NPDA
National Paediatric Diabetes Audit

National Paediatric Diabetes Audit Report 2015-2016
Part 1: Care Processes and Outcomes

HQIP
Healthcare Quality Improvement Partnership

RCPCH
Royal College of Paediatrics and Child Health
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National Paediatric Diabetes Audit 2015-16
Report 1:

Care Processes and Outcomes

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Contents

Foreword

I am pleased to introduce the 13th Annual Report of the National Paediatric Diabetes Audit, the sixth 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 2015/16. It includes details of the prevalence of diabetes, compliance with care processes recommended by the National Institute for Health and Care Excellence, and recommendations for improvements in care for the growing number of children with this life-long disease.

The positive outcomes of several initiatives to improve care are reflected by further improvement in the key target, HbA1c. For six consecutive years there has been an increase in the number of children and young people achieving excellent diabetes control, indicating reduction in their lifetime risk of complications such as kidney disease, visual impairment, and amputation. Sadly those living in the most deprived areas continue to fare much less well than those more well off. The number of infants, children and young people with Type 1 diabetes that had all recommended checks has increased to 35.5% but this is still a wholly unsatisfactory proportion. Worryingly, we identify high numbers of children over the age of 12 showing early signs of complications.

I commend the audit to all those who wish to see improvements in services for infants, children and young people with diabetes. The implications of poor care in early life on life-long health, and the impact of adversity are important considerations for Government, commissioners, healthcare providers, clinicians, and families.

Neena Modi.

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 13th 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 2015/16 NPDA included all 173 PDUs in England and Wales, and captured information on 28,439 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

For the first time, the audit has reported the care process and outcomes achieved separately for patients with Type 1 and Type 2 diabetes. This executive summary contains key findings and recommendations from the audit which are presented in more detail in later chapters.

1.8 Overall National HbA1c results

- There have been reductions of 3.2 and 2 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 2014/15.
- There has been a 8.5mmol/mol reduction in median HbA1c in England and Wales for children and young people with diabetes over the last 6 years from 73mmol/mol in 2009/10 to 64.5mmol/mol in 2015/16.
- The national median in 2015/16 for all children and young people being managed within a PDU with all types of diabetes was 64.5mmol/mol, and the national mean was 67.8 mmol/mol.

1.9 Key findings: Type 1 diabetes

Incidence, prevalence, and patient characteristics

- 27,115 children and young people with Type 1 diabetes were reported to the audit in 2015/16 (96.0% of the total cohort).
- The prevalence of Type 1 diabetes in children and young people aged 0 to 15 years old in England and Wales in 2015/16 is 195.4 per 100,000 of the general population.
- There were 2,834 children and young people aged 0 to 15 years old diagnosed with Type 1 diabetes in England and Wales in 2015/16, giving an incidence of 25.9 per 100,000 general population.
- Prevalence and incidence of Type 1 diabetes is higher amongst males than females.
- There has been a year on year increase in the incidence of Type 1 diabetes since the 2013/14 audit, with the greatest increase amongst females.

Completion of health checks

- Almost all children and young people with Type 1 diabetes had an HbA1c (99.3%) and a BMI recorded (97.9%), whilst only two thirds of young people aged 12 and above had a foot check (65.8%), a retinopathy screen (66.2%) or urinary albumin screen (66.0%) recorded.
- A little over a third (35.5%) of young people aged 12 and above with Type 1 diabetes completing a year of care received all the key care processes recommended for this patient group in 2015/16.
- There was significant variation in the percentage of young people aged 12 and above with Type 1 diabetes completing a year of care who received all key care processes per unit, ranging from zero to nearly 100%.
- Fewer than half (48.3%) 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.
- Around two thirds of children and young people newly diagnosed with Type 1 diabetes were screened within 90 days for coeliac (62.3%) or thyroid (67.8%) disease.

Blood glucose diabetes control targets (HbA1c)

- There has been an increase in the percentage of children and young people with Type 1 diabetes achieving good control (HbA1c levels <58 mmol/mol) from 23.5% in 2014/15 to 26.6% in 2015/16.
- A corresponding reduction in the percentage of children and young people with Type 1 diabetes with poor control (HbA1c >80mmol/mol) was found from 21.3% in 2014/15 to 17.9% in 2015/16.
- Considerable variability in HbA1c target outcomes persists between PDUs even

after case-mix adjustment.
- There were differences in HbA1c target outcomes associated with age, deprivation, gender and ethnicity. In general, children and young people with Type 1 diabetes had poorer outcomes if they lived in a deprived area, were of non-white ethnicity, were adolescent, or female.

Microvascular complications

- Albuminuria was found in 9.7% of young people aged 12 years and above with Type 1 diabetes screened in the audit year.
- The risk of albuminuria was increased amongst older young people with Type 1 diabetes, and amongst those living in the most deprived areas.
- Abnormal eye screening results were found in 13.8% of young people aged 12 and above with Type 1 diabetes screened in the audit year.
- Older young people with Type 1 diabetes were at increased risk of eye disease, with 20.5 % of 17 year olds screened having an abnormal screening result compared to 6.4% of 12 year olds.
- Young people aged 12 and above living in the most deprived areas (16.4%) had a higher risk of eye disease compared to those in the least deprived areas (14.8%).

Macrovascular complications and risk factors

- High blood pressure (hypertension) was found in just over a quarter (26.3%) of young people aged 12 years and older with Type 1 diabetes screened in the audit year.
- A fifth (19.7%) of young people aged 12 years and older with Type 1 diabetes screened had a total blood cholesterol level exceeding the target of 5 mmol/L or less.
- 16.4% of children aged 0 to 11 years with Type 1 diabetes and a recorded BMI were overweight, and 16.5% were obese. These figures rose to 18.1% and 20.8%, respectively, for those aged 12 years and above.

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

- Of the children and young people with Type 1 diabetes with recorded observations, 3.5% were being treated for thyroid disease, and 4.0% were following a gluten-free diet indicative of coeliac disease.

Outcomes of psychological assessment

- Thirty percent of children and young people with Type 1 diabetes screened within the audit period required referral and were seen by expert CAMHS/psychology services in 2015/16.

1.10 Key findings: Type 2 diabetes

Incidence, prevalence, and patient characteristics

- 621 children and young people with Type 2 diabetes were reported to the audit (2.2% of the total cohort).
- Calculation of prevalence and incidence of Type 2 diabetes cannot be calculated from NPDA data since there are likely to be young patients with Type 2 diabetes being managed outside of a PDU, in primary care.
- Children and young people from Black and and Asian ethnic backgrounds were more highly represented within the NPDA Type 2 cohort.
- There were twice as many female children and young people with Type 2 diabetes within the Type 2 diabetes cohort than males.
- More young people with Type 2 diabetes live in deprived areas.

Completion of health checks

- Completion rates for HbA1c and BMI measurements were high amongst children and young people with Type 2 diabetes completing a year of care in 2015/16, with 97.3% and 94.4% receiving at least one of these, respectively.
- Only 16.7% of young people aged 12 years and above with Type 2 diabetes completing a year of care in 2015/16 received all key care processes. This is just under half the key care process completion rate for Type 1 diabetes (35.5%).
- Fewer than a third (29.6%) of children and young people with Type 2 diabetes completing a full year of care over the audit period had four or more HbA1c measurements recorded, compared to 48.3% of children and young people with Type 1 diabetes.
- Only 58% of children with Type 2 diabetes received psychological assessment.
- Overall, completion rates of care processes were higher amongst patients with Type 1 diabetes compared to those with Type 2 diabetes.

Structured education for self-management

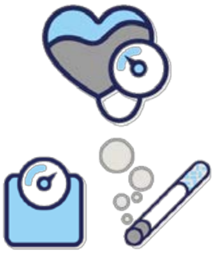
- Nearly 60% of patients with Type 2 diabetes were recorded as receiving structured patient education in 2015/16 - a considerable improvement from the 2014/15 audit when 39.7% of children and young people with Type 2 diabetes were recorded as receiving it.

Blood glucose diabetes control targets (HbA1c)

- The mean and median HbA1c for children and young people with Type 2 diabetes were 59.7 mmol/mol and 51.0 mmol, respectively.
- Overall, children and young people with Type 2 diabetes had poorer control if they lived in a deprived area or were Black.

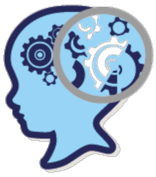
Microvascular complications

- Albuminuria was found in 14.5% of children and young people with Type 2 diabetes screened in the audit year.
- Eye disease was found in 5.4% of young people with Type 2 diabetes who received screening.



Macrovascular complications

- Hypertension was found in 40.4% of children and young people with Type 2 disease, a markedly higher prevalence compared to the 26.3% within the Type 1 cohort.
- 78.5% of children and young people with Type 2 diabetes were obese.
- 2.1% of young people with Type 2 diabetes aged 12 and above with a recorded smoking status were current smokers.



Outcomes of psychological assessment

- Of those screened within the audit, 33.8% of children and young people with Type 2 diabetes required referral and were seen by expert CAMHS/psychology services in 2015/16.

1.11 Summary of recommendations

Prevalence and Incidence

Multidisciplinary paediatric diabetes teams should:

- Be aware of the gender, ethnic and deprivation differences between childnen and young people with Type 1 and Type 2 diabetes including the higher rates of Type 2 diabetes amongst females, those of Asian and Black ethnicity, and amongst those living in the most deprived areas.
- 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.

Commissioners should:

- Ensure that prevention strategies to reduce prevalence of Type 2 diabetes in young people take account of the risk factors for Type 2 diabetes identified by the audit (female gender, non-white ethnicity and deprivation).

Completion of health checks

Multidisciplinary paediatric diabetes teams should:

- Ensure children and young people with diabetes are receiving the key care processes specific to their diabetes type.
- Ensure that screening for thyroid and coeliac disease takes place at of 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.
- Managing diabetes in children and young people is complex, in particular when it is associated with other psychological co-morbidities such as eating disorders, anxiety, and depression. Screening for such factors is important as treatment strategies can be employed to improve patient welfare.
- Identify barriers to the annual provision of key care processes and develop quality improvement initiatives to mitigate these.
- Be aware that completion rates of care processes tend to be higher amongst patients with Type 1 diabetes compared to those with Type 2 diabetes, and attempt to improve engagement with patients with Type 2 diabetes to ensure that these checks are carried out annually.

Commissioners and regional diabetes networks should:

- Ensure PDUs have the resource to collect accurate data and provide consistent care in accordance with NICE standards.

Structured education

Multidisciplinary paediatric diabetes teams should:

- Ensure that all children and young people with diabetes are provided with an ongoing programme of structured patient 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 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 a 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:

- 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 (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 family receives optimal self-management education that is age and maturity appropriate, delivered by trained educators, 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 sub-group 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 control.
- 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 control (adolescence, non-white ethnicity, female gender, and living in a deprived area), and adapt communications and structured education provision in order to be able to meet the different needs of vulnerable subgroups.

Commissioners should:

- Be aware of the socioeconomic and patient demographic factors associated with poorer diabetes control (adolescence, non-white ethnicity, female gender, and living in a deprived area), and ensure services catering to higher percentages of patients from vulnerable subgroups are resourced sufficiently to meet their needs.
- Be aware of the cultural diversity amongst the paediatric diabetes population and ensure community groups and schools are sufficiently aware and trained to help young people to further improvements in diabetes control especially amongst vulnerable subgroups.
- Be aware of deprivation gradients associated with insulin regimen.
- 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 where funding issues arise.

Diabetes complications and risk factors

Multidisciplinary paediatric diabetes teams should:

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

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 to ensure that care pathways are in place to 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.

1.12 Conclusion

This report evidences real improvements in diabetes care and control since the 2014/15 audit. The impact of the improvement in blood glucose levels over the last six years should not be underestimated and will reduce the risk of future complications significantly. The improvements reflect and reward the significant amount of work and quality improvement activity undertaken by healthcare teams, parents and patients to achieve better outcomes for children and young people in England and Wales.

However, there remains considerable variability in diabetes outcomes across the two nations which require attention. PDUs need to be aware of their individual outcomes for which they are accountable and work on quality improvement initiatives either locally, regionally or nationally to improve. Annual benchmarking, utilising NPDA data, against other similar PDUs allows a measure of performance to be created which should drive future improvements. Paediatric diabetes care in England and Wales has improved dramatically but still lags behind some of our European counterparts (McKnight et. al, 2015; Maahs et al., 2015; Sherr, Herman et al., 2016). There is more work to be done but progress is clearly visible, and should be celebrated.

2. Introduction

The NPDA is commissioned by the Healthcare Quality Improvement Partnership (HQIP), funded by NHS England and the Welsh Government and delivered by the Royal College of Paediatrics and Child Health (RCPCH) as part of the national clinical audit and patient outcomes programme (NCAPOP).

The audit has been reporting for 13 years and collects information from healthcare professionals in all Paediatric Diabetes Units (PDUs) in England and Wales about the care received by the children and young people with diabetes. 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, all of which are vital to monitoring and improving the long-term health and well-being of children and young people with diabetes.

All 173 PDUs in England and Wales participated in the 2015/16 audit, capturing information on 28,439 children and young people with diabetes up to the age of 24 years remaining in paediatric care. Ninety-six percent of the children and young people in the audit have Type 1 diabetes.

The NPDA is designed to measure and motivate change at local, regional and national levels across England and Wales. 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. Past NPDA audits have shown great variations in the quality of care and outcomes achieved by PDUs, with examples of difference levels of performance highlighted. The audit provides an essential baseline for measuring unit performance, and enables benchmarking of year on year progress and of the performance of different PDUs, regions, commissioning groups and nations. These results support efforts within PDUs, regions and at a national level to understand variability, and by doing so focus efforts to improve care within centres performing less well, which will ultimately contribute to overall national improvement.

2.1 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, but, despite recent improvements, still has the lowest proportion achieving good diabetes control (Lacobucci, 2013). Complications associated with poor diabetes control 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 control, the risks of complications are markedly reduced, enabling children and young people to enjoy a healthy and longer life.

The burden of diabetes impacts heavily on the NHS. Diabetes complications increase the costs to the NHS more than fivefold and significantly increase the demands on hospitals. Expenditure on diabetes complications is estimated to account for 10% of the NHS budget (Hex et al, 2012).

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 deep understanding of the targets associated with good glucose control and the need for regular health checks to prevent complications is an essential part of high quality care (NICE, 2015).

Improving standards of care delivery

The NPDA has previously demonstrated poor diabetes outcomes across England and Wales compared to those of other countries, which has been the catalyst for a programme of service improvement initiatives and sharing of good practice. In England the Best Practice Tariff (BPT) (Randell, 2012) was introduced in 2012. It set strict criteria for the delivery of paediatric diabetes services, including a requirement for participation in the NPDA, with increased funding for centres meeting them. In Wales, following the launch of the Diabetes Delivery Plan in 2013 and the National Peer Review Programme in 2014/15 (National Peer Review Programme, 2015a), considerable investment has been made by the Local Health Boards to support improvements in quality of care.

The National Peer Review Quality Assurance Programme for children and young people with diabetes (DQuINS, 2015) in England and Wales was developed in 2012 to check that quality standards in line with NICE recommendations (NICE, 2004) and BPT were being achieved by PDUs and regional networks. The Peer Review Programme aims to examine services and check on quality standards of care and resources. It also provides suggestions for the future direction of quality assurance (Campbell and Waldron, 2015; National Peer Review Programme 2015a; National Peer Review Programme 2015b). NPDA data is included as part of the evidence submitted by PDUs to demonstrate the quality of care they provide.

The NPDA also runs a patient and parent/carer survey to enable families to describe their experience and views on the healthcare received from their PDU. Providing this feedback provides an opportunity for respondents to influence the shaping of paediatric diabetes services by highlighting deficits and successes of care experienced. Individual PDU level results are available via the NPDA website.

NPDA outputs

The NPDA produces the following reports, all of which can be viewed and downloaded from 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 through the same link and also 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 centres, and contains outlier information.
- The Complications report measures rates of admission to hospital for complications such as Diabetic Ketoacidosis (DKA) or hypoglycaemia. A comparative hospital admissions report for the submission periods 2012/13, 2013/14 and 2014/15 will be published in April 2017.
- 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.

Research collaborations

The NPDA has collaborated with national (Khanolkar et al., 2016) and international researchers (McKnight et al., 2015; Maahs et al., 2015; Sherr et al., 2016) to benchmark UK performance and gain insight into approaches to the shared challenge of reducing blood glucose levels in children. The NPDA has found that the majority of centres and countries in these samples have significantly better diabetes control in their children with diabetes and consequently better medical outcomes compared to the results from England and Wales. Although diabetes outcomes are improving in England and Wales, further improvements are required to align with our European counterparts with an aim to reduce the serious risk of future diabetes complications and poorer quality of life.

2.2 Scope of the 2015/16 NPDA report

The NPDA is an analysis of 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 2015/16 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 2015 through to 31st March 2016. 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 receiving key age-specific processes of diabetes care, as recommended by NICE?
- How many achieve outcome measures within specified treatment targets?
- Are children and young people with diabetes demonstrating evidence of small vessel disease (microvascular) and/or abnormal risk factors associated with large vessel disease (macrovascular) prior to transition into adult services?

