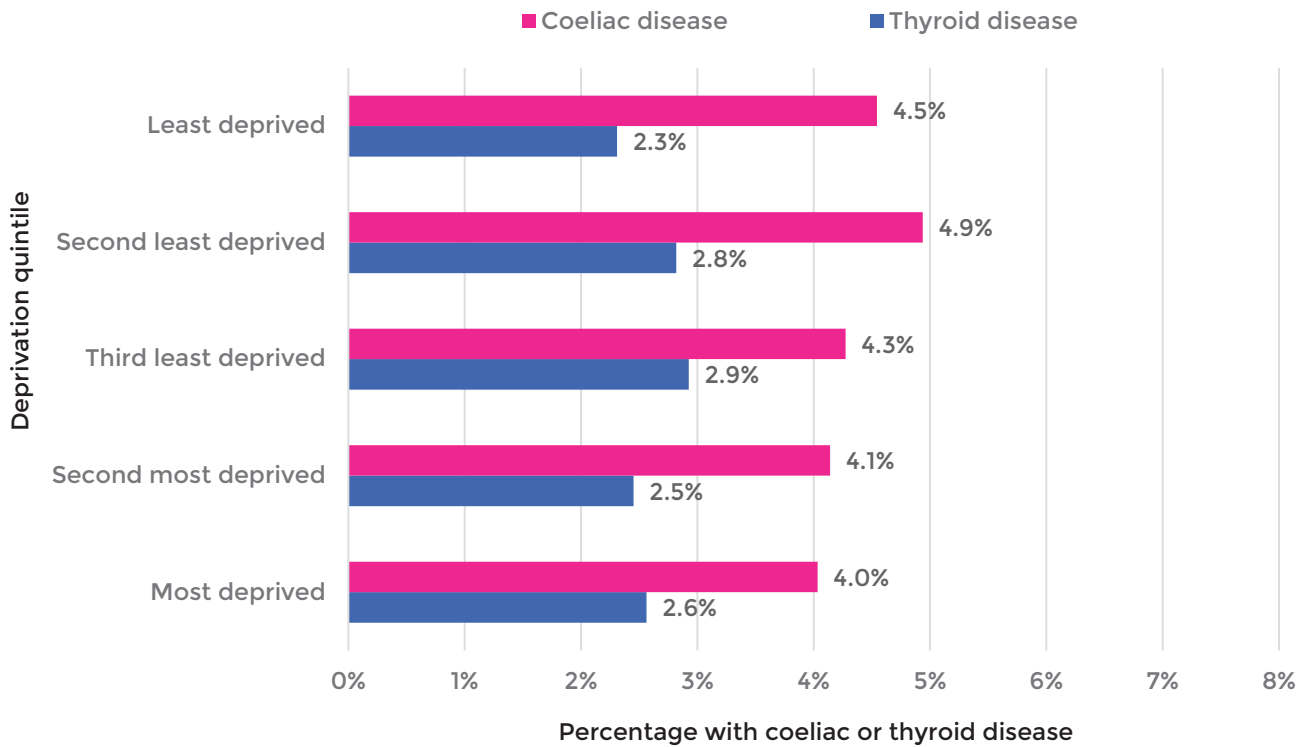
Table 29 shows that there was higher prevalence of both autoimmune conditions amongst females compared to males, despite there being a slightly higher prevalence of Type 1 diabetes amongst males.

**Table 29: Percentage and number of children and young people with Type 1 diabetes with coeliac and thyroid disease, 2016-17**

	% with coeliac disease (n)	% with thyroid disease (n)
Male	3.6% (516)	1.8% (255)
Female	5.3% (694)	3.5% (464)

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 51).

**Figure 51: Percentage of children and young people with Type 1 diabetes and comorbid coeliac or thyroid disease by deprivation quintile, 2016-17**



## 9.1 Key findings

- 4.4% of children and young people in England and Wales with Type 1 diabetes were following a gluten free diet indicative of coeliac disease, and 2.6% were receiving treatment for thyroid disease.
- Prevalence of both co-morbid autoimmune disorders was higher amongst females compared to males.

## 9.2 Recommendations

- Health care professionals should continue to screen children and young people with Type 1 diabetes for the existence of treatable co-morbid autoimmune disease.

# 10. Conclusion

The results of this 2016/17 audit provide justification both for celebration and for continuing focus on improving the diabetes care of children and young people with diabetes in England and Wales.

The key successes identified include the continuing downward trend in national HbA1c, and increases in the percentages of children and young people with Type 1 and Type 2 diabetes receiving recommended health checks. However, the audit continues to identify variation in care and outcomes at unit, regional, and national level. Poorer outcomes continue to be associated with non-white ethnicity, adolescence, female gender, and living in a deprived area. Inequalities in treatment deprivation observed previously were also shown to be widening, with children and young people in the least deprived areas being even more likely to be using an insulin pump compared to those in the most deprived areas than in previous audit cycles. Patient and PDU factors responsible for the inequalities identified by the audit must be explored and addressed as part of local and national improvement strategies to improve diabetes management and outcomes.

