NPDA
National Paediatric Diabetes Audit

National Paediatric Diabetes Audit Report 2014-15

Part 1: Care Processes and Outcomes

HQIP
Healthcare Quality Improvement Partnership

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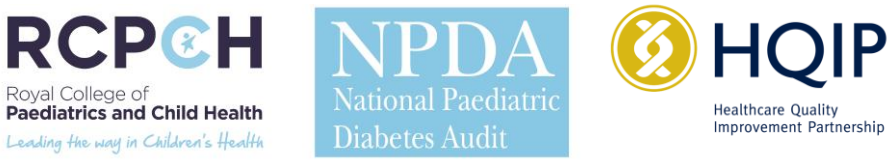
National Paediatric Diabetes Audit 2014-15
Report 1:

Care Processes and Outcomes



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Foreword

I'm pleased to introduce the 12th annual report of the National Paediatric Diabetes Audit and the 5th published by the Royal College of Paediatrics and Child Health. The audit provides an analysis of data from healthcare professionals caring for children and young people with diabetes in England and Wales between 2014/15. It includes a summary of diabetes prevalence, compliance with care processes, outcomes, and makes recommendations for improvements.

For the fifth consecutive year, there has been an increase in the number of children and young people achieving excellent diabetes control, thereby reducing their lifetime risk of diabetes associated complications. However, the report also demonstrates the impact of inequality on outcomes for children and young people, with those living in the most deprived areas having worse outcomes.

Only a quarter of 12-year-olds received all seven of the health care checks recommended by the National Institute of Clinical Excellence. Worryingly, the report also shows that high numbers of children over the age of 12 are showing early signs of complications.

The Audit confirms its continuing relevance as a tool for highlighting deficiencies in care, measuring progress towards improved outcomes, and demonstrating the impact of inequality. I recommend this report as essential reading for Government, health care provider organisations, commissioners, clinical teams, and families.

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 12th annual report of the Audit, which in 2014/15 included all 176 PDUs in England and Wales, and captured information on over 27,600 children and young people up to the age of 24 years under the care of a Consultant Paediatrician.

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 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.

1.4 Quality standards used

The health checks (care processes) audited were those recommended by the National Institute of Clinical Excellence (NICE) in their guidance for the management of Type 1 diabetes in children and young people that was in place during the audit period (NICE, 2004). This guidance has since been updated (NICE, 2015).

1.5 What comparisons are made 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, region and country. Since deprivation is 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 having taken deprivation into account.

1.6 Key findings and recommendations

Prevalence and incidence

- Over 27,600 children and young people from England and Wales cared for in a PDU up to the age of 24 years are included in the 2014/15 audit.
- 95.5% have Type 1 diabetes requiring daily injections of insulin.
- The number of children and young people with diabetes cared for in a PDU continues to rise in line with international data at 4% per year (Patterson et al, 2009; International Diabetes Federation, 2015).

Completion of health checks (care processes)

- Completion of all seven key health checks has improved having risen from 16.1% in 2013/14 to 25.4% in 2014/2015.

However:

- Considerable variation exists across PDUs, with the percentage of patients receiving all seven ranging from 0% to 93.5%.
- The completion rate for HbA1c screening remains high at 98.7%.
- Height, weight, and blood pressure are reported for over 80% of children and young people aged 12 years and older.

Recommendations

PDUs should:

- Ensure that 100% of health checks are undertaken and there is sufficient staff resource allocated to input the data into the database.

Commissioners should:

- Regard the completion of all key health checks as an essential quality marker for the delivery of good diabetes care to their patient populations.

Diabetes complications and risk factors

- Microvascular disease in the kidney (albuminuria) was found in 11.6% of young people (12 years and over) with diabetes.
- Early signs of increased risk of blindness were found in 12.8% of young people (12 years and over).
- Obesity was found in 15.9% (0-11 years) and 20.7% (12 years and over).
- High blood pressure (hypertension) was found in 27.1% and high cholesterol in 21.8% of young people with diabetes (12 years and over).
- Smoking was prevalent in a small percentage of young people.