2.3 Changes to NICE guidance since publication of the 2014/15 NPDA report

New NICE guidance for the management of Type 1 and Type 2 diabetes was published in 2015 (NG18, NICE 2015). The data presented within this 2015/16 report reflect the updated guidance in line with the following changes:

- Cholesterol screening is no longer a mandatory requirement as a healthcare check for children and young people with type 1 diabetes although remains essential for Type 2 diabetes.
- Thyroid screening has now been included as one of the seven essential healthcare checks for children and young people with type 1 diabetes.
- Coeliac disease screening is only mandatory at diagnosis of Type 1 diabetes.

This 2015/16 report also acknowledges the differences in management of children and young people with Type 1 or 2 diabetes, as recommended by NG18, and reports these separately.

2.4 Changes to NPDA reporting in 2015/16

Historically, the NPDA has reported the outcomes and care processes received by children with Type 1 diabetes, or by children and young people with all types of diabetes. Given the increasing incidence of Type 2 diabetes in young people, the differences in management of Type 2 diabetes recommended by NG18, and in recognition of different outcomes associated with Type 2, the results of the 2015/16 NPDA are now reported separately for this patient group.

Patients who have received care in more than one PDU, region or country within the period covered by the audit have previously had their care processes and outcomes attributed to all units/regions or countries within which they received care within the year. For the analysis of the 2015/16 data, patients' care and outcomes have been attributed to the most recent unit in which they have received care, recognising that these are the units responsible for ensuring that all care processes that should have been received in the audit period have been provided.

2.5 National Diabetes Audit for adults (NDA) and the NPDA

The National Diabetes Audit (NDA) for adults (National Diabetes Audit, NHS Digital) reports on the provision of core diabetes care for adults with diabetes.

The NDA and NPDA have collaborated 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.

2.6 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 2015/16 audit was the first time that a comprehensive data completeness report was available upon upload of audit data, enabling detection of missing data. It was also the first 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 both of these developments will have had an impact on the overall quality of data submitted to the NPDA this year.

3. Patient characteristics, prevalence and incidence

3.1 Audit cohort

A total of 28,439 children and young people with diabetes were included in the 2015/16 audit, an increase of 757 from 2014/15.

Table 1: Number of children and young people with diabetes included in the audit by age and type of diabetes, 2015/16

	0 – 4 years	5 – 9 years	10 – 14 years	15 – 19+ years	20 – 24+ years	Total (% of cohort)
Type 1 Insulin-dependent diabetes mellitus	1,679	5,912	10,958	8,540	26	**27115 (96.0%)**
Type 2 Non-insulin-dependent diabetes mellitus	*	15	243	359	*	**621 (2.2%)**
Cystic fibrosis related diabetes	0	12	83	73	0	**168 (0.6%)**
Monogenic types of diabetes	23	28	48	40**		**139 (0.5%)**
Other specified diabetes mellitus	13	32	6	58		**167 (0.6%)**
Not specified diabetes mellitus	21	38	74	63	0	**196 (0.7%)**
Missing type of diabetes	*	9	9	10	*	**33 (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

3.2 Characteristics of children and young people with Type 1 diabetes

3.2.1 *Gender*

Table 2 provides a breakdown by age and gender of the children and young people with Type 1 diabetes included in the audit. Overall, and in every age category, there are more male than female children and young people with Type 1 diabetes.

Table 2: Number of children and young people included in the audit with Type 1 diabetes by age and gender, 2015/16

	0 - 4 years	5- 9 years	10 - 14 years	15 - 19 years	20 - 24 years	Total (% of total sample)
Male	887	3018	5627	4659	15	**14,206 (52.4%)**
Female	786	2872	5306	3866	11	**12,841 (47.4%)**
Not specified	6	22	24	15	0	**67 (0.2%)**
Missing	0	0	*	0	0	**(0.0%)**

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

3.2.2 *Location*

Table 3 shows the distribution of children and young people with Type 1 diabetes by country, regional network and age category.

Table 3: Number of children and young people included in the audit with Type 1 diabetes by country, region and age, 2015/16 (based on PDU location)

	0-4 years	5-9 years	10-14 years	15-19 years	20-24 years	Total aged (% of Total ≤19)
England and Wales	1,679	5,912	10,958	8,540	26	**27,089**
England	1,602	5,588	10,354	8,172	26	**25,716 (94.9%)**
Wales	77	324	604	368	0	**1,373 (5.1%)**
East of England	192	655	1,213	1,017	*	**3,077 (12.0%)**
East Midlands	109	402	820	480	0	**1,811 (7.0%)**
London and South East	383	1,324	2,322	1,814	*	**5,843 (22.7%)**
North East and North Cumbria	88	321	635	539	5	**1,583 (6.2%)**
North West	221	760	1,333	1,072	0	**3,386 (13.2%)**
South Central	155	503	971	718	0	**2347 (9.1%)**
South West	149	459	903	670	5	**2181 (8.5%)**
West Midlands	162	575	1,105	950	9	**2,792 (10.9%)**
Yorkshire and the Humber	143	589	1,052	912	*	**2,696 (10.5%)**

* indicates a number less than 5 which has been suppressed

3.2.3 *Ethnicity*

Prevalence of disease per ethnic group can be calculated using denominators from census data. However, the most recent census data available were collected in 2011. The 2013-14 NPDA national report (RCPCH, 2015) contains the most contemporaneous NPDA ethnicity data for comparison with the census and should therefore be referred to for the most accurate estimates of prevalence and incidence figures for Type 1 diabetes by ethnic group.

Table 4 shows the ethnicity of the children and young people with Type 1 diabetes. A high proportion of patients (14.5%) have an ethnicity as 'not stated'. To allow comparison of ethnic category percentages to the 2011 census data, which does not contain a 'not stated' category, the percentages have also been calculated excluding this category.

Table 4: Ethnic group of children and young people with Type 1 diabetes England and Wales, 2015/16

	Number	Percentage of total sample	Percentage of total with stated ethnicity*	Percentage of population in 2011 England and Wales Census
White	19,929	73.5%	86.5%	86.0%
Mixed	623	2.3%	2.7%	2.2%
Asian	1,243	4.6%	5.4%	7.5%
Black	834	3.1%	3.6%	3.3%
Other	398398	1.5%	1.7%	1.0%
Not stated	3,945	14.5%	-	-
Unallocated ethnic group	143	0.5%	-	-

*to allow comparison with 2011 census data, ethnicity percentages have been calculated excluding the 'not stated' and unallocated groups.

3.2.4 *Deprivation*

Table 5 shows the breakdown of children and young people with Type 1 diabetes by deprivation quintile, derived from patient postcode data and multiple indices of deprivation data for England (IMD, 2016) and Wales (WIMD, 2015).

Table 5: Number of children and young people with Type 1 diabetes by deprivation quintile, 2015/16

Deprivation quintile	Number	Percentage of total sample
Most deprived	5,853	21.6%
2nd most deprived	5,428	20.0%
3rd most deprived	5,198	19.2%
2nd least deprived	5,256	19.4%
Least deprived	5,317	19.6%
Missing deprivation data	63	0.2%

3.3 Prevalence and Incidence of Type 1 diabetes

3.3.1 *Prevalence*

In 2015/16 the prevalence of Type 1 diabetes in children and young people aged 0 to 15 years old in England and Wales was 195.4 per 100,000 of the general population; slightly higher among males (197.9 per 100,000) compared to females (191.7 per 100,000).

Table 6: Prevalence of Type 1 diabetes per 100,000 general population by age and gender in England and Wales 2015/16

Gender	Age group	Prevalence per 100,000
Males	0 to 4 years	47.9
	5 to 9 years	166.6
	10 to 14 years	347.4
	0 to 15 years	197.9
Females	0 to 4 years	44.7
	5 to 9 years	166.4
	10 to 14 years	343.4
	0 to 15 years	191.7
All	0 to 4 years	46.5
	5 to 9 years	167.1
	10 to 14 years	346.2
	0 to 15 years	195.4

Figure 1: Prevalence of Type 1 diabetes per 100,000 general population by age and gender in England and Wales 2013/14 to 2015/16

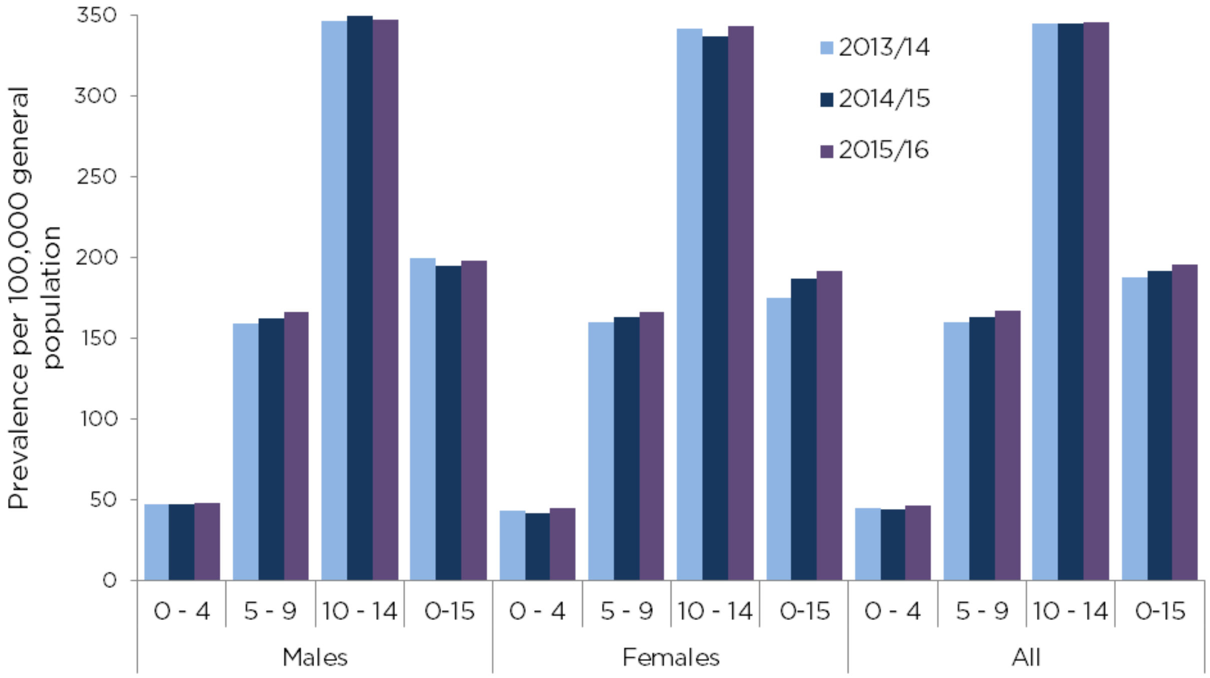


Figure 1 shows that the prevalence of Type 1 diabetes amongst children and young people with Type 1 diabetes has increased each year since 2013/14, with the greatest increase occurring amongst females. These figures should be interpreted with caution, however, as they may simply reflect improved case ascertainment in the NPDA.

3.3.2 *Incidence*

In 2015/16 there were 2,834 children and young people aged 0 to 15 years old newly diagnosed with Type 1 diabetes in England and Wales giving an incidence of 25.9 per 100,000 general population. The incidence was higher amongst males (26.6 per 100,000) compared to females (24.7 per 100,000) as shown in Table 7.

Table 7: Incidence of Type 1 diabetes per 100,000 general population by age and gender in England and Wales 2015/16

Gender	Age group	Incidence per 100,000 in 2015-16
Males	0 to 4 years	16.7
	5 to 9 years	26.9
	10 to 14 years	37.3
	0 to 15 years	26.6
Females	0 to 4 years	17.2
	5 to 9 years	27.1
	10 to 14 years	32.1
	0 to 15 years	24.7
All	0 to 4 years	17.0
	5 to 9 years	27.2
	10 to 14 years	35.0
	0 to 15 years	25.9

3.4 Characteristics of patients with Type 2 diabetes

In 2015/16, 621 children and young people under the age of 25 with Type 2 diabetes were cared for in PDUs in England and Wales. This is an increase of 77 from 2014/15. However, this may not represent a true change in the prevalence of Type 2 diabetes in young people. It is not possible to calculate rates for Type 2 diabetes for children and young people based on the NPDA collected data. There will be cases uncaptured by the NPDA receiving their care outside of a PDU either in primary care or adult secondary diabetes clinics, and these numbers are not included in the audit.

3.4.1 *Location*

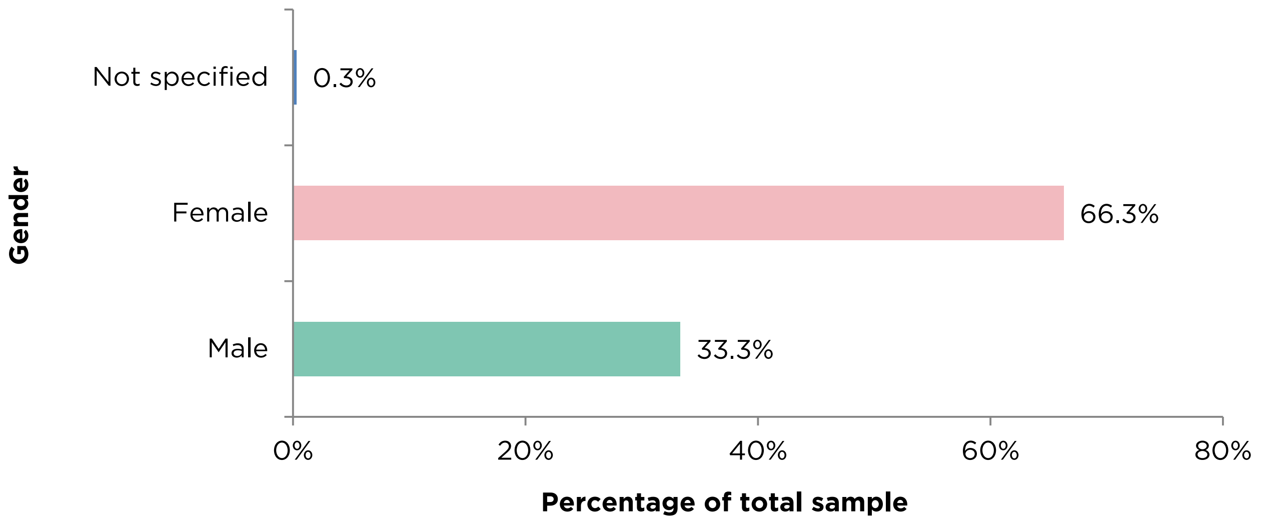
Table 8: Number of children and young people included in the audit with Type 2 diabetes by country and region, 2015/16 (based on PDU location)

	Total	% of total sample
England and Wales	621	
England	595	95.8%
Wales	26	4.2%
East Midlands	31	5.0%
East of England	34	5.5%
London and South East	190	30.6%
North East and North Cumbria	26	4.2%
North West	65	10.5%
South Central	38	6.1 %
South West	31	5.0 %
West Midlands	108	17.4%
Yorkshire andHumber	72	11.6%

3.4.2 *Gender*

Figure 2 shows that approximately twice as many females compared to males with Type 2 diabetes were treated in a PDU in 2015/16.

Figure 2: Gender breakdown of children and young people with Type 2 diabetes reported to the NPDA, 2015/16



3.4.3 *Ethnicity*

Whilst it is not valid to estimate prevalence of Type 2 diabetes based on NPDA data, the data in Table 9 suggest that proportionally higher numbers of non-white children and young people are being treated for Type 2 diabetes in PDUs in England and Wales. This is consistent with the findings from previous years and with those of Khanolkar et al. (2016), who analysed NPDA data from 2012-13 and found an increased prevalence of Type 2 diabetes amongst children and young people of non-white ethnicity compared to White children, with Asian females being particularly affected.

Table 9: Ethnic group of children and young people with Type 2 diabetes England and Wales, 2015/16

	Number	Percentage of total sample	Percentage of total with stated ethnicity*	Percentage of population in 2011 England and Wales Census
White	221	35.6%	44.5%	86.0%
Mixed	18	2.9%	3.6%	2.2%
Asian	175	28.2%	35.2%	7.5%
Black	67	10.8%	13.5%	3.3%
Other	16	2.6%	3.2%	1.0%
Not stated	121	19.5%	-	-
Unallocated ethnic group	3	0.5%	-	-

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

3.4.4 *Deprivation*

As Table 10 shows, there was a positive association between deprivation and Type 2 diabetes, with nearly seven times as many children and young people with Type 2 diabetes living in the most deprived quintile compared to those in the least deprived quintile.

Table 10: Numbers and percentages of children and young people with Type 2 diabetes by deprivation quintile, 2015/16

Deprivation quintile	Number	Percentage of total sample
Most deprived	284	45.7%
2nd most deprived	155	25.0%
3rd most deprived	92	14.8%
2nd least deprived	46	7.4%
Least deprived	42	6.8%
Missing deprivation data	2	0.3%

3.4.5 *Summary*

- There has been a year on year increase in the incidence of Type 1 diabetes since the 2013/14 audit, with the greatest increase amongst females.