# 11. Glossary

**Autoimmune disorder** - an autoimmune disorder occurs when the body's immune system attacks and destroys healthy body tissue by mistake. There are more than 80 types of autoimmune disorder.

**Body Mass Index (BMI)** - a measure of someone's size based on their weight and height. BMI is a value derived from the weight and height of an individual and is calculated by the weight divided by the square of the body height, and is expressed in units of kg/m<sup>2</sup>. BMI is used to determine if someone is a healthy weight for their height.

**Cardiovascular disease (CVD)** is a general term that describes a disease of the heart or blood vessels. Blood flow to the heart, brain or body can be reduced as the result of a blood clot (thrombosis), or by a build-up of fatty deposits inside an artery that cause the artery to harden and narrow (atherosclerosis) causing heart disease and strokes.

**Care processes** - these are the various medical tests that healthcare professionals should take to measure things in the blood or screen various parts of the body to ensure they are not damaged. They are also referred to as health checks.

**Cholesterol** - a fatty substance which is vital for the normal functioning of the body. Cholesterol levels in the blood should be within a particular range and excessively high levels of cholesterol can contribute towards diabetes complications.

**Coeliac disease** - an autoimmune disease caused by the gut's reaction to gluten. It is treated by omitting gluten from the diet. Gluten is found in wheat, barley, and rye.

**Diabetes mellitus (DM)** is commonly referred to as diabetes. It is a condition where the blood glucose levels remain high because the body cannot use the glucose properly without treatment. If left untreated diabetes complications will occur, the common ones include eye and kidney damage, cardiovascular disease, strokes and foot damage.

**Glucose** - a simple sugar with a specific chemical formula and is classed as a monosaccharide. Glucose is the sugar that is found in blood and blood glucose acts as a major source of energy for the body.

**HbA1c (Glycated haemoglobin)** - a blood test that measures how much glucose binds to the red blood cells. It gives a measure of the average blood glucose level approximately 6 - 8 weeks before the test.

**Health checks** - the various medical tests that health care professionals should take to measure things in the blood or screen various parts of the body to ensure they are not damaged. They are also referred to as care processes.

**Hyperlipidaemia** - abnormal elevated levels of any or all fats (lipids) in the blood. Cholesterol is one of the fats that are measured in diabetes.

**Macroalbuminuria** - as kidney disease progresses, more albumin leaks into the urine, a condition called macroalbuminuria or proteinuria. As the amount of albumin in the urine increases, the kidneys' ability to filter the blood decreases.

**Macrovascular complications** - regular elevation of blood glucose levels over a long period of time leads to damage of blood vessels. Over time the lining of the large blood vessels (arteries) become weaker resulting in macrovascular disease. Damage to the large vessels will contribute to cardiovascular disease and strokes.

**Mean** - a measure of the 'average' of a set of numbers. Add up all the numbers, then divide by how many numbers there are in the sample.

**Median** - the median is the middle number of a list of numbers when they are sorted from the smallest to the largest number.

**Microalbuminuria** - small amounts of protein in the urine. It is the first sign of kidney damage (nephropathy) caused by many years of high blood glucose levels. Microalbuminuria is reversible if blood glucose levels are improved.

**Microvascular complications** - regular elevation of blood glucose levels over a long period of time leads to damage of blood vessels. Over time the lining of the small blood vessels become weaker resulting in microvascular disease. This can be found at the back of the eye (retinopathy) and in the kidneys when they become damaged.

**Nephropathy**- any disease of the kidneys.

**Normoalbuminuria** - the presence of the normal amount of albumen in the urine.

**Retinopathy** - a complication of diabetes, caused by high blood glucose levels damaging the back of the eye (retina). It usually takes several years for diabetic retinopathy to reach a stage where it could threaten your sight. To prevent retinopathy control blood glucose levels, blood pressure, cholesterol and attend diabetic eye screening (above 12 years of age). Retinopathy can cause blindness if left undiagnosed and untreated.

**Structured Patient Education Programme** - a programme of self-management education, tailored to the child or young person's maturity and their family's needs. Specific education should be given at the initial diagnosis and on an on-going basis throughout the child's or young person's attendance at the diabetes clinic. This is a programme offered in addition to the education provided at routine outpatient consultations.

**Thyroid disease** - a disease which causes the thyroid to produce either too much or too little of the thyroid hormone.

**Urinary albumin** - a test to check urine for the presence of a protein called albumin. Small amounts of albumin leak into the urine when the kidney is damaged. Therefore, urinary albumin can be used as a test for kidney disease.

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