Recommendation

PDUs should

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

Blood Glucose Diabetes Control (HbA1c)

- The percentage of children and young people with diabetes achieving the NICE (2004) target for HbA1c <58 mmol/mol has increased year on year:
  - 15.8% in 2012/13
  - 18.4% in 2013/14
  - 23.5% in 2014/15
- The percentage of children and young people with diabetes exceeding the NICE (2004) target for HbA1c >80 mmol/mol has decreased year on year:
  - 25.9% in 2012/13
  - 23.9% in 2013/14
  - 21.3% in 2014/15
- The national median HbA1c for children and young people with all types of diabetes is lower than those in previous audit years:
  - 69.0 mmol/mol in 2012/13
  - 69.0 mmol/mol in 2013/14
  - 66.5 mmol/mol in 2014/15
- Children and young people with Type 1 diabetes are achieving better blood glucose control in the first year following diagnosis compared to the longer term, with a mean HbA1c of 66.4 mmol/mol in the first year rising to a mean of 76.4 mmol/mol 10-14 years following diagnosis.

Recommendations

PDUs should:

- Ensure their multi-disciplinary teams are aiming 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.

Screening for thyroid and coeliac disease in Type 1 Diabetes

- Screening for thyroid disease was undertaken for 71% of patients.
- Nearly 60% of patients received screening for coeliac disease.

Recommendation

PDUs should:

- Ensure children and young people with diabetes are receiving appropriate screening for coeliac, thyroid and other associated diseases in accordance with NICE guidance.

Impact of social deprivation

- Children and young people from deprived areas were found to have poorer blood glucose control, a higher risk of obesity and more microvascular changes in the kidney compared with those living in more affluent areas.

Recommendations

PDUs should:

- Tailor their service to make it accessible and effective for all and ensure an equitable service is provided.

Commissioners should

- Consult closely with PDUs to ensure that 'casemix' is considered for the population for whom they are providing diabetes services.

Structured Patient Education Programmes

- Around 50% of children and young people were offered structured education to support effective self-management of their diabetes in 2014/15.

Recommendations

PDUS should:

- Deliver age- and maturity-appropriate, structured self-management education programmes from the day of diagnosis. Education should be on-going throughout the life of the child, appropriate to the individual child and family, and regularly evaluated to ensure that they are meeting the needs of the children and families (Waldron & Campbell, 2014).

Regional diabetes networks should:

- Develop agreed standards and a quality assurance programme for standardised, structured self-management education programmes. The programme should be delivered by experienced trained paediatric diabetes educators in a family centred way (Campbell & Waldron, 2013).

Psychological assessment of children and young people

- Data collected on the use of Child and Adolescent Mental Health Services (CAMHS) and psychological support was poor.
- Data was missing for nearly half (44.3%) of the children and young people with diabetes.

Recommendations

PDUs should

- Ensure greater completeness of data.
- Provide timely intervention to help patients avoid the further development of other conditions such as depression, anxiety, eating disorders or drug taking.
- Train the multidisciplinary team in child and family centred approaches to recognise and deal with psychological issues as soon as they are recognised (Delamater, 2012; Delamater et al, 2014).
- Ensure an annual screening process is in place to help identify those needing expert psychological assessment and ongoing support.

Regional diabetes networks should

- Agree a national approach to psychological assessment and multidisciplinary support (Binney & Roswess-Bruce, 2015; Roswess-Bruce & Binney, 2016).

Summary

This 12th annual NPDA report (2014/15) has demonstrated continued improvement in outcomes for children and young people with diabetes. It also demonstrates that service improvement strategies, currently in place in the regional networks, are helping us to improve outcomes toward those that are already being demonstrated by our global counterparts.

However, there is more work to be done to reduce the variability in outcomes seen across the two nations and significant ongoing improvements are still required. All stakeholders including PDUs, regional networks, families, Trusts/Health Boards and commissioners, must continue to work closely together to ensure high quality diabetes care can be accessed by all who need it and variability in outcomes is reduced. PDUs and regional networks are also urged to ensure that clinical data are accurately captured and that the submission to the NPDA is complete to ensure accurate unit and national representation of PDU outcomes.

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 programme.

The audit has been reporting for 12 years and collects information from healthcare professionals in PDUs. The effectiveness of diabetes care is measured against NICE guidelines and includes treatment targets, health checks, structured patient education, psychological and complication assessments, all of which are vital to improving the long-term health and well-being of children and young people with diabetes.