- There are marked differences in ethnic background, gender and deprivation status between the Type 1 and Type 2 diabetes cohorts. Children and young people from Black and Asian ethnic backgrounds are more highly represented within the Type 2 cohort compared to 2011 census population data. Overall, there is a predominance of female patients with Type 2 diabetes compared to males, and more young people with Type 2 diabetes live in deprived areas.

3.4.6 *Recommendations:*

- Healthcare professionals caring for children with diabetes need to be aware of the gender, ethnic and deprivation differences between Type 1 and Type 2 diabetes.

- Prevention strategies to reduce prevalence of Type 2 diabetes in young people should take account of the risk factors for Type 2 diabetes identified by the audit.

- 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.

4. Completion of health checks (care processes)

4.1 Health checks for children and young people with diabetes

4.1.1 *The seven key care processes for children and young people with Type 1 diabetes*

There are seven key care processes 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.

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 hyper/hypothyroidism)
6. Eye screening (photographic test for eye risk)
7. Foot examination (foot examination for ulcer risk)

For 2015/16, thyroid screening has replaced cholesterol screening as one of the seven key healthcare checks. Guidelines specify a starting age of 12 years for commencing all care processes with the exception of HbA1c and measurement of height and weight, which should be recorded in children and young people with different types of diabetes of all ages, and thyroid screening, which should be performed on diagnosis and annually thereafter.

4.1.2 *The seven key care processes for children and young people with Type 2 diabetes*

The key care processes for children and young people with Type 2 diabetes recommended in NG18 and NG19 (NICE, 2015) differ slightly from those for Type 1 diabetes with cholesterol screening being included in the seven key healthcare checks rather than thyroid screening. All should be performed annually from diagnosis, with the exception of foot examination and eye screening, which are indicated from age 12.

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

It is not possible to make direct comparison with completion rates of the seven key care processes reported previously as this is the first time the NPDA has presented this information for children and young people with Type 1 diabetes only. Furthermore there has been a change in one of the seven included healthcare checks. However, given that over 95% of the patients within the NPDA sample in 2014/15 and 2015/16 had Type 1 diabetes, the improvements in completion rates of all care processes shown in Figure 3 can be taken to reflect real improvements in care process completion or completeness of data submitted to the NPDA.

Figure 3: Percentage of children and young people with Type 1 diabetes receiving a complete year of care recorded as receiving key care processes by audit year

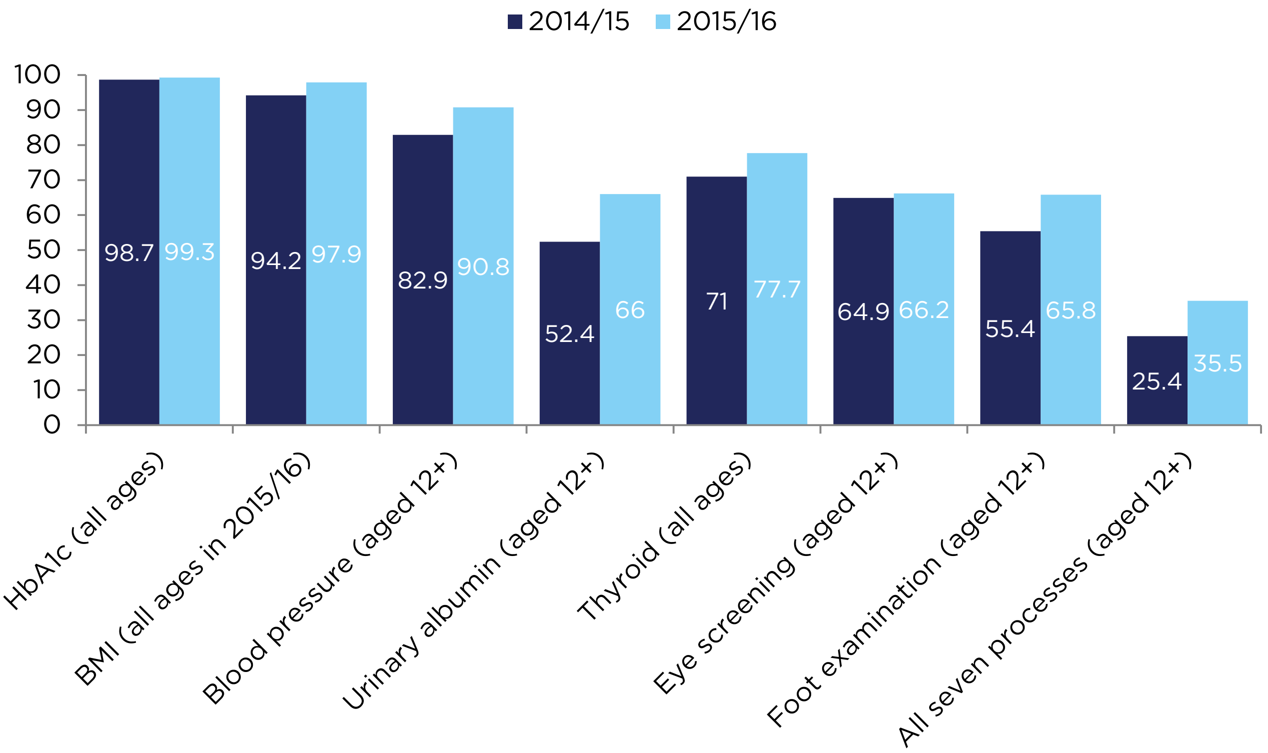


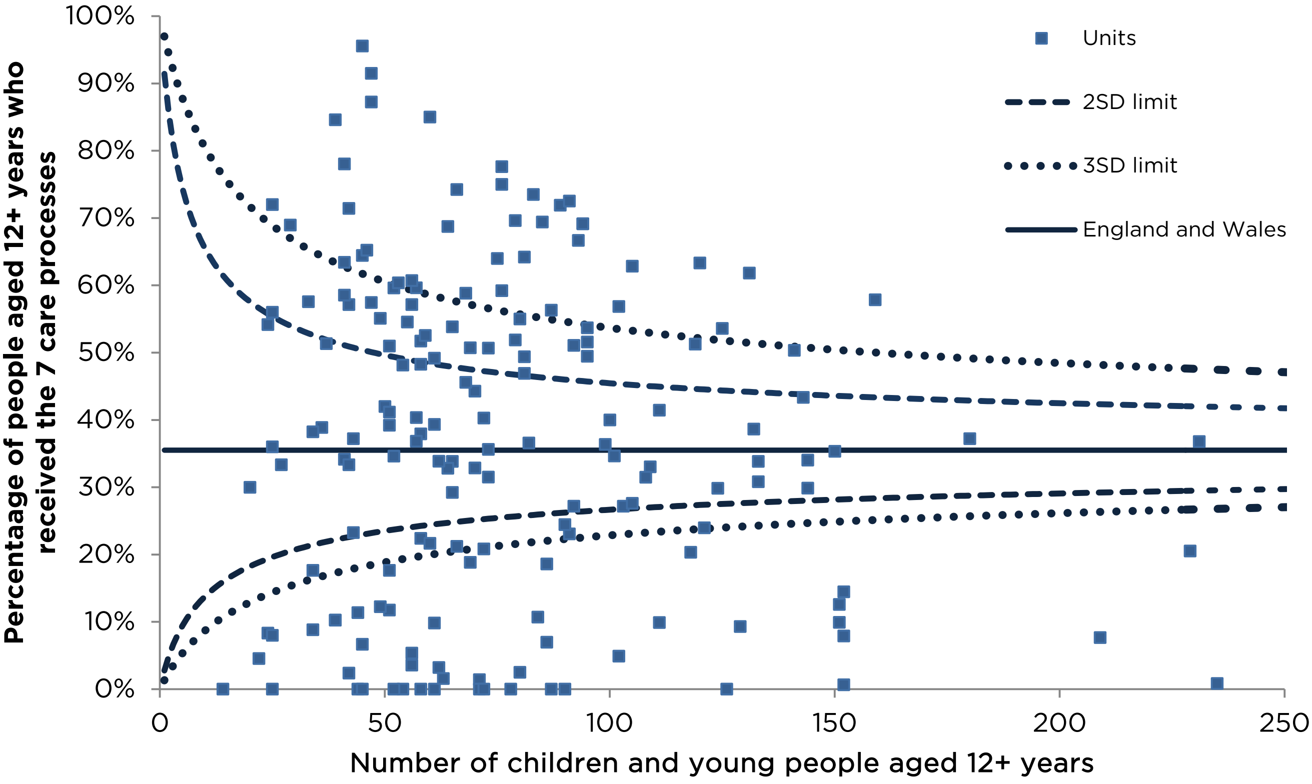
Table 11 provides a breakdown of the care processes received by children and young people with Type 1 diabetes with a complete year of care in 2015/16 by country, region and overall in England and Wales. It shows that recording of HbA1c and BMI is nearing 100% completion, and that the lowest completion rates were found for eye screening and foot examination.

Table 11: Percentage of children and young people with Type 1 diabetes with a complete year of care receiving the key care processes in 2015/16, 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+)**
England and Wales	99.3	97.9	90.8	66.0	77.7	66.2	65.8	**35.5**
England	99.3	97.9	90.9	65.5	77.3	65.8	65.1	**34.7**
Wales	99.6	98.5	89.4	76.3	84.4	74.2	79.4	**50.6**
East of England	99.5	98.7	90.2	60.8	70.9	63.4	64.8	**29.9**
East Midlands	99.5	99.1	85.4	76.2	86.4	74.2	79.5	**49.9**
London and South East	98.8	96.0	93.2	63.1	72.8	54.3	49.9	**21.3**
North East and North Cumbria	99.1	98.1	85.0	74.0	83.8	73.5	64.9	**40.3**
North West	99.5	99.0	90.7	67.6	84.6	64.2	70.5	**36.7**
South Central	99.6	98.7	89.0	69.5	81.6	74.4	76.4	**43.4**
South West	99.6	97.4	86.5	63.1	74.6	73.0	65.4	**32.1**
West Midlands	98.6	98.3	94.6	64.2	80.1	71.8	76.4	**45.5**
Yorkshire and the Humber	99.7	97.9	95.0	61.2	70.7	65.1	59.1	**35.7**

Figure 4 shows the variation in the percentage of young people aged 12 years and older who had all seven care processes completed by PDU in England and Wales. The horizontal black line shows the mean national completion rate, and the dotted lines indicate units whose results are within two standard deviations of this (dashes) or three standard deviations (dots). Units below the bottom dotted or dashed lines performed significantly worse that those above on this measure, and those above the top dotted or dashed lines performed significantly better. Individual PDU level reports will be published at www.rcpch.ac.uk/npda to detail unit level performance.

Figure 4: Percentage of young people aged 12 years and older with Type 1 diabetes receiving a complete year of care who received all seven care processes by unit, 2015/16

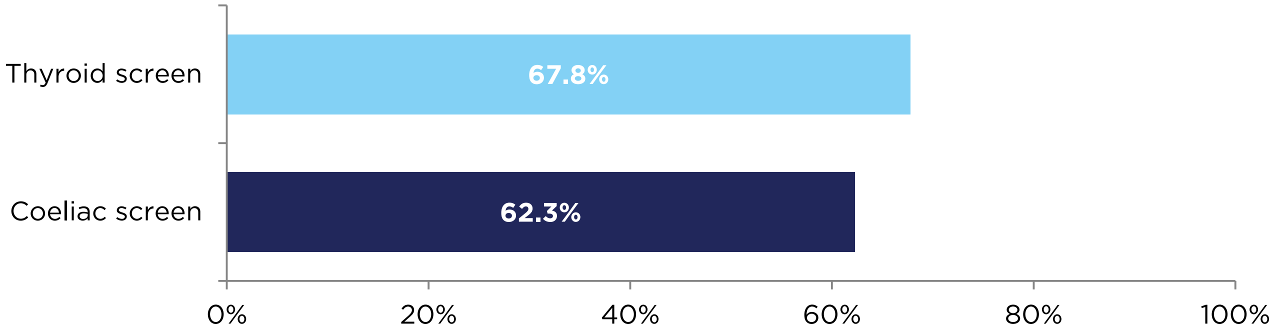


4.2.1 *Screening for coeliac and thyroid disease at diagnosis of Type 1 diabetes*

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, respectively, at diagnosis.

Figure 5 shows the percentage of patients diagnosed more than 90 days before the end of the audit year (N= 2260), who received screening for coeliac and thyroid disease within 90 days of diagnosis.[1]

Figure 5: Percentage of patients with Type 1 diabetes who received screening for thyroid or coeliac disease within 90 days of diagnosis in 2015/16.



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[1] This is the first year that these results have been reported so comparable data from previous audit is not available.

4.2.2 *Psychological assessment and smoking status checks for patients with Type 1 diabetes*

The audit also collects data on two additional health checks for patients with Type 1 diabetes:

- smoking status 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 12.

Table 12: Percentage of children and young people with Type 1 diabetes receiving the individual care processes of smoking status and psychological assessment by country and region, 2015/16

	Smoking status recorded (aged 12+ years)	Psychological assessment (all ages)
England and Wales	78.7	68.5
England	78.1	68.1
Wales	89.8	77.3
East of England	74.6	67.1
East Midlands	74.6	84.2
London and South East	74.3	72.1
North East and North Cumbria	69.5	55.9
North West	87.5	76.4
South Central	73.1	73.5
South West	67.9	68.6
West Midlands	90.9	57.0
Yorkshire and the Humber	83.7	52.2

4.2.3 *Number of HbA1c checks in audit year for patients 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. Table 13 shows the percentage of patients with Type 1 diabetes receiving a full year of care over the audit period (N= 22,567) with four or fewer recorded HbA1c measurements.

Table 13: Percentage of patients with Type 1 diabetes completing a full year of care with four or fewer HbA1c measurements recorded, 2015/16[2]

Number of HbA1c measurements	Percentage
4 or more	48.3
3	28.8
2	13.5
1	8.8
0	0.7

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[2] This is the first year that these results have been reported so comparable data from previous audit is not available.

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

Table 14 shows the percentage of children and young people with Type 2 diabetes completing a full year of care in 2015/16 who received each of the seven recommended healthcare checks.

Table 14: Percentage of children and young people with Type 2 diabetes with a complete year of care receiving key care processes, 2015/16

	All ages (N=412 for England and Wales)					Aged 12 + (N= 390 for England and Wales)		
	HbA1c	BMI	Cholesterol	Albumin	Blood pressure	Retinopathy	Foot examination	% receiving all 7
England and Wales	97.3	94.4	59.2	51.7	85 %	47.2	50.0	**16.7**

Table 15 shows the percentage of patients with Type 2 diabetes receiving a full year of care over the audit period (N=412) who met the Paediatric Diabetes Best Practice Tariff criteria requiring a minimum of four HbA1c measurements per year.

Table 15: Percentage of patients with Type 2 diabetes completing a full year of care with four or fewer HbA1c measurements recorded, 2015/16

Number of HbA1c measurements	Percentage
4 or more	29.6
3	24.8
2	24.3
1	18.7
0	2.7

The audit also collects data on two additional health checks for patients with Type 2 diabetes:

- smoking status 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 16.

Table 16: Percentage of children and young people with Type 2 diabetes receiving the care processes of psychological assessment and smoking status check by country, 2015/16

	Smoking status recorded (aged 12+ years)	Psychological assessment (all ages)
England and Wales	80.0	58.0
England	79.2	58.6
Wales	94.7	47.6

4.4 Summary of care process provision for children and young people with Type 1 and 2 diabetes

- A little over a third (35.5%) of young people aged 12 and above with Type 1 diabetes completing a year of care received all the key care processes recommended for this patient group in 2015/16.
- There was significant variation in the percentage of young people aged 12 and above with Type 1 diabetes completing a year of care who received all key care processes per unit, ranging from none to nearly 100%.
- Almost all children and young people with Type 1 diabetes had an HbA1c (99.2%) and a BMI recorded (97.9), whilst only two thirds of young people aged 12 and above had a foot check (65.8%), a retinopathy screen (66.2%) or urinary albumin screen (66.0%) recorded.
- Less than half (48%) of children and young people with Type 1 diabetes completing a full year of care over the audit period had four or more HbA1c's recorded.
- Two thirds of children and young people newly diagnosed with Type 1 diabetes were screened within 90 days for coeliac (62.3%) or thyroid (67.8%) disease.
- Just over two thirds (68.5%) of children and young people with Type 1 diabetes received psychological assessment, and only 58% of children with Type 2 diabetes did so.
- Only 19.2% of young people aged 12 years and above with Type 2 diabetes completing a year of care in 2015/16 received all key care processes. This is just over half the key care process completion rate for Type 1 diabetes (35.5%).
- Completion rates for HbA1c and BMI measurements were high amongst children and young people with Type 2 diabetes completing a year of care in 2015/16, with 97.3% and 94.4% receiving at least one of these, respectively.
- Less than a third (29.6%) of children and young people with Type 2 diabetes completing a full year of care over the audit period had four or more HbA1cs recorded, compared to 48% of children and young people with Type 1 diabetes.
- Overall, completion rates of care processes were higher amongst patients with Type 1 diabetes compared to those with Type 2 diabetes.

4.5 Recommendations

Multidisciplinary paediatric diabetes teams should:

- Ensure children and young people with diabetes are receiving the key care processes specific to their diabetes type.
- 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.
- Managing diabetes in children and young people is complex, in particular when it is associated with other psychological co-morbidities such as eating disorders, anxiety, and depression. Screening for such factors is important as treatment strategies can be employed to improve patient welfare.
- Identify barriers to the annual provision of key care processes and develop quality improvement initiatives to mitigate these.
- Be aware that completion rates of care processes tend to be higher amongst patients with Type 1 diabetes compared to those with Type 2 diabetes, and attempt to improve engagement with patients with Type 2 diabetes to ensure that these checks are carried out annually.

Commissioners and regional diabetes networks should:

- Ensure PDUs have the resources to collect accurate data and provide consistent care in accordance with NICE standards.

5. 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.

5.1 Type 1 diabetes

Table 17 provides a breakdown of the treatment regimens recorded by nation and region for children with Type 1 diabetes.

Table 17: Percentage of children and young people with Type 1 diabetes on each treatment regimen by country and region in England and Wales, 2015/16

	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	Oral hypoglycaemic agents and insulin	Missing data
England and Wales	2.2	4.7	1.8	54.0	28.1	0.1	0.5	8.7
England	2.3	4.3	1.7	54.2	27.9	0.1	0.5	9.0
Wales	1.5	11.8	2.3	49.6	30.2	*	0.0	4.5
East of England	1.1	2.7	2.2	58.9	26.1	0.3	0.6	8.0
East Midlands	4.5	6.8	1.0	49.1	31.6	*	0.7	6.2
London and South East	3.8	4.9	0.9	51.2	25.7	*	0.6	12.8
North East and North Cumbria	2.3	8.4	5.2	46.9	32.1	0.0	0.3	4.9
North West	3.8	6.1	2.9	55.0	25.8	*	0.8	5.6
South Central	2.4	1.7	1.6	56.8	26.9	*	0.0	10.4
South West	0.3	5.2	1.3	55.7	28.0	*	0.2	9.2
West Midlands	0.5	2.6	1.5	59.5	28.7	*	0.4	6.7
Yorkshire and the Humber	0.3	1.6	0.9	53.0	32.6	0.3	0.3	11.0

* represents a percentage derived from a number less than 5 which has been suppressed

Although the majority of children and young people with Type 1 diabetes were recorded as being on insulin in some form, there was a small cohort recorded as on 'no insulin' or 'oral hypoglycaemic medication' alone. By definition, children and young people with a diagnosis of Type 1 diabetes require insulin as part of their ongoing treatment. Therefore, care should be taken in interpreting the results of the small number of children and young people with a diagnosis of Type 1 diabetes where the treatment regimen has been recorded as 'no insulin' and/or 'oral hypoglycaemic agents' alone.

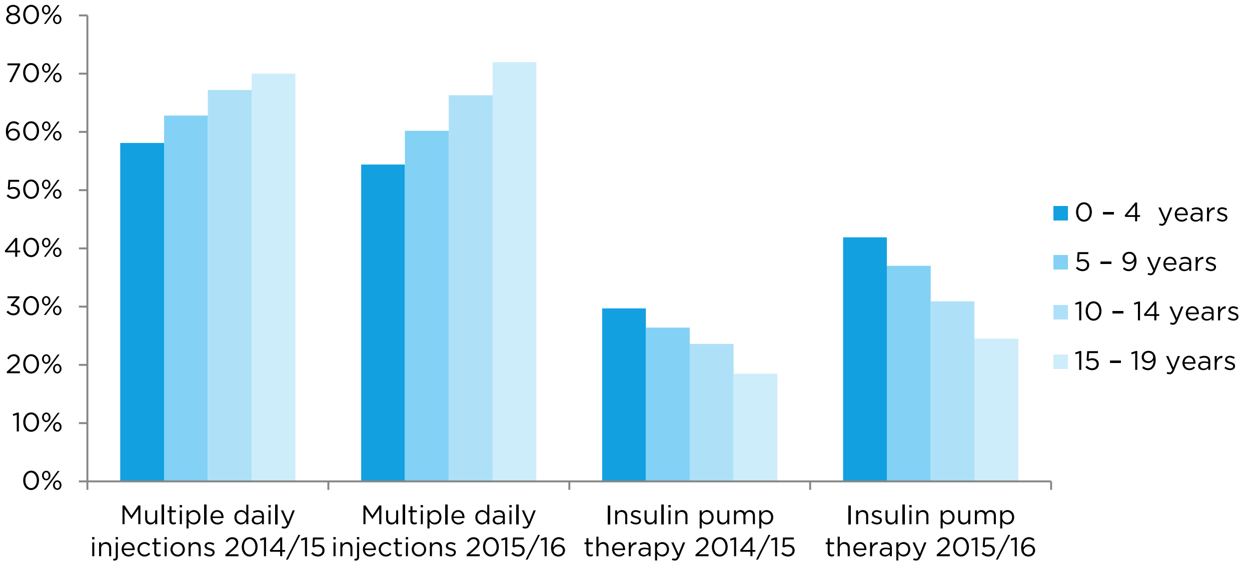
Table 18 shows there is variability in insulin treatment regimen by age group.

Table 18: Percentage of children and young people with Type 1 diabetes on insulin injections or pump therapy by age category in England and Wales, 2015/16

	1-4 + daily injections	Insulin pump therapy
0 – 4 years	54.4%	41.9%
5 – 9 years	60.2%	37.0%
10 – 14 years	66.3 %	30.9%
15 – 19 years	72.0%	24.5%

Figure 6 shows that there has been an increase in the percentage of children and young people using an insulin pump since 2014/15 in each age group.

Figure 6: Percentage of children and young people either on daily insulin injection or pump therapy by age group for 2014/15 and 2015/16 for England and Wales



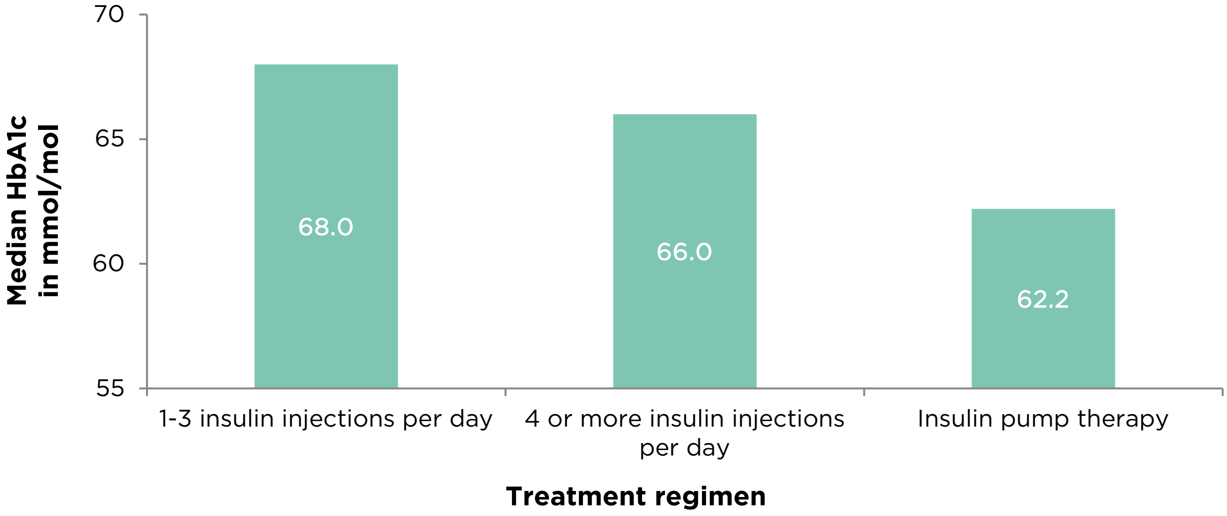
A higher proportion of those on insulin pump therapy were living in the least deprived areas in contrast to those on multiple daily injections where the reverse trend is apparent (Table 19).

Table 19: Percentage of children and young people with Type 1 diabetes either on daily insulin injection or pump therapy by deprivation quintile, 2015/16

	Multiple daily injections	Insulin pump therapy
Most deprived	73.2%	24.2%
2nd most deprived	68.9%	28.2%
3rd most deprived	65.0%	32.0%
2nd least deprived	61.6%	34.9%
Least deprived	61.4%	35.3%

Figure 7 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 7: Median HbA1c of children and young people by treatment regimen in mmol/mol



5.2 Type 2 diabetes

Table 20 shows the percentages of all children and young people with Type 2 diabetes recorded as following a particular treatment regimen:

Table 20: Percentage of children and young people with Type 2 diabetes on each treatment regimen, 2015/16

	No insulin	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	15.6%	3.2%	6.6%	1.0%	38.5%	18.2%	16.9%

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 a considerable amount of missing data. Caution should therefore be taken in interpretation of these results.

5.3 Summary

- There is variation in the percentage of children and young people with Type 1 diabetes receiving insulin either via injection or pump therapy, with younger children and those living in the least deprived areas more likely to be using pump therapy.
- Data quality for treatment regimen remains a problem in both Type 1 and Type 2 diabetes.

5.4 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 PDU's 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.

6. ‘Structured patient education’ for self-management

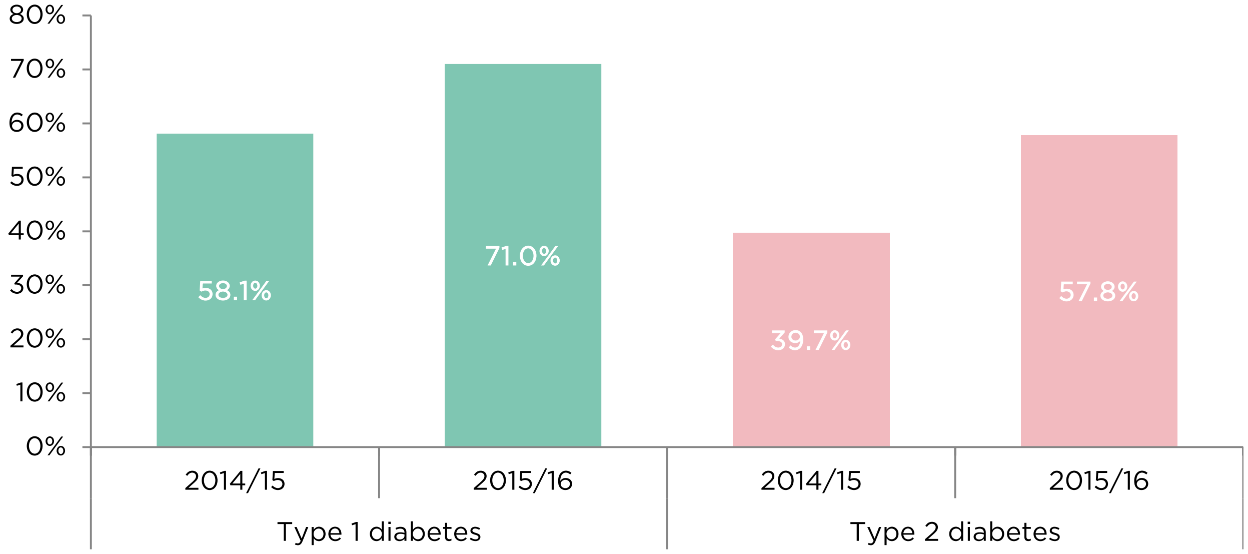
Structured education is important to support children and young people with diabetes and their families to understand the optimal management of their treatment regimen, blood glucose monitoring, the effects of diet, physical activity and illness, and how to detect and manage hypoglycaemia, hyperglycaemia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

The NPDA defines 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 8 shows an improvement in the percentage of children and young people with Type 1 and 2 diabetes receiving structured patient education between 2014/15 and 2015/16.

Figure 8: Percentage of children and young people with Type 1 and 2 diabetes included in the 2014/15 and 2015/16 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 results include those from all children and young people with Type 1 or 2 diabetes included in the audit.

Table 21 gives a breakdown of the percentage of children receiving structured education for self-management in the audit period by country and region, and shows considerable variation between regions and between England and Wales.

Table 21: Percentage of children and young people with Type 1 and 2 diabetes documented as receiving structured patient education in the audit period by country and regional network, 2015/16

	Type 1 diabetes	Type 2 diabetes
England and Wales	71.0%	57.8%
England	72.4%	58.8%
Wales	43.6%	34.6%
East of England	67.2%	55.9%
East Midlands	67.5%	54.8%
London and South East	76.1%	68.4%
North East and North Cumbria	71.5%	57.7%
North West	83.8%	80.0%
South Central	70.6 %	42.1 %
South West	45.7 %	29.0 %
West Midlands	75.0%	46.4%
Yorkshire and the Humber	80.6%	58.3%

6.1 Summary

- There has been a considerable increase in the percentage of patients recorded as receiving structured patient education between 2014/15 and 2015/16.
- Nearly 30% of children and young people with Type 1 diabetes, and over 40% of patients with Type 2 diabetes, were NOT recorded as receiving structured patient education in 2015/16.

6.2 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 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:

- 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 (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).

7. 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 disease. 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 control)
- indicators of small vessel (microvascular) disease
- large vessel (macrovascular) disease including cardiovascular risk, and
- autoimmune disease

7.1 HbA1c

HbA1c is a marker of overall diabetes blood glucose control 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 achieving good diabetes control in childhood tracks into continued good control in adulthood and a lower risk of developing vascular complications and early mortality in the future.

New NICE guidance (NG18, 2015) has introduced stricter HbA1c targets to indicate excellent diabetes control for both Type 1 and 2 diabetes with a 'cutoff' of 48mmol/mol or below. It also asks hospitals 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 previous NICE (2004) targets of below 58 mmol/mol. An HbA1c level >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 outcome analysis if they were within the acceptable range (20-195mmol/mol), dated within the audit, and were recorded at least 90 days following diagnosis, since newly diagnosed patients are unlikely to have established a level of control prior to this cut off and may therefore skew results. Where more than one HbA1c was recorded, the median value was used.

Average HbA1c and the proportion of children and young people meeting specific HbA1c targets vary depending on the type of diabetes. Children and young people with non-Type 1 diabetes tend to have a lower HbA1c than those with Type 1 diabetes. Some of the data presented below refers 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.

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 2015/16 were 67.8 and 64.5 mmol/mol respectively (Table 22). This is a reduction in the national mean and median of 3.3 and 2.0 mmol/mol respectively, compared to those recorded in 2014/15 of 71.1 and 66.5 mmol/mol. This means that for the sixth consecutive year there has been a fall in the median HbA1c level for England and Wales (Figure 9).

Figure 9: Change in median HbA1c for children and young people with all types of diabetes in England and Wales 2005/06 to 2015/16 with associated NHS policy and/or paediatric diabetes delivery structural changes

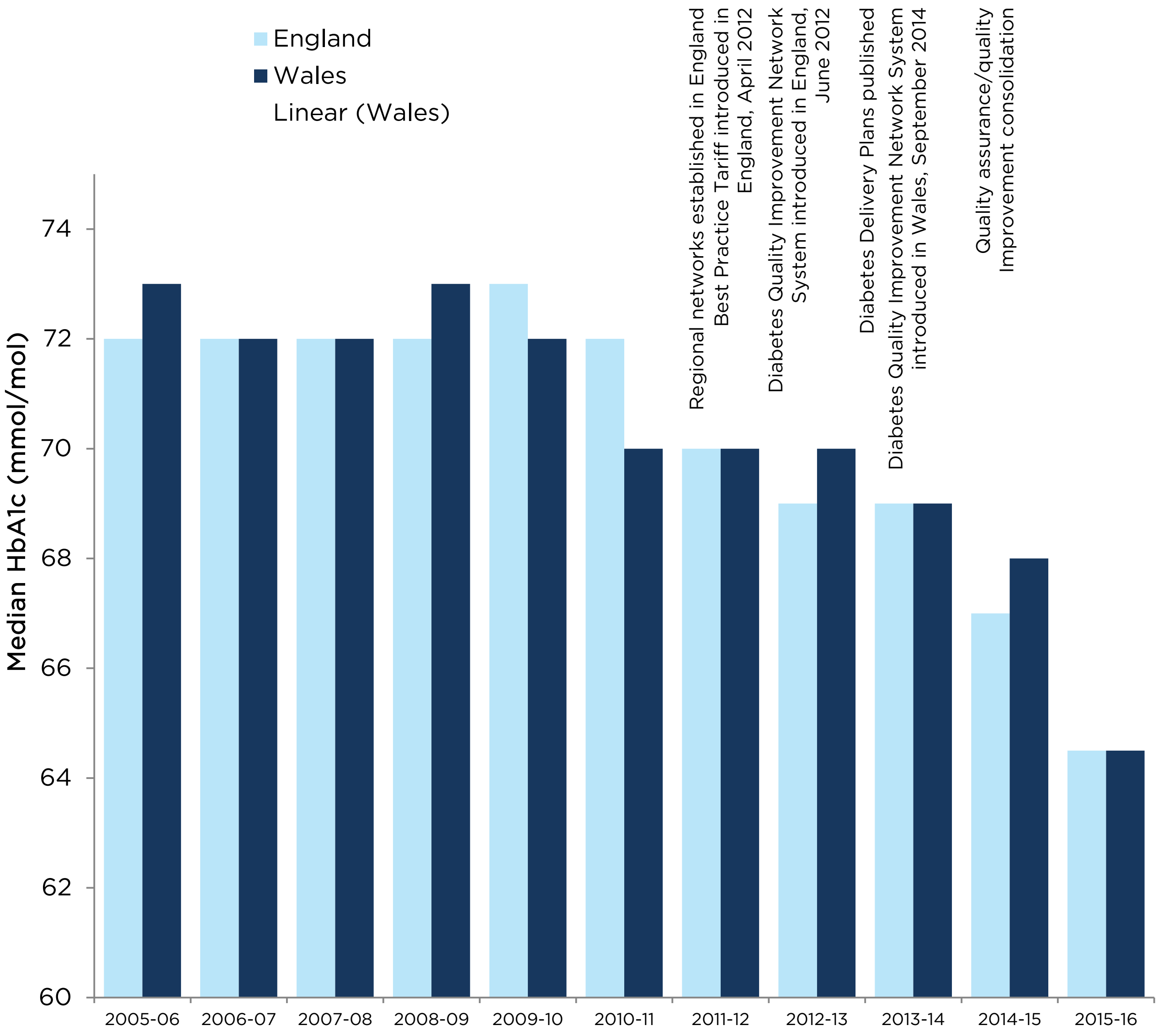


Table 22 provides a breakdown of the unadjusted mean and median HbA1c results achieved by each region and country, and the level of variation within them.