Participation for 2014/15 included 176 PDUs capturing information on over 27,600 children and young people up to the age of 24 years. Over 95% 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 with diabetes to work together including healthcare managers, commissioners, children, young people, families as well as all members of the multi-disciplinary team. Past NPDA audits have shown great variations between PDUs in the quality of care, with examples of poor and excellent care highlighted. The audit provides a strong baseline, delivering consistent year on year feedback to PDUs on their performance, and facilitates benchmarking against all other centres. These results alongside discussions within regions and at national level help us to understand why variability exists and provides help to poorly performing centres which will ultimately contribute to national improvements.

The NPDA also plays a key role in the delivery of the National Peer Review Programme by supplying information for the assessment of each PDU.

2.1 Background

Diabetes mellitus occurs when blood glucose levels are highly elevated because the body is unable to use it properly. Diabetes complications are caused by 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.

Diabetes care is complex and requires partnerships between healthcare professionals, children and young people and their families, carers and friends. These teams require adequate resources and the training and expertise 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 patients and families are informed with a deep understanding of the targets required to achieve good glucose control and the need for regular health checks to prevent complications is an essential part of high quality care (NICE, 2015).

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 quoted to account for 10% of the NHS budget (Hex et al, 2012).

Maintaining standards for care delivery and quality assurance

Poor past results demonstrated by the NPDA when compared to some other countries have been the catalyst for a programme of service improvement initiatives and sharing good practice. In England the Best Practice Tariff (BPT) (Department of Health, 2012; Randell, 2012) was introduced in 2012. It set strict criteria for the delivery of paediatric diabetes services, with increased funding for those centres meeting these standards which included submission to the NPDA. In Wales,

following the National Peer Review Programme in 2014/15 (National Peer Review Programme, 2015a), considerable investment is being made by the 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). The NPDA runs a patient and parent/carer survey to enable families to describe their experience and views on the healthcare received from their PDU. This important programme now forms part of Quality Assurance and provides an opportunity for stakeholders to influence the shaping of paediatric diabetes services. Individual PDU level results are available via the NPDA website.

NPDA suite of reports for different audiences

The year on year collection of data from the NPDA provides evidence for commissioners that quality measures to improve care have been implemented and have reduced Hba1c levels as a consequence. In the long term this will help to reduce diabetes complications in children and young people across England and Wales. The following NPDA reports are available:

- The Care Processes and Outcomes Report produced annually compares results across England (by region) and Wales.
- Individualised unit level reports provide details of each unit's performance and are available alongside this report at www.rcpch.ac.uk/npda.
- A lay report 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.
- 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 as soon as the data for these periods are available.
- Patient Related Experience Measure (PREM) reports provide each Unit with feedback from questionnaires completed by parents and patients who use their service. The 2015-16 online PREM survey closed in April 2016.for reporting later in 2016.

Comparisons with international data sets

The NPDA collaborates with international researchers (McKnight, 2015; Maahs, 2015; Sherr, 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. 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.

Recommended targets and health checks (care processes)

All children and young people should have four HbA1c blood tests per year (Randell, 2012; NICE, 2015) and aim to keep blood glucose levels within the NICE (2004) target:

HbA1c levels: < 58 mmol/mol = Excellent control
HbA1c levels: > 80 mmol/mol = Poor control with lifetime risk of complications

The 2015 NICE guidance (NG18) includes even tighter targets for excellent diabetes control (HbA1c < 48mmol /mol) and requests services to provide statistics on those with an HbA1c < 53mmol/mol. Both these new targets are presented in the 2014/15 report whilst maintaining the reporting of previous targets to allow historical comparison.

Guidelines specify a starting age of 12 years for commencing all care processes with the exception of HbA1c, which should be recorded in children and young people of all ages. Completing and recording the following seven health checks for young people over 12 years can highlight problems at an early stage and therefore prompt immediate action.

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. Cholesterol (blood test for cardiovascular risk)
6. Eye screening (photographic test for eye risk)
7. Foot examination (foot examination for ulcer risk)

2.2 Scope of the 2014/15 National Paediatric Diabetes Audit 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 2014/15 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 2014 through to 31st March 2015. 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 paucity of data for all seven key care processes and the clear inequalities in outcomes across England and Wales. Technical information about the analysis is provided via the NPDA website.