Table 22: HbA1c for all children and young people with all types of diabetes and one or more valid HbA1c measurements by country and regional network, 2015/16

	No. of children & young people	Mean mmol/mol (%)	Standard deviation mmol/mol (%)	Median mmol/mol (%)	IQR mmol/mol (%)
England and Wales	26,658	67.8	17.8	64.5	18.2
England	25,296	67.8	17.8	64.5	18.5
Wales	1362	68.0	17.3	64.5	19.0
East of England	2945	68.2	17.8	65.0	19.5
East Midlands	1775	64.8	16.2	63.0	18.5
London and South East	5851	68.7	18.9	65.0	19.0
North East and North Cumbria	1550	68.3	16.5	66.0	17.5
North West	3355	68.4	18.2	65.0	18.0
South Central	2253	64.2	15.7	62.0	15.5
South West	2099	67.9	17.3	65.0	18.0
West Midlands	2779	68.9	18.3	66.0	18.5
Yorkshire and the Humber	2689	68.4	17.5	65.0	17.5

7.1.1 *HbA1c outcomes of children and young people with Type 1 diabetes*

Table 23 provides a breakdown of the unadjusted mean and median HbA1c results for patients with Type 1 diabetes achieved by each region and country, and the level of variation within them.

23: HbA1c for all children and young people with Type 1 diabetes and one or more valid HbA1c measurements by country and regional network, 2015/16

	No. of children & young people	Mean mmol/mol (%)	Standard deviation mmol/mol (%)	Median mmol/mol (%)	IQR mmol/mol (%)
England and Wales	25531	68.3	17.4	65.0	18.0
England	24218	68.3	17.4	65.0	18.0
Wales	1313	68.4	16.9	65.0	18.5
East of England	2871	68.4	17.7	65.0	19.0
East Midlands	1712	65.3	15.8	63.0	18.0
London and South East	5504	69.3	18.3	65.5	18.6
North East and North Cumbria	1511	68.5	16.2	66.0	17.0
North West	3220	68.8	17.8	65.0	17.0
South Central	2182	64.6	15.4	62.5	15.0
South West	2041	68.2	17.1	65.0	18.0
West Midlands	2625	69.7	17.7	66.1	17.5
Yorkshire and the Humber	2552	68.8	17.1	65.5	17.5

Table 24 below shows the new NICE (2015) and historical NICE (2004) treatment targets, and the percentages of children and young people who achieved these targets. Figure 10 shows an increase in the percentage of children and young people with diabetes in the lower HbA1c ranges and a decrease in the percentages with higher HbA1c values since 2014/15.

Table 24: Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by country and regional network, 2015/16

	≤48 mmol/mol	≤53 mmol/mol	<58 mmol/ mol	≥69 mmol/mol	> 75 mmol/mol	> 80 mmol/ mol
England and Wales	6.5%	14.7%	26.6%	38.6%	24.5%	17.9%
England	6.6%	14.7%	26.6%	38.6%	24.4%	17.9%
Wales	5.9%	14.4%	25.6%	39.1%	26.3%	18.4%
East of England	6.8%	15.6%	27.9%	39.0%	25.5%	19.0%
East Midlands	9.1%	19.3%	33.4%	31.9%	19.6%	13.5%
London and South East	6.2%	14.0%	25.9%	41.3%	26.8%	19.7%
North East and North Cumbria	5.7%	13.7%	24.4%	41.8%	24.8%	18.0%
North West	6.4%	13.7%	24.4%	38.3%	24.8%	18.5%
South Central	8.9%	19.3%	33.9%	28.7%	16.6%	11.2%
South West	6.2%	15.0%	26.2%	39.0%	24.1%	18.0%
West Midlands	5.2%	11.7%	23.2%	42.2%	26.2%	19.0%
Yorkshire and the Humber	5.9%	12.9%	23.8%	39.7%	25.2%	18.8%

Figure 10: Percentage of children and young people with Type 1 diabetes achieving HbA1c targets in England and Wales in 2014/15 and 2015/16

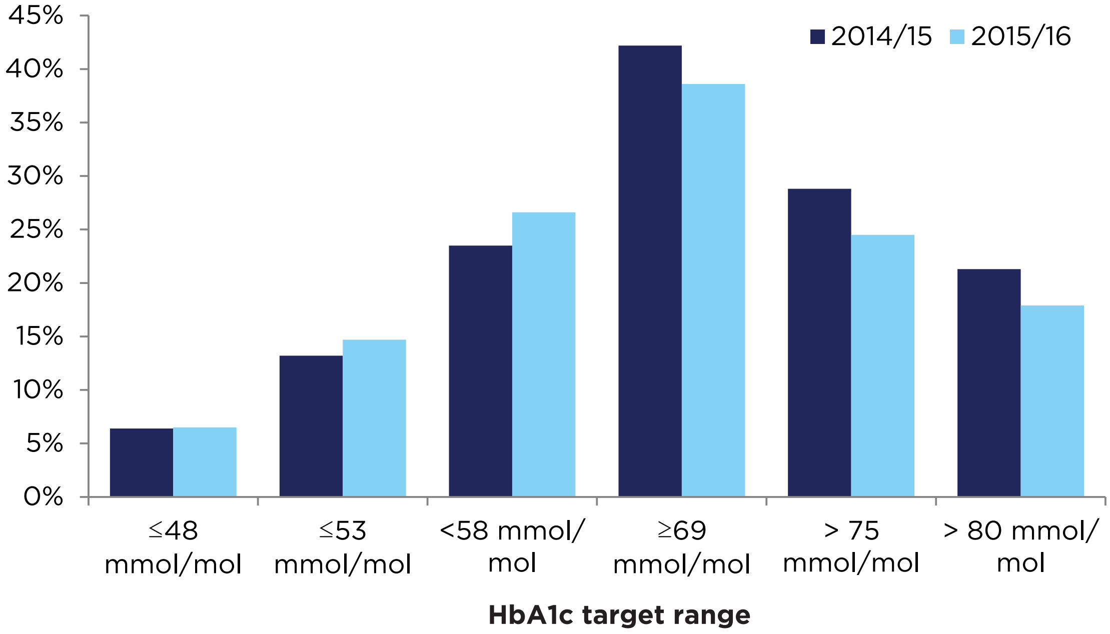


Figure 11 shows a rise in mean HbA1c with duration of Type 1 diabetes. This may well reflect increasing age as borne out by Figure 12, which shows older children tend to have poorer control.

Figure 11: Mean HbA1c for children and young people with Type 1 diabetes by duration of diabetes for England and Wales, 2015/16

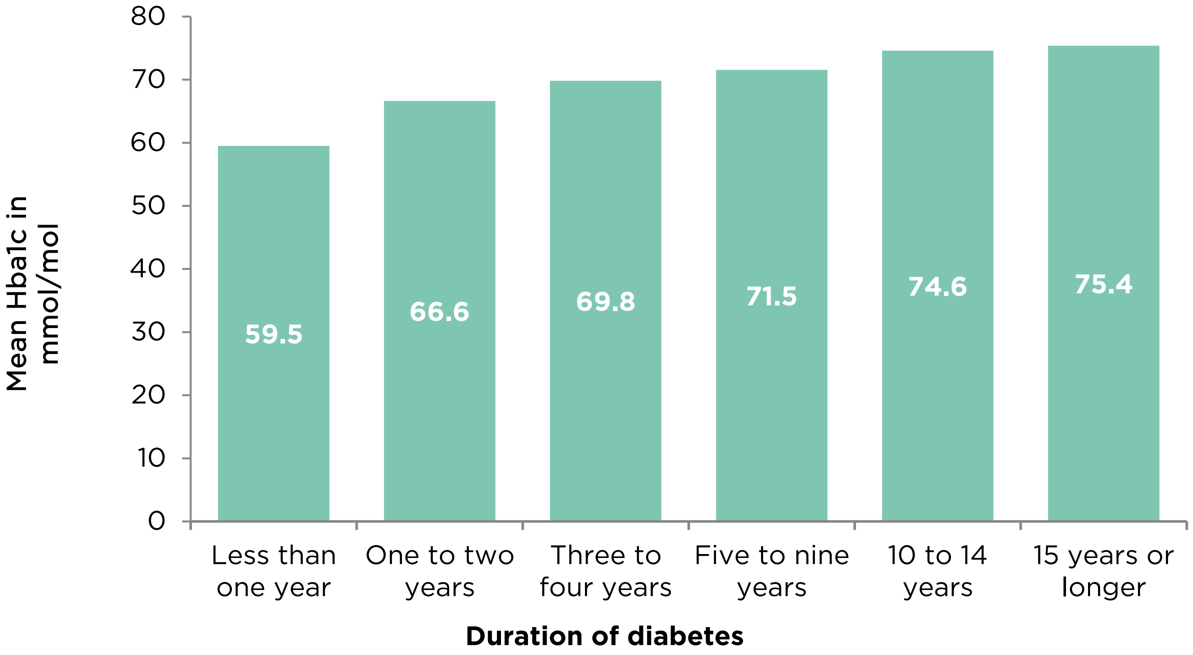
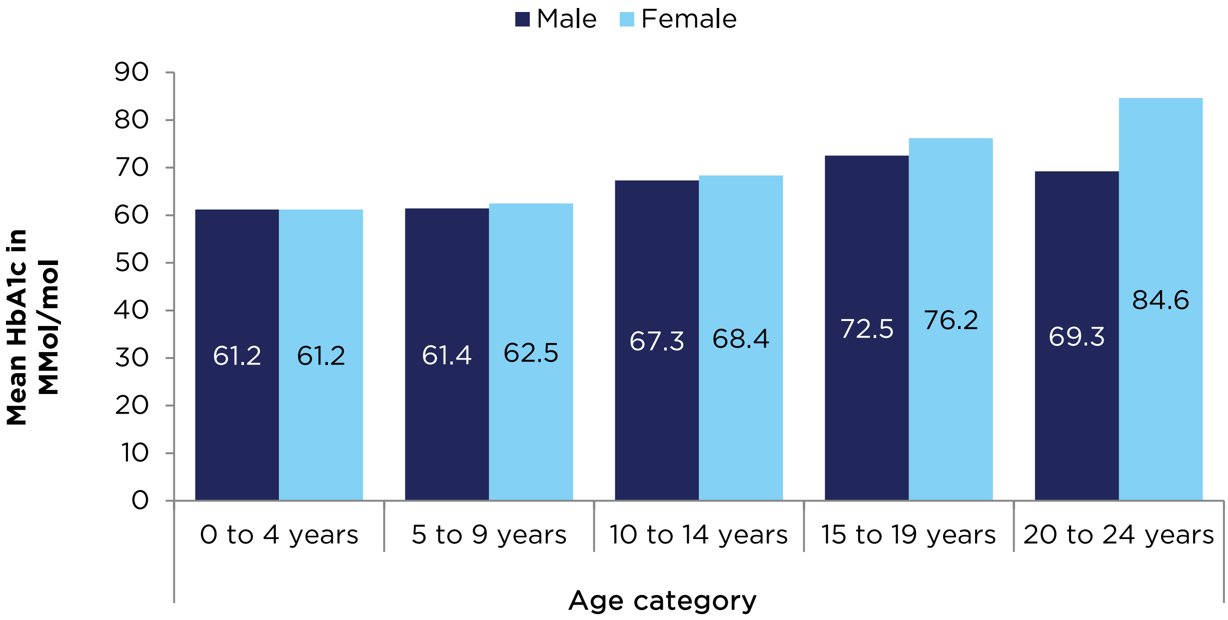


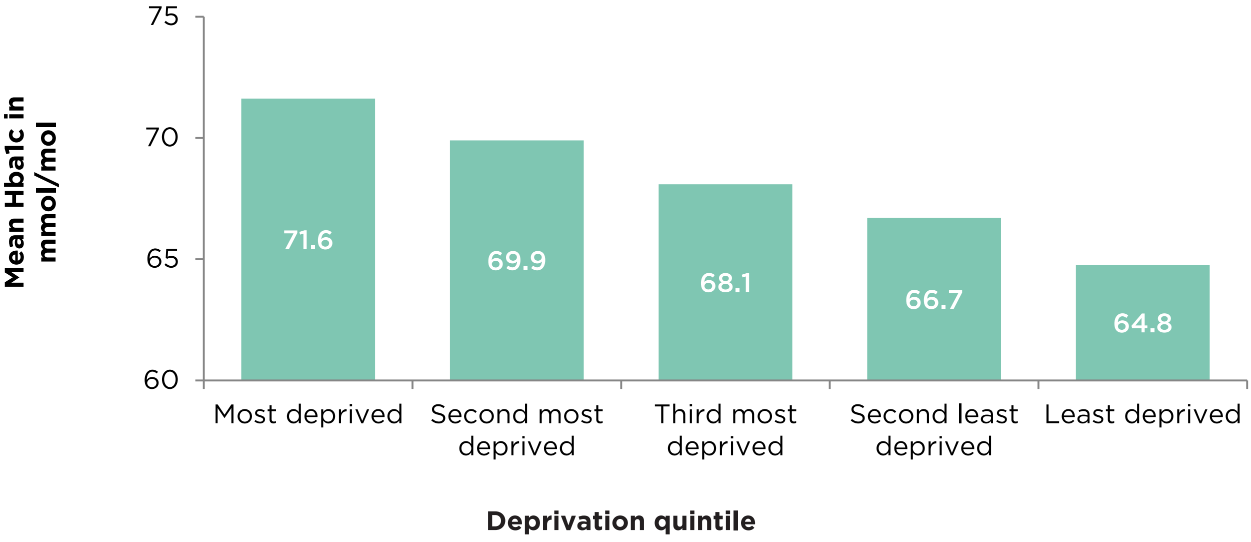
Figure 12 shows that younger children with Type 1 diabetes achieved better control than older children and young people, and males tended to achieve better control than females.

Figure 12: Mean HbA1c for children and young people with Type 1 diabetes by age and sex, 2015/16



Children and young people with Type 1 diabetes living in the most deprived areas achieved poorer diabetes control compared to those living in the least deprived areas of England and Wales (Figure 13).

Figure 13: Mean HbA1c for children and young people with Type 1 diabetes in England and Wales by deprivation quintile, 2015/16



Children and young people with Type 1 diabetes from ethnic minority groups achieved poorer diabetes control than white children and young people (Table 25).

Table 25: Percentage of children and young people with Type 1 diabetes in England and Wales achieving HbA1c targets by ethnic group, 2015/16

	Mean in mmol/mol	≤48 mmol/mol	≤53 mmol/mol	<58 mmol/mol	≥69 mmol/mol	> 75 mmol/mol	> 80 mmol/mol
White	67.8	6.5%	14.8%	27.2%	37.3%	23.3%	17.0%
Mixed	69.4	5.4%	11.2%	20.9%	43.5%	30.4%	21.4%
Asian	75.1	4.7%	12.5%	21.7%	43.2%	27.7%	19.8%
Black	70.9	5.2%	9.7%	16.2%	55.1%	38.2%	29.1%
Other	68.9	7.4%	17.9%	27.7%	40.9%	23.9%	18.7%
Not stated	68.3	7.6%	15.9%	27.8%	39.4%	25.6%	18.8%

Given the variations in HbA1c associated with different patient 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 2015/16 data take account of patient age, sex, ethnicity, duration of diabetes and deprivation.

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 14 shows the mean adjusted HbA1c for each PDU in England and Wales, and Figures 15 and 16 show the percentage of patients per clinic with an HbA1c lower than the treatment target of 58 mmol/mol and higher than the upper limit of 80 mmol/mol, respectively.

Figure 14: Funnel plot of mean adjusted HbA1c for children and young people with Type 1 diabetes in England and Wales by PDU, 2015/16

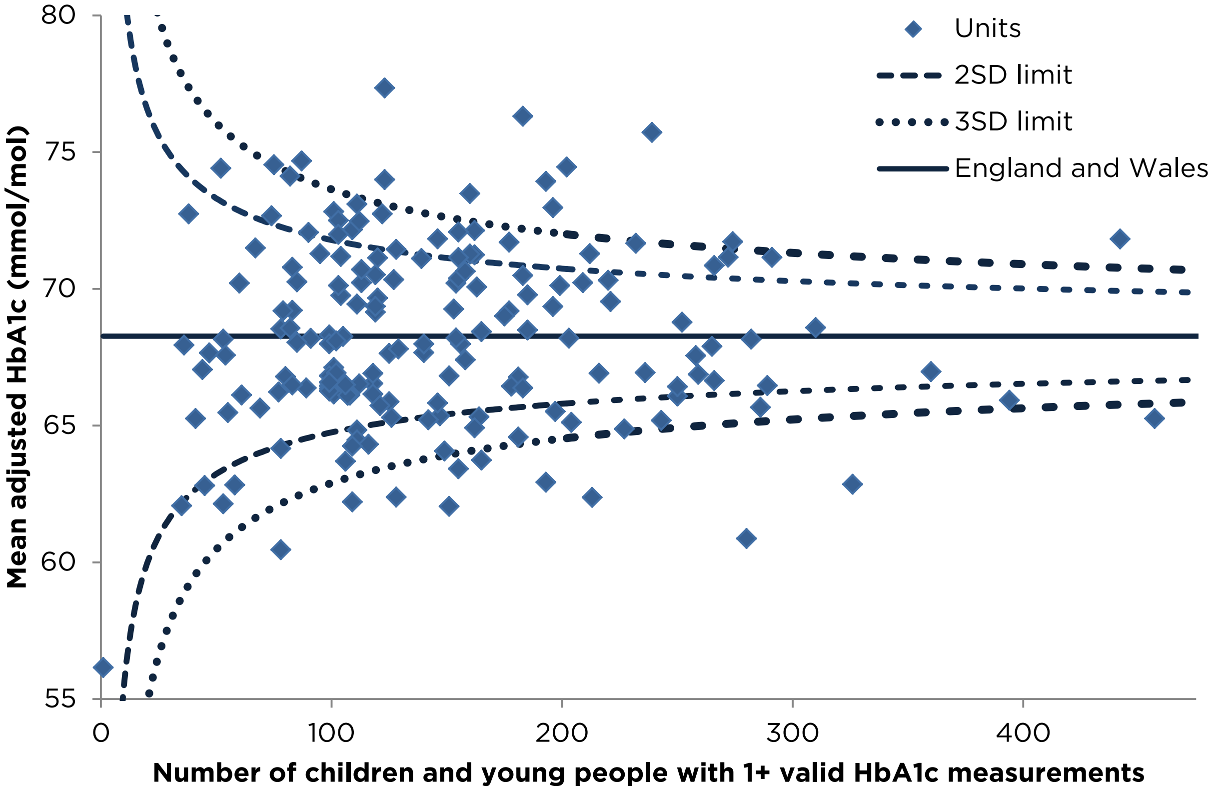


Figure 15: Funnel plot of percentage of children and young people with Type 1 diabetes in England and Wales with an adjusted HbA1c <58 mmol/mol by PDU, 2015/16

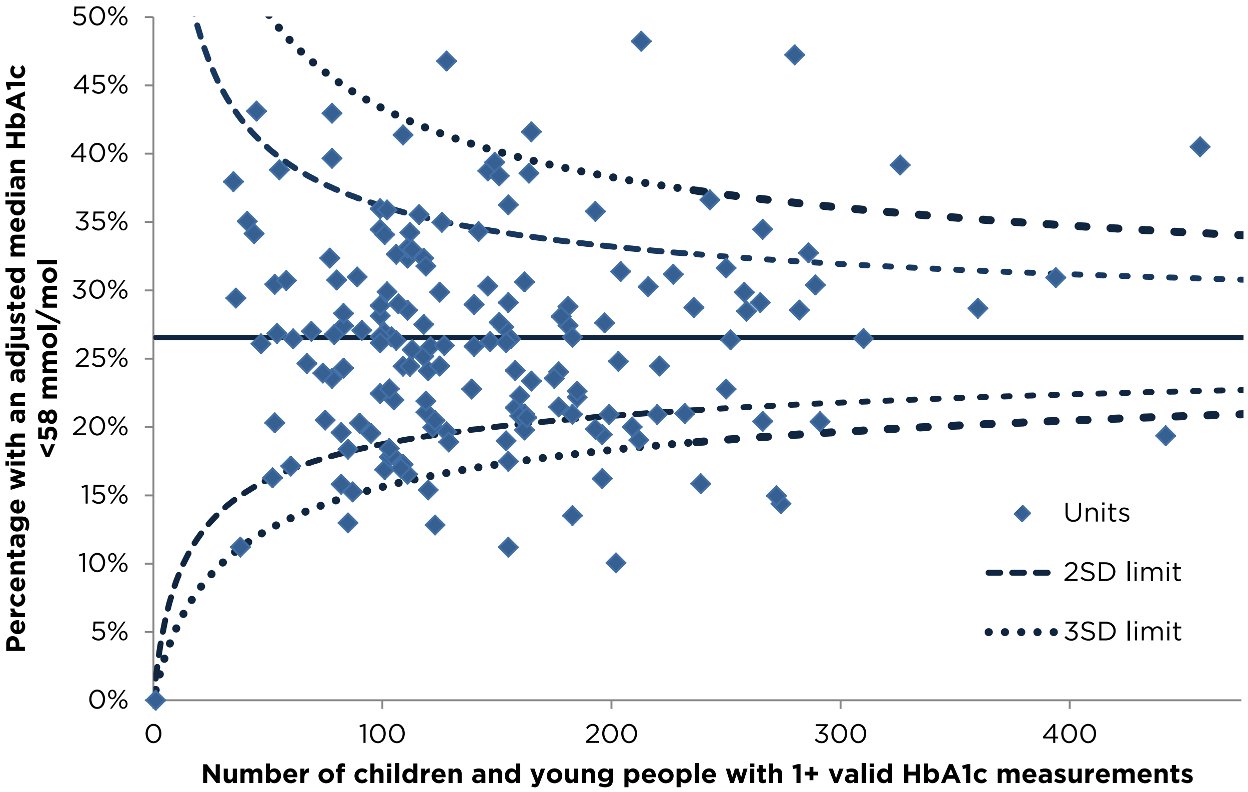
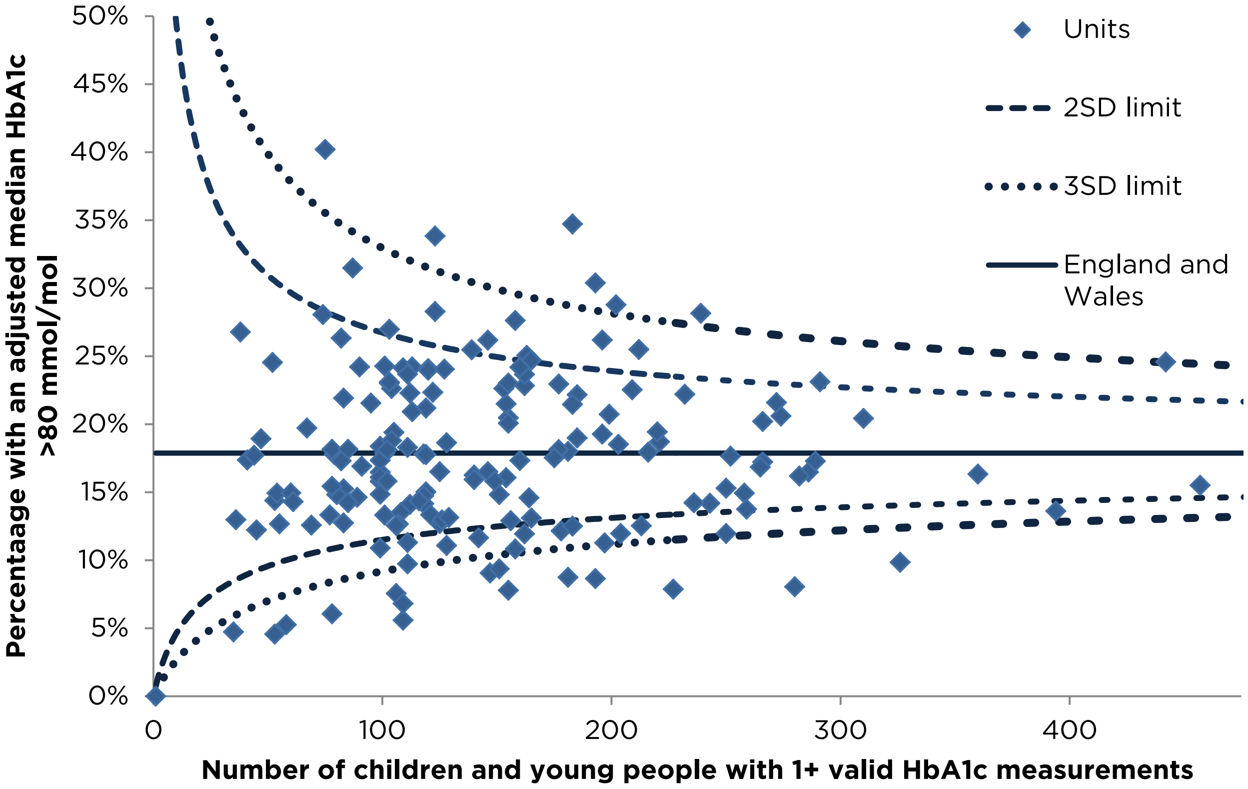


Figure 16: Funnel plot of percentage of children and young people with Type 1 diabetes in England and Wales with an adjusted HbA1c >80 mmol/mol by PDU, 2015/16



7.1.2 *HbA1c outcomes of children and young people with Type 2 diabetes*

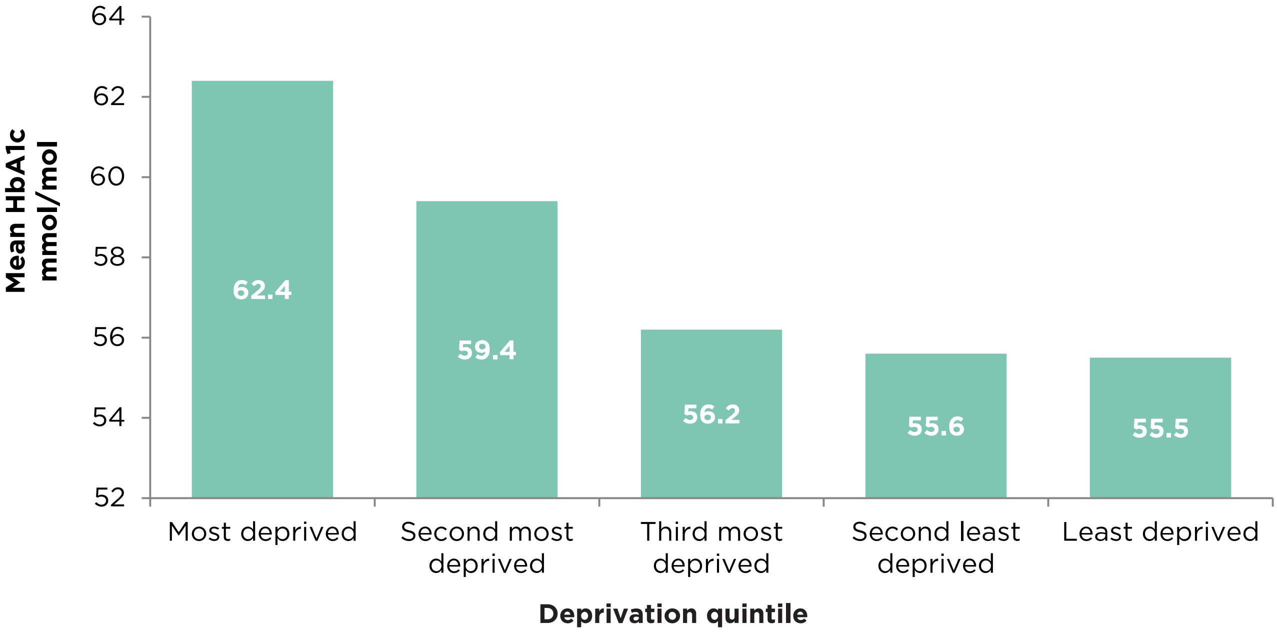
Table 26 provides a breakdown of the unadjusted mean and median HbA1c results for patients with Type 2 diabetes in England and Wales.

Table 26: HbA1c for all children and young people with Type 2 diabetes and one or more valid HbA1c measurements in England and Wales, 2015/16

	No. of children & young people	Mean mmol/mol (%)	Standard deviation mmol/mol (%)	Median mmol/mol (%)	IQR mmol/mol (%)
England and Wales	539	59.7	25.4	51.0	30.5

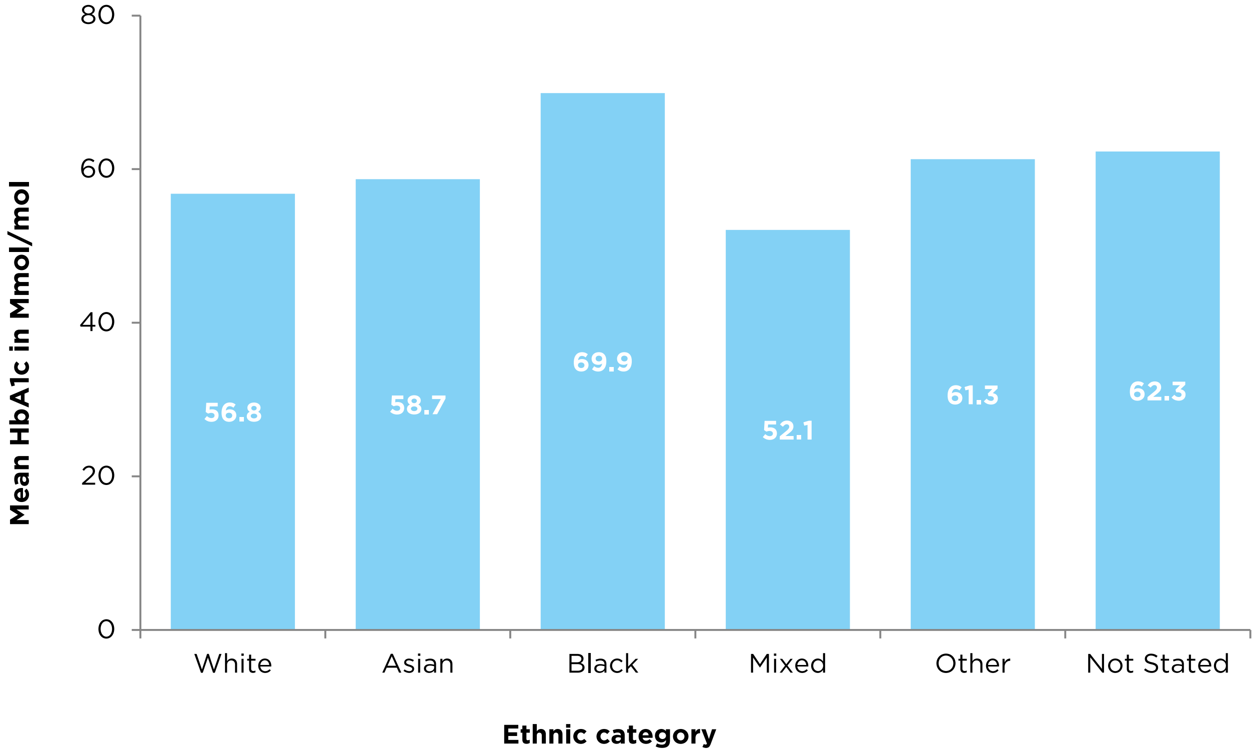
Figure 17 shows an association between level of deprivation and mean HbA1c, with children and young people living in the most deprived areas having a markedly higher HbA1c level compared to those in the least deprived areas. However, this association is less marked in the Type 2 cohort compared to the Type 1 cohort.

Figure 17: Mean HbA1c for children and young people with Type 2 diabetes in England and Wales by deprivation quintile, 2015/16



18 shows variation in mean HbA1c associated with ethnicity, with Black children and young people having a higher HbA1c level compared to those of other ethnic backgrounds.