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 the key age-specific processes of diabetes care, as recommended by NICE?
- How many achieve outcome measures within specified treatment targets and how this changes with subsequent audits?
- 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 National Diabetes Audit for adults (NDA) and the NPDA

The National Diabetes Audit (NDA) for adults (National Diabetes Audit, Health & Social Care Information Service) reports on the provision of core diabetes care for everyone with diabetes. This provides commissioners with age, ethnicity and social deprivation-related perspectives across the whole population for which they are responsible. The NDA also reports to participating individual General Practices and adult specialist services, allowing them to benchmark their care against their peers. The NPDA reports separately to individual participating PDUs. Those reviewing the NDA and NPDA reports side-by-side need to be aware of these differences but, equally, those wanting to get the most complete picture of local needs and service provision should consider the two reports together.[1]

2.4 Using this report

This report is publicly available in order to provide information for clinical staff, healthcare managers, commissioners, children and young people with diabetes and their families.

NPDA reports make recommendations for healthcare professionals to improve the care they deliver to patients. Since 2011, aggregated data available at unit provider level is used for benchmarking, interaction and learning from others about how to improve clinical outcomes. Data for all units is freely accessible in the public domain.

The most recent findings (2014/15) revealed some improvements in the quality of care for children and young people with diabetes in England and Wales, but with notable differences between regions. Case-mix adjusted funnel plots presented in this report demonstrate the level of variability in a particular outcome measure and outlier status of individual providers across the two nations. Individual service providers can now explore where their unit sits in relation to others by accessing the individual unit level PDU level results.

[1] Because the care of adults and children with diabetes is combined between GP services (includes ALL patients) and hospital, paediatric and community specialist services (each include SOME patients), the different "views" that the two national audits (NDA for adults and NPDA for children and young people) give to the providers of the services will inevitably include overlapping patients. Thus someone with diabetes attending a specialist service should also appear in the relevant GP report. The NDA integrates data from participating specialist and GP services for adults with diabetes so that if a care process or treatment target is recorded by one but not by the other, both receive the complete data reported, i.e. a "whole person" view. This makes sense because it reflects the fact that there is no clinical value in duplicating something carried out elsewhere. The population level that NDA reports includes all people with diabetes in a geographical area irrespective of their mix of provider services and uses integrated data where they are available.

The NPDA runs independently of the NDA and of GP services so its data are not integrated, making it possible that GP reports do not include all care processes or treatment targets measured in specialist paediatric units and vice versa. Specialist paediatric diabetes units are primarily responsible for the care of most children and young people with diabetes and for the collection of their care process and outcome data. Although GPs do not provide the majority of care for children and young people living with diabetes, they do prescribe all of their medications. Therefore, it is these age groups and adults with Type 1 or complex diabetes that attend specialist services not participating in NDA, where lack of data integration is most likely to result in a slightly deficient "whole systems" view. Furthermore, for under-17s, the age cutoff for the QOF GP incentive scheme means that there is no financial value to the practice in replicating results from external services. Nonetheless, because less than 10% of all people with Type 1 diabetes, and less than 1% of people with diabetes in general are under 17 years old, the overall impact on population level NDA results is minimal.

The NDA report entitled "National Diabetes Audit – 2013-14: Report 1, Care Processes and Treatment Targets" was published on 28 January, 2016. This is now available from the Health and Social Care Information Centre (HSCIC) and can be found on the NDA website.

Variations in outcomes across diabetes services in England and Wales can be associated with differences in expenditure in the current system of care, potentially stalling improvement in health outcomes with inequity of service provided to children, young people and their families in certain areas. This variation in quality of care inevitably results in a variation in outcomes for the patients themselves.

2.5 Data completeness

Over the five 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. There is also considerable variability across PDUs with respect to their ability to resource adequate IT systems to collect and submit accurate data during the audit year. NPDA results are utilised by commissioners to measure performance and PDUs are urged to improve the completeness of their record-keeping and data completeness to ensure it reflects their practice.

NB: Due to a data corruption of ethnicity data submitted, this 2014/15 report does not include ethnicity data for patients in individual units or for comparison across units regionally and nationally. Ethnicity has therefore not been used as a variable in the HbA1c case-mix adjustments (Appendix I).