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



7.1.3 *HbA1c summary*

- There have been reductions of 3.2 and 2.0 mmol/mol in the national mean and median HbA1c, respectively, for all children and young people being treated within a PDU in England and Wales since 2014/15
- There has been a 8.5mmol/mol reduction in median HbA1c in England and Wales for children and young people with diabetes over the last 6 years from 73mmol/mol in 2009/10 to 64.5mmol/mol in 2015/16
- There has been an increase in the percentage of children and young people with Type 1 diabetes achieving good control (HbA1c levels <58 mmol/mol) from 23.5% in 2014/15 to 26.6% in 2015/16
- There has been a reduction in the percentage of children and young people with Type 1 diabetes with poor control (HbA1c >80mmol/mol) from 21.3% in 2014/15 to 17.9% in 2015/16
- 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

7.1.4 *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 control
- 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 control, and adapt communications and structured education provision in order to be able to meet the different needs of vulnerable subgroups

Commissioners should:

- Be aware of the socioeconomic and patient demographic factors associated with poorer diabetes control, and ensure services catering to higher percentages of patients from vulnerable subgroups are resourced sufficiently to meet their needs
- Be aware of the cultural diversity amongst the paediatric diabetes population and ensure community groups and schools are sufficiently aware and trained to help young people to further improvements in diabetes control especially amongst vulnerable subgroups

7.2 Small vessel (microvascular) disease

People with diabetes are at increased risk of microvascular disease including chronic kidney disease (nephropathy) and eye disease (retinopathy).

NICE guidance (NG18, 2015) states, based on research in adults with Type 1 diabetes (The Diabetes Control and Complications Trial Research Group, 1993), that a 1 percentage point (11mmol/mol) decrease in HbA1c halves the risk of diabetes-related complications, including retinopathy and nephropathy. With good diabetes control and care, many of the complications can be minimised or avoided.

7.2.1 *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. Table 27 shows the results of the (N=9,555) young people with Type 1 diabetes aged 12 and above with an albuminuria screen dated during the audit period. There has been an overall reduction in the percentage with microalbuminuria or macroalbuminuria from 11.6% in 2014/15 to 9.7% in 2015/16. Although this is a reassuring improvement, given that these data only represent 60.8% (of 15,721) of the cohort of patients aged 12 and above with Type 1 diabetes this comparison and all other kidney disease outcome results should be interpreted with caution.

Table 27: Percentage of young people with Type 1 diabetes aged 12 years and older with albuminuria by country and region, 2015/16

	Normoalbuminuria	**Microalbuminuria or Macroalbuminuria**	**Missing Data***
England and Wales	88.3%	9.7%	2.0%
England	88.0%	10.0%	2.1%
Wales	93.0%	5.1%	1.8%
East of England	77.0%	13.4%	9.5%
East Midlands	89.2%	8.5%	2.3%
London and South East	88.3%	10.9%	0.8%
North East and North Cumbria	91.4%	7.9%	0.8%
North West	87.0%	12.6%	0.4%
South Central	91.0%	5.5%	3.5%
South West	86.8%	11.7%	1.5%
West Midlands	89.6%	10.1%	0.3%
Yorkshire and the Humber	93.7%	5.8%	0.4%

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

Table 28 shows that the risk of kidney disease was increased amongst older young people with Type 1 diabetes with a recorded interpretation of an albuminuria result.

Table 28: Percentage of children and young people with Type 1 diabetes aged 12 years and older with albuminuria by age, 2015/16

Age	Microalbuminuria or Macroalbuminuria
12 years	7.9%
13 years	8.9%
14 years	9.8%
15 years	10.3%
16 years	10.2%
17 years	11.3%
18 years	13.8%

Table 29 shows that the risk of albuminuria was increased amongst those living in the most deprived areas with a recorded interpretation of an albuminuria result.

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

	Microalbuminuria or Macroalbuminuria
Most deprived	10.7%
2nd most deprived	10.0%
3rd most deprived	10.0%
2nd least deprived	9.8%
Least deprived	9.0%

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

7.2.2 *Kidney disease in young people with Type 2 diabetes*

Table 30 shows the results of the 256 children and young people with Type 2 diabetes included in the audit who received screening for albuminuria (42.2% of the Type 2 cohort).

It shows that of the children and young people with a result dated within the audit period, 14.5% were at increased risk of kidney disease. This risk is higher than for that recorded for the young people with Type 1 diabetes screened within the audit year (9.7%), however the data should be interpreted with caution given the absence of albuminuria screening data for a large percentage of both cohorts.

Table 30: Percentage of children and young people with Type 2 diabetes with albuminuria in England and Wales, 2015/16

	Normoalbuminuria	Microalbuminuria or Macroalbuminuria	Missing Data
England and Wales	84.4%	14.5%	1.2%

7.2.3 *Eye disease in young people with Type 1 diabetes*

Table 31 shows the outcome results of the of the Type 1 diabetes cohort with an eye screen dated within the audit period (N=9,788). It shows 13.8% had an abnormal retinopathy screening result in England and Wales in 2015/16 compared to 12.8% in 2014/15, but there was considerable variation between regions and a large amount of missing data.

Table 31: Percentage of young people with Type 1 diabetes aged 12 years and older with a normal/abnormal retinopathy screening result by country and region, 2015/16

	Normal	Abnormal	Missing eye screening result
England and Wales	76.5%	13.8%	9.7%
England	76.1%	14.1%	9.7%
Wales	83.3%	8.6%	8.2%
East of England	69.7%	17.0%	13.4%
East Midlands	78.1%	13.4%	8.5%
London and South East	75.5%	11.9%	12.6%
North East and North Cumbria	83.3%	13.2%	3.5%
North West	66.3%	13.6%	20.1%
South Central	77.8%	10.8%	11.4%
South West	82.5%	14.5%	2.9%
West Midlands	78.9%	14.8%	6.3%
Yorkshire and the Humber	80.1%	18.7%	1.2%

Table 32 shows the percentage who had an abnormal eye screen result by age category, demonstrating increasing prevalence of retinopathy with age.

Table 32: Percentage of young people with Type 1 diabetes aged 12 years and older with an abnormal eye screening result by agegroup in England and Wales, 2015/16

	Abnormal
12 years	6.4%
13 years	9.4%
14 years	11.6%
15 years	14.5%
16 years	17.2%
17 years	20.5%

Table 33 shows the percentage of young people with Type 1 diabetes aged 12 years and older in each deprivation category with an eye screening result (9,770) that was abnormal. It shows an association between risk of eye disease and deprivation, with those living in the most deprived areas at greater risk of eye disease.

Table 33: Percentage of children and young people with Type 1 diabetes aged 12 years and older with abnormal eye screening by deprivation in England and Wales, 2015/16

	Abnormal
Most deprived	16.4%
2nd most deprived	15.6%
3rd most deprived	15.0%
2nd least deprived	14.9%
Least deprived	14.8%

7.2.4 *Eye disease in young people with Type 2 diabetes*

Table 34 shows the outcome results of the young people with Type 2 diabetes aged 12 and above with a recoded eye screen (N=240). It shows that 5.4% of these had an abnormal eye result indicative of eye disease.

Table 34: Eye screening results for children and young people aged 12 years and above with Type 2 diabetes, 2015/16

	Normal	Abnormal	Missing eye screening data
England and Wales	81.7%	5.4%	12.9%

*Missing data relates to patients with a retinopathy screen dated within the audit period, but no submitted interpretation of this result.

7.3 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.

7.3.1 *Blood pressure and cholesterol*

High blood pressure and/or raised blood cholesterol increases lifetime risk of cardiovascular disease including strokes 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 of outcome are still presented where data has been recorded. 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).

7.3.2 *Blood Pressure and cholesterol in patients with Type 1 diabetes*

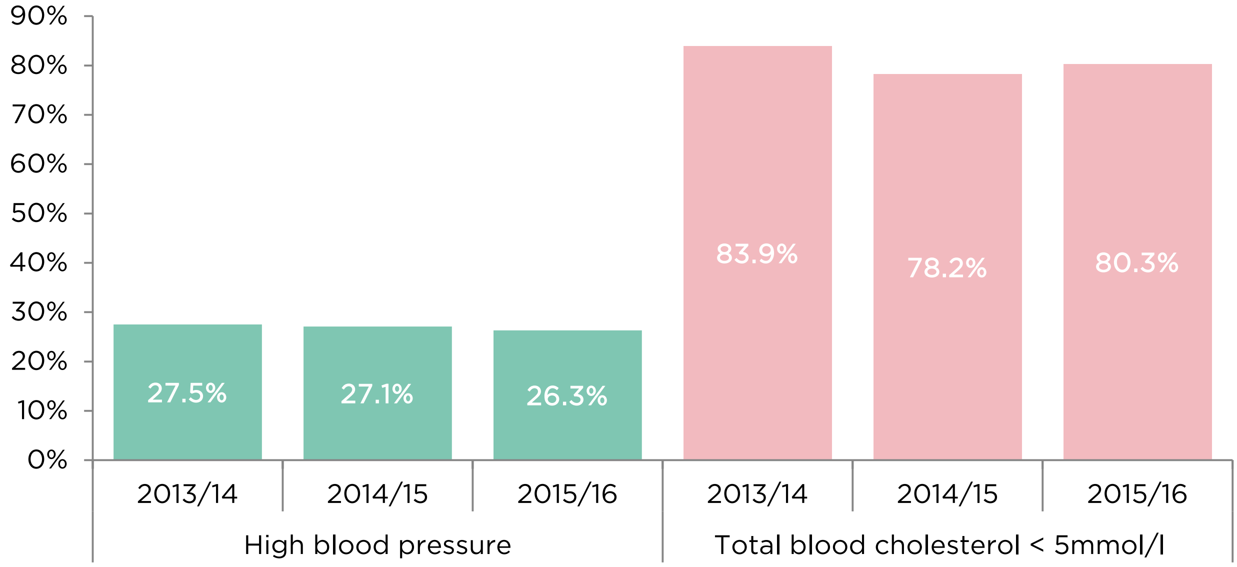
Table 35 shows the percentages of young people aged 12 years and above with Type 1 diabetes with a recorded blood pressure in the audit period (N=13,750) classified as ‘high normal’ or ‘high’ blood pressure, and those with a recorded cholesterol screen (N=9,873) within the target for total blood cholesterol. It shows that over a quarter of young people (26.3%) with Type 1 diabetes had high blood pressure (hypertension), and that 19.7% exceeded the target for total blood cholesterol.

Table 35: 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, 2015/16

	'High normal' blood pressure (91st–98th centile)			'High' blood pressure (>98th centile)			Total blood cholesterol	
	Diastolic	**Systolic**	**Diastolic and/or systolic**	**Diastolic**	**Systolic**	**Diastolic and/or systolic**	**4 mmol/l or less**	**5 mmol/l or less**
England and Wales	27.3%	9.8%	34.3%	24.8%	4.6%	26.3%	40.5%	80.3%
England	27.2%	9.8%	34.2%	25.1%	4.6%	26.5%	40.5%	80.2%
Wales	29.3%	10.1%	36.6%	19.7%	3.7%	21.2%	40.0%	82.8%
East of England	25.1%	9.4%	32.2%	26.6%	6.0%	28.4%	38.7%	81.1%
East Midlands	28.1%	10.4%	35.6%	25.4%	4.4%	27.7%	44.5%	82.7%
London and South East	27.2%	9.0%	33.6%	24.1%	3.0%	25.0%	33.9%	76.0%
North East and North Cumbria	27.2%	4.7%	28.3%	24.5%	1.6%	23.0%	45.1%	85.5%
North West	25.8%	9.4%	33.3%	26.4%	4.1%	27.8%	42.4%	80.1%
South Central	27.1%	10.9%	34.9%	22.9%	5.2%	25.1%	43.9%	82.6%
South West	32.0%	11.7%	40.5%	29.1%	6.2%	31.3%	44.9%	80.0%
West Midlands	27.3%	10.8%	35.1%	23.7%	5.1%	25.4%	42.4%	81.1%
Yorkshire and the Humber	27.0%	11.3%	34.9%	24.1%	6.7%	26.2%	40.0%	80.3%

Figure 19 shows little change in the percentage of young people with Type 1 diabetes with significant hypertension or hypercholesterolaemia (at increased cardiovascular risk) over the last three audit cycles.

Figure 19: Percentage of young people aged 12 years and older with Type 1 diabetes with high blood pressure and within target for total blood cholesterol in England and Wales, in 2013/2014, 2014/15 and 2015/16



7.3.3 *Blood Pressure and cholesterol in patients with Type 2 diabetes*

Table 36 shows the percentages of children and young people with Type 2 diabetes with a recorded blood pressure in the audit period (N= 503) classified as 'high normal' or 'high' blood pressure, and those with a recorded cholesterol screen (N=321) within the target for total blood cholesterol. It shows that 40.4% of children and young people with Type 2 diabetes have high blood pressure, and 25.5% are exceeding the target for total blood cholesterol.

Table 36: Percentage of children and young people with Type 2 diabetes falling within blood pressure and total cholesterol targets by country, 2015/16

	'High normal' blood pressure (91st-98th centile)			'High' blood pressure (>98th centile)			Total blood cholesterol	
	Diastolic	Systolic	Diastolic and/or systolic	Diastolic	Systolic	Diastolic and/or systolic	4 mmol/l or less	5 mmol/l or less
England and Wales	24.6%	16.8%	38.0%	37.5%	13.0%	40.4%	33.3%	74.5%
England	24.9%	15.9%	37.2%	37.0%	13.4%	39.9%	33.3%	73.9%
Wales	*	38.1%	57.1%	47.6%	*	52.4%	33.3%	86.7%

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

7.3.4 *Body Mass Index*

Having a higher Body Mass Index (BMI, weight/height^2) increases cardiovascular risk. In children and young people BMI requires standardisation for age and gender using centile charts. BMI can be converted into the following categories using the centile definitions based on the UK 1990 standards (Pan & Cole, 2012) (Table 18).

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

Comparisons can be made with the National Child Measurement Programme in England 2015/16 (NHS Digital, 2016) and the Child Measurement Programme in Wales (2014/15). 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 2015/16, in England 33.7% of children aged 4 to 5 years old with Type 1 diabetes are overweight or obese (an increase from 31.6% in 2014/15) compared to 22.1% in the National Child Measurement Programme for England.

A similar pattern is found in Wales where 45.4% of children with Type 1 diabetes aged 4-5 years are overweight or obese (an increase from 44.4% in 2014/15) 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 33.7% (an increase from 32.9% in 2014/15) compared to 34.1% 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.

7.3.5 *Body Mass Index and Type 1 diabetes*

Table 37 shows the percentage of all children and young people with Type 1 diabetes included in the 2015/16 audit within each BMI category. It shows that a higher percentage of those aged 0-11 years had a healthy weight (62.6%) compared to those aged 12 years and older (54.1%), and that higher percentages of children and young people with Type 1 diabetes were overweight or obese than were underweight.

Table 37: Percentage of children aged 0-11 years and young people 12 years and older with Type 1 diabetes within BMI categories by country and region, 2015/16

	% of children aged 0 to 11 years with Type 1 diabetes in the following categories					% of young people aged 12 years and older with Type 1 diabetes in the following categories				
	Underweight	Healthy weight	Overweight	Obese	Missing BMI data	Underweight	Healthy weight	Overweight	Obese	Missing BMI data
England and Wales	1.5%	62.6%	16.4%	16.5%	2.9%	2.8%	54.1%	18.1%	20.8%	4.2%
England	1.5%	62.9%	16.3%	16.3%	3.0%	2.8%	54.2%	18.1%	20.7%	4.2%
Wales	1.3%	57.0%	18.3%	21.4%	2.0%	2.6%	52.5%	16.4%	23.2%	5.2%
East of England	1.9%	60.3%	15.5%	20.6%	1.7%	5.2%	54.6%	18.0%	18.3%	3.9%
East Midlands	2.0%	66.0%	16.0%	15.2%	0.9%	2.2%	56.3%	16.3%	22.5%	2.8%
London and South East	2.0%	63.5%	15.4%	14.1%	5.0%	2.5%	56.4%	17.6%	19.0%	4.5%
North East and North Cumbria	*%	62.0%	15.5%	19.3%	2.7%	2.6%	49.3%	17.7%	25.5%	5.0%
North West	1.1%	62.8%	18.7%	16.1%	1.4%	2.6%	52.4%	19.4%	23.0%	2.6%
South Central	1.7%	65.5%	17.8%	13.1%	1.9%	2.8%	56.0%	18.4%	18.6%	4.3%
South West	0.7%	60.1%	15.5%	18.1%	5.7%	1.9%	53.3%	18.7%	19.4%	6.8%
West Midlands	1.3%	62.9%	16.7%	17.2%	2.0%	2.3%	53.4%	17.6%	22.9%	3.8%
Yorkshire and the Humber	1.6%	63.2%	16.2%	16.0%	3.0%	2.6%	53.2%	19.2%	20.6%	4.4%

Figure 20 shows the distribution of body mass index of children and young people with Type 1 diabetes in 2014/15 and 2015/16 in comparison to the 1990 standards. It shows that overall, children and young people with Type 1 diabetes have a higher BMI than the wider population.

Figure 20: Distribution of body mass index of children and young people with Type 1 diabetes in 2013/14, 2014/15 and 2015/16

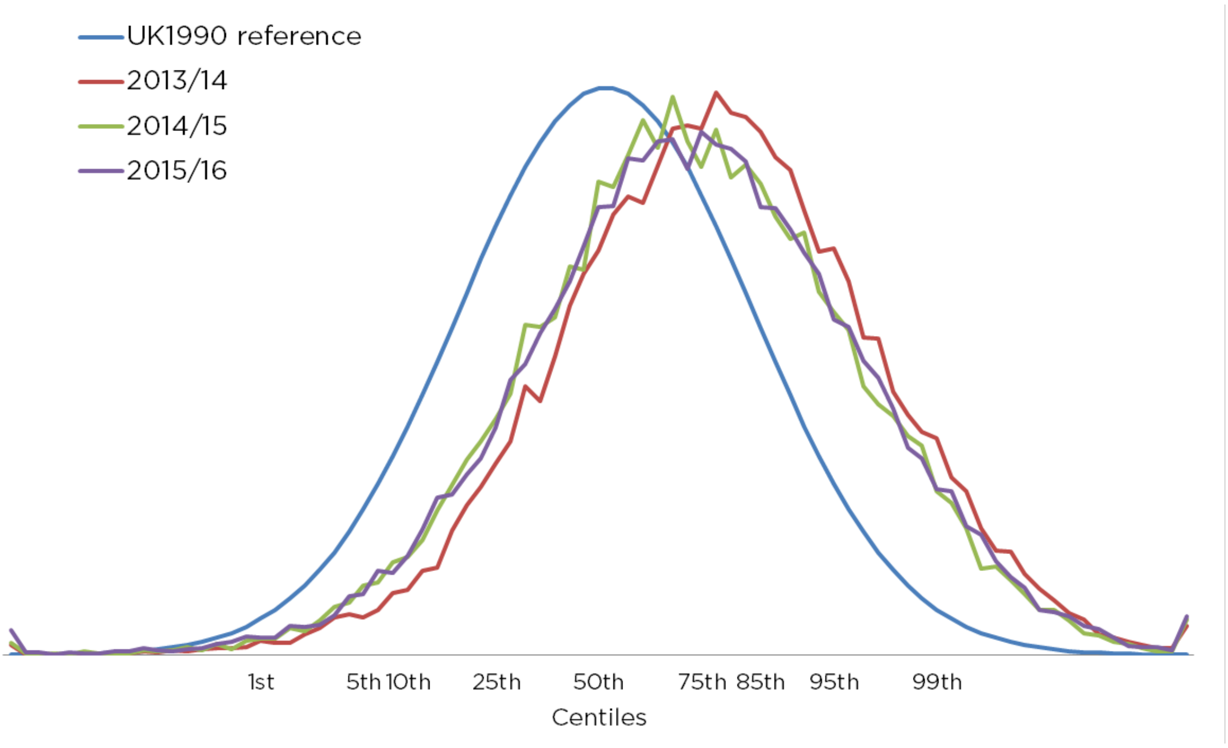
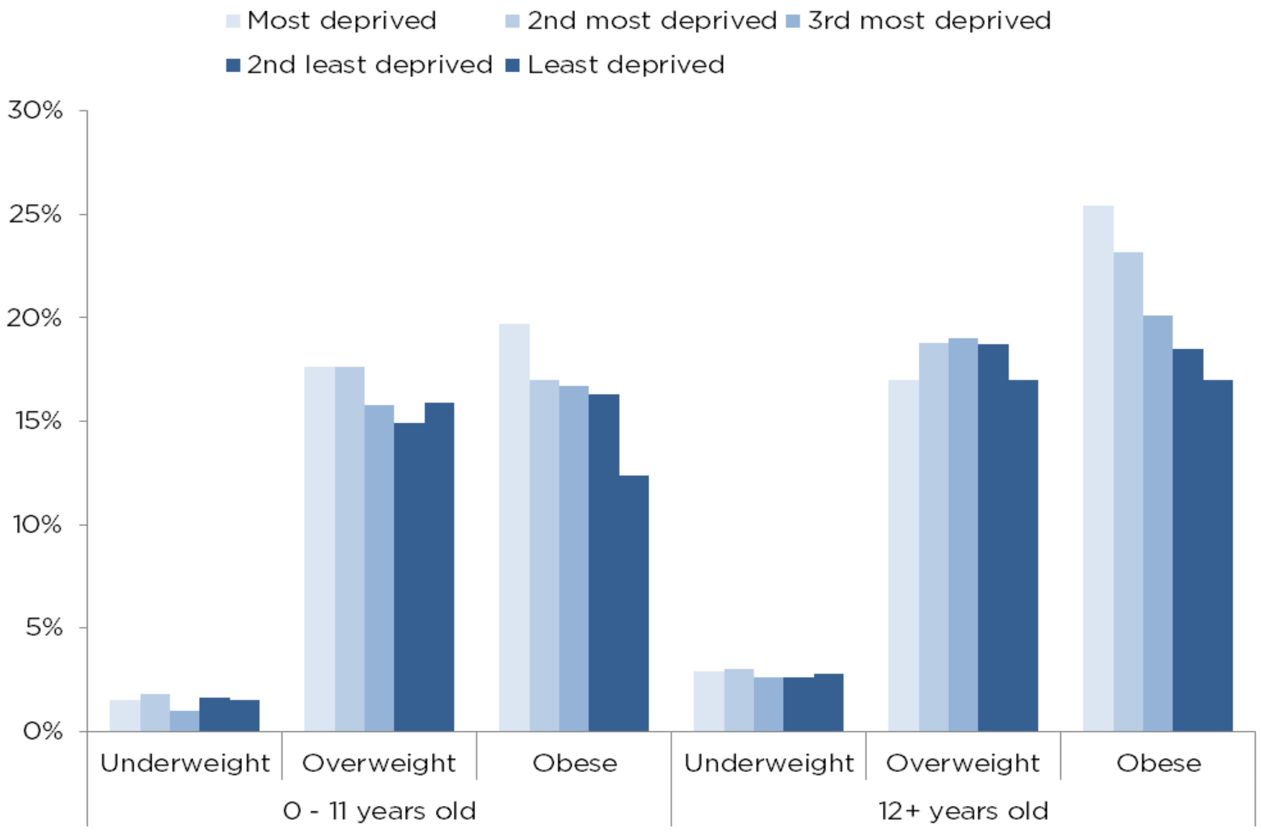


Table 38 and Figure 21 show the percentage of children and young people with Type 1 diabetes within the BMI categories by area of deprivation. Similar to the background population, they show a clear deprivation gradient for being overweight and/or obese in children and young people with Type 1 diabetes.

Table 38: Body mass index categories for children and young people with Type 1 diabetes by deprivation quintile, 2015/16

	% of children aged 0 to 11 years with Type 1 diabetes in the following categories					% of children aged 12+ years with Type 1 diabetes in the following categories				
	Underweight	Healthy weight	Overweight	Obese	Missing BMI data	Underweight	Healthy weight	Overweight	Obese	Missing BMI data
Most deprived	1.5%	57.9%	17.6%	19.7%	3.3%	2.9%	50.6%	17.0%	25.4%	4.1%
2nd most deprived	1.8%	60.3%	17.6%	17.0%	3.4%	3.0%	50.5%	18.8%	23.2%	4.5%
3rd most deprived	1.0%	63.5%	15.8%	16.7%	3.1%	2.6%	53.8%	19.0%	20.1%	4.4%
2nd least deprived	1.6%	65.0%	14.9%	16.3%	2.3%	2.6%	56.1%	18.7%	18.5%	4.1%
Least deprived	1.5%	67.8%	15.9%	12.4%	2.3%	2.8%	59.4%	17.0%	17.0%	3.8%

Figure 21: Percentage of children and young people with Type 1 diabetes within each body mass index category by deprivation quintile



7.3.6 *Body Mass Index and Type 2 diabetes*

Table 39 shows the percentage of children and young people with Type 2 diabetes within BMI categories for England and Wales.

Table 39: Body mass index categories for children and young people with Type 2 diabetes, 2015/16

	% of children and young people with Type 2 diabetes in the following categories				
	Underweight	Healthy weight	Overweight	Obese	Missing data
England and Wales†	*	6.9%	7.3%	78.5%	7.3%

† Percentages were calculated from the total number of those who were of a healthy weight, overweight, obese or had a missing result.

*indicates a percentage derived from a number <5

7.4 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 40 shows the percentages of children and young people age 12 and over with Type 1 diabetes with a recorded smoking result in the audit period (N=12,287) classified as 'current smoker'. It shows that just under one in 30 patients were smoking at the time of audit. Table 41 shows the percentages of children and young people age 12 and over with Type 2 diabetes with a recorded smoking result in the audit period (N=435) classified as a 'current smoker', showing a lower rate of smoking within this cohort.

Table 40: Percentage of young people aged 12 years and older with Type 1 diabetes who were smoking by country and regional network, 2015/16

	% with 'current smoker' status recorded
England and Wales	3.1%
England	3.2%
Wales	2.8%
East of England	2.9%
East Midlands	4.4%
London and South East	2.0%
North East and North Cumbria	2.8%
North West	3.8%
South Central	4.4%
South West	3.7%
West Midlands	2.8%
Yorkshire and the Humber	3.5%

Table 41: Percentage of young people aged 12 years and older with Type 2 diabetes who were smoking in England and Wales, 2015/16

	% with 'current smoker' status recorded
England and Wales	2.1%
England	2.2%
Wales	0.0%

7.5 Micro and macrovascular outcomes and risks summary

Microvascular disease

- Microvascular disease in the kidney (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 risk of kidney disease was increased amongst older young people with Type 1 diabetes, and amongst those living in the most deprived areas.
- Kidney disease was found in 14.5% of children and young people with Type 2 diabetes who were screened in the audit year.
- Eye disease was found in 13.8% of young people aged 12 and above with Type 1 diabetes who received screening in the audit year.
- Older young people with Type 1 diabetes were at increased risk of eye disease, with 22.6 % of 17 year olds with a recorded result showing signs of it compared to 7.1% of 12 year olds.
- Young people with Type 1 diabetes living in the most deporived areas were at greater risk of eye disease than those living in the most deprived areas.
- Eye disease was 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 26.3% of young people aged 12 years and older with Type 1 diabetes screened in the audit year.
- A fifth (19.17%) 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 40.4% of children and young people with Type 2 diabetes, a markedly higher prevalence compared to the 26.3% within the Type 1 cohort.
- 16.4% of children aged 0 to 11 years with Type 1 diabetes were overweight, and 16.5% were obese. These figures rose to 18.1% and 20.8%, respectively, for young people aged 12 years and above with Type 1 diabetes.
- 78.5% of children and young people with Type 2 diabetes were obese.
- 4.0% of young people with Type 1 diabetes aged 12 and above with a recorded smoking status were current smokers, as were 2.1% of young people with Type 2 diabetes aged 12 and above.

7.6 Micro and macrovascular recommendations

Multidisciplinary paediatric diabetes teams should:

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

7.7 Psychological assessment

Psychological assessment and access to psychology services should be available to all children and young people and their families with diabetes. Following the introduction of the Best Practice Tariff in England and implementation of peer review concerns by Local Health Boards in Wales, the presence of psychologists and the development of psychological support for children, young people and families has expanded enormously. However, further work needs to be done to develop national agreement on the best way to utilise the expertise of psychologists in the diabetes clinical setting (Binney & Roswess-Bruce, 2015; Roswess-Bruce & Binney, 2016).

7.7.1 *Psychological outcomes of children and young people with Type 1 diabetes*

Table 42 shows the latest outcome recorded in the audit year for the children and young people with Type 1 diabetes who had a psychological assessment dated within the audit period (N=18,629). This data should be interpreted with caution, as it only reflects the outcomes of 68.7% of the cohort with Type 1 diabetes.

Table 42: Last recorded outcome per child or young person with Type 1 diabetes of assessment for need of Child and Adolescent Mental Health Services/ psychological support by country and region, 2015/16

	No referral required	Referred and seen	Referred but no evidence of being seen	Missing data
England and Wales	59.7%	30.0%	6.1%	4.2%
England	58.1%	31.1%	6.3%	4.5%
Wales	85.4%	12.1%	2.2%	0.3%
East of England	54.5%	41.5%	2.2%	1.8%
East Midlands	48.1%	49.0%	2.9%	0.0%
London and South East	52.4%	29.4%	11.9%	6.2%
North East and North Cumbria	60.4%	16.7%	1.4%	21.5%
North West	71.9%	21.6%	3.3%	0.2%
South Central	63.2%	28.2%	7.9%	0.8%
South West	63.3%	29.5%	6.6%	0.6%
West Midlands	64.7%	22.9%	5.6%	6.9%
Yorkshire and the Humber	47.2%	39.1%	6.2%	7.4%

7.7.2 *Psychological outcomes of children and young people with Type 2 diabetes*

Table 43 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=333). As this only represents 53.6% of the Type 2 cohort, these figures should be interpreted with caution.

Table 43: Last recorded outcome per child or young person with Type 2 diabetes of assessment for need of Child and Adolescent Mental Health Services/ psychological support by country and region, 2015/16

	No referral required	Referred and seen	Referred but no evidence of being seen	Missing data
England and Wales	58.6%	33.8%	4.4%	3.2%

Summary

- Thirty percent of children and young people with Type 1 diabetes and 33.8% of those with Type 2 diabetes required referral and were seen by expert CAMHS/psychology services in 2015/16.

Recommendations

Multidisciplinary paediatric diabetes teams should:

- Be aware of the complex psychological needs of children and young people with diabetes, and work with commissioners to ensure that care pathways in place enable all children and young people with diabetes to be reviewed by 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.

8. Thyroid and coeliac disease amongst patients with Type 1 diabetes

Table 44 shows that of the 21,178 children and young people with Type 1 diabetes who had a recorded observation for thyroid treatment, 3.4% were being treated for thyroid disease, and that 4.0% of the 24,117 children and young people with a dietary observation recorded were following a gluten-free diet indicative of coeliac disease in England and Wales.

Table 44: Percentage of children and young people with Type 1 diabetes with thyroid or coeliac disease by country and region in England and Wales, 2015/16

	Percentage on thyroxine for hypothyroidism or anti-thyroid medication for hyperthyroidism	Percentage on gluten free diet
England and Wales	3.5 %	4.0%
England	3.4%	3.9%
Wales	5.0%	4.4%
East of England	3.3%	4.7%
East Midlands	4.2%	4.0%
London and South East	3.4%	3.1%
North East and North Cumbria and Cumbria	3.7%	3.2%
North West	2.0%	3.5%
South Central	3.2%	4.4%
South West	4.4%	4.6%
West Midlands	3.3%	4.4%
Yorkshire and the Humber	3.5%	4.2%

9. Conclusion

In 2009, Dr Sheila Shribman, the National Clinical Director for Children, Young People and Maternity Services wrote in the forword to the NPDA 2007/08 report:

"This disappointing situation cannot be allowed to continue. Action to prevent and manage acute and long-term complications of diabetes must start on day one of diagnosis and continue lifelong. NICE produced clear guidance five years ago, and more recently. Why has so little progress been made in implementing it?"

She was referring to the poor state of paediatric diabetes outcomes which had not shown any improvement since the instigation of the NPDA in 2003/04. She went on to say:

"……act now. The progression of diabetes is relentless. We have the knowledge. We need to use it and take responsibility and benchmark our efforts against others in order to improve further. Children and Young People deserve nothing less."

Now in 2015/16, nearly 10 years later the NPDA are reporting on considerable improvements in diabetes care leading to improved outcomes. The impact of the fall in the national HbA1c over the last 6 years should not be underestimated, and reflects the massive amount of work and quality improvement provided by healthcare teams, parents and patients. This has been supported by high level strategies including the formation of the National Regional Networks, the Best Practice Tariff in England, Paediatric Diabetes Health Board investment in Wales, Quality Assurance (peer review) programmes, and national and local Quality Improvement programmes.

Based on adult studies of Type 1 diabetes and extrapolation from the Diabetes Control and Complications Trial, the fall in HbA1c by nearly one percentage point (11mmol/mol) will reduce the risk of long term complications by nearly half. It will take several more years before the benefits of the improved diabetes control is recognised in reduced complication, but it will clearly reduce the burden on patients, families and the NHS.

However, there remains considerable variability in diabetes outcomes across the two nations which require attention. PDUs need to be aware of their individual outcomes for which they are accountable and work on quality improvement initiatives either locally, regionally or nationally to improve. Annual benchmarking, utilising NPDA data, against other similar PDUs allows a measure of performance to be created which should drive future improvements. Paediatric diabetes care in England and Wales has improved dramatically but still lags behind some of our European counterparts (McKnight et al., 2015; Maahs et al., 2015; Sherr et al., 2016). There is more work to be done but progress is clearly visible.

10. 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^2. 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.

Macroalbuniuria – 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.

11. List of Tables

12. List of Figures

13. References

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