3. Coverage of audit: Prevalence and incidence

3.1 Characteristics of children and young people with diabetes

A total of 27,682 children and young people with diabetes[2] were included in the 2014/15 audit, an increase of 1084 from 2013/14 with the rise predominately in the 15-19 years age band (Table 1). The majority (95.5%) have Type 1 diabetes (Table 2).

Table 1: Number of children and young people included in the audit by country, region and age, 2014/15 (based on PDU location)

	0-4 years	5-9 years	10-14 years	15-19 years	20-24 years	Total
England and Wales	1,667	5,770	11,279	8,880	86	27,682
England	1,584	5,443	10,659	8,486	86	26,258
Wales	84	330	627	397	0	1,438
East of England	187	652	1,201	1,043	*	3,084
East Midlands	110	398	846	504	0	1,858
London and South East	373	1,308	2,376	1,877	62	5,996
North East	86	315	636	561	0	1,598
North West	212	741	1,447	1,015	16	3,431
South Central	154	420	889	685	*	2,149
South West	152	518	1,027	827	*	2,528
West Midlands	162	551	1,205	1,049	*	2,968
Yorkshire and The Humber	160	579	1,082	948	*	2,770

* indicates a number less than 5 which has been suppressed

Table 2: Number of children and young people included in the audit by age and type of diabetes, 2014/15

	0 – 4 years	5 – 9 years	10 – 14 years	15 – 19 years	20 – 24 years
Type 1 Insulin-dependent diabetes mellitus	1,603	5,635	108,15	8,311	72
Type 2 Non-insulin-dependent diabetes mellitus	*	11	204	318	10
Cystic fibrosis related diabetes	0	18	60	72	0
Monogenic types of diabetes	19	25	30	45	0
Other specified diabetes mellitus	15	34	80	58	*
Not specified diabetes mellitus	25	40	70	60	0
Missing type of diabetes	*	7	20	16	0

* indicates a number less than 5 which has been suppressed

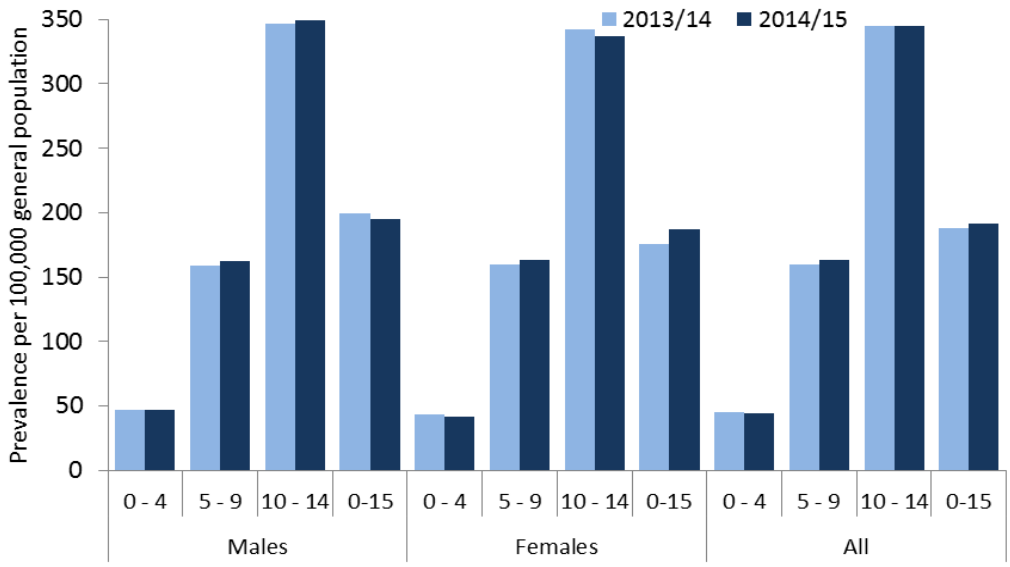
[2] Children and young people are included in the audit if they have diagnosed diabetes, are aged between 0 and 24 years old and received care from a PDU in the audit period.

3.2 Prevalence and Incidence of Type 1 diabetes

3.2.1 Prevalence

In 2014/15 the prevalence of Type 1 diabetes in children and young people aged 0 to 15 years old in England and Wales is 192.0 per 100,000 of the general population; slightly higher among males (194.9 per 100,000) compared to females (187.2 per 100,000). Figure 1 shows the prevalence breakdown by age and gender.

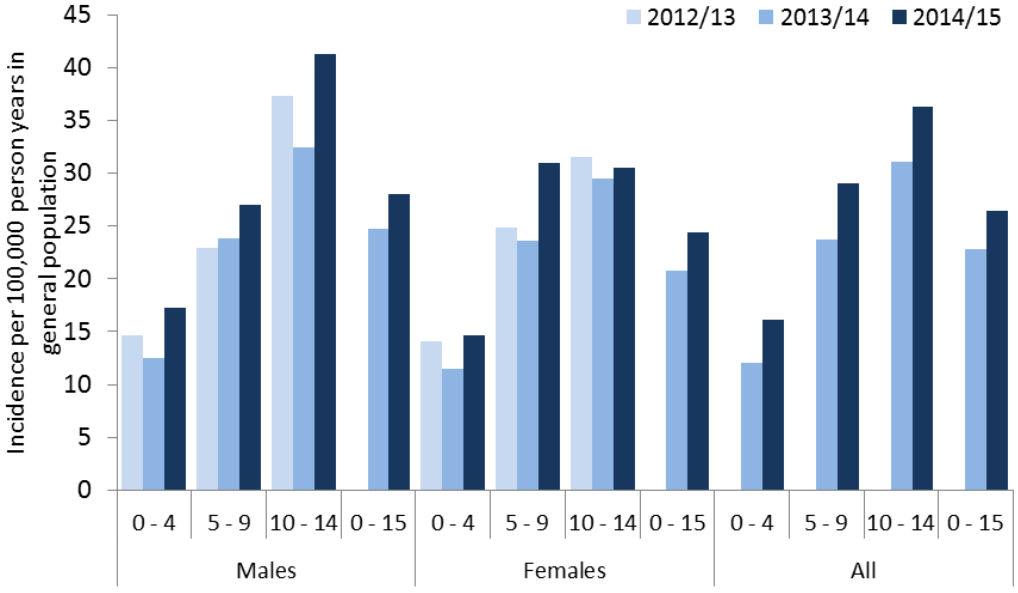
Figure 1: Prevalence of Type 1 diabetes per 100,000 general population



Incidence

In 2014/15 there were 2,873 children and young people aged 0 to 15 years old diagnosed with Type 1 diabetes in England and Wales giving an incidence of 26.5 per 100,000 general population. The incidence was higher amongst males (28.0 per 100,000) compared to females (24.4 per 100,000) as shown in Figure 2.

Figure 2: Incidence of Type 1 diabetes per 100,000 general population[3]



[3] The 2012/13 analysis did not report combined male and female figures and so this data is not available for comparison.

4. Completion of health checks (care processes)

Summary

- The completion rate for individual health checks (care processes) has improved compared to previous years with more than 98% of children and young people having their HbA1c measured in 2014/15.
- 25.4% of young people aged 12 years and over completed all seven key care processes with substantial variability amongst PDUs.
- Thyroid and coeliac disease screening was being achieved for 71.0% and 58.4% of patients with Type 1 diabetes, respectively.
- Smoking status was only recorded for half of children and young people.
- Assessment for expert psychological review was undertaken for just over half of children and young people with diabetes.

Recommendations

Commissioners and regional diabetes networks are urged to ensure PDUs have the resource to collect accurate data and provide consistent care in accordance with NICE standards.

PDUs should ensure children and young people with diabetes are receiving the key care processes and appropriate screening for thyroid, coeliac and other disease associations.

Children with diabetes must be cautioned against smoking as they have a higher risk of cardiovascular disease and these discussions should be included in their on-going education programme.

Annual psychological review is important as caring for diabetes is extremely psychologically demanding and it is well documented in the literature that many forms of psychological disturbances can be found in young people with diabetes.

4.1 Completion of the seven key care processes

There are seven key care processes recommended by NICE for children and young people with diabetes (NICE 2004).

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. Cholesterol (blood test for cardiovascular risk)
6. Eye screening (photographic test for eye risk)
7. Foot examination (foot examination for ulcer risk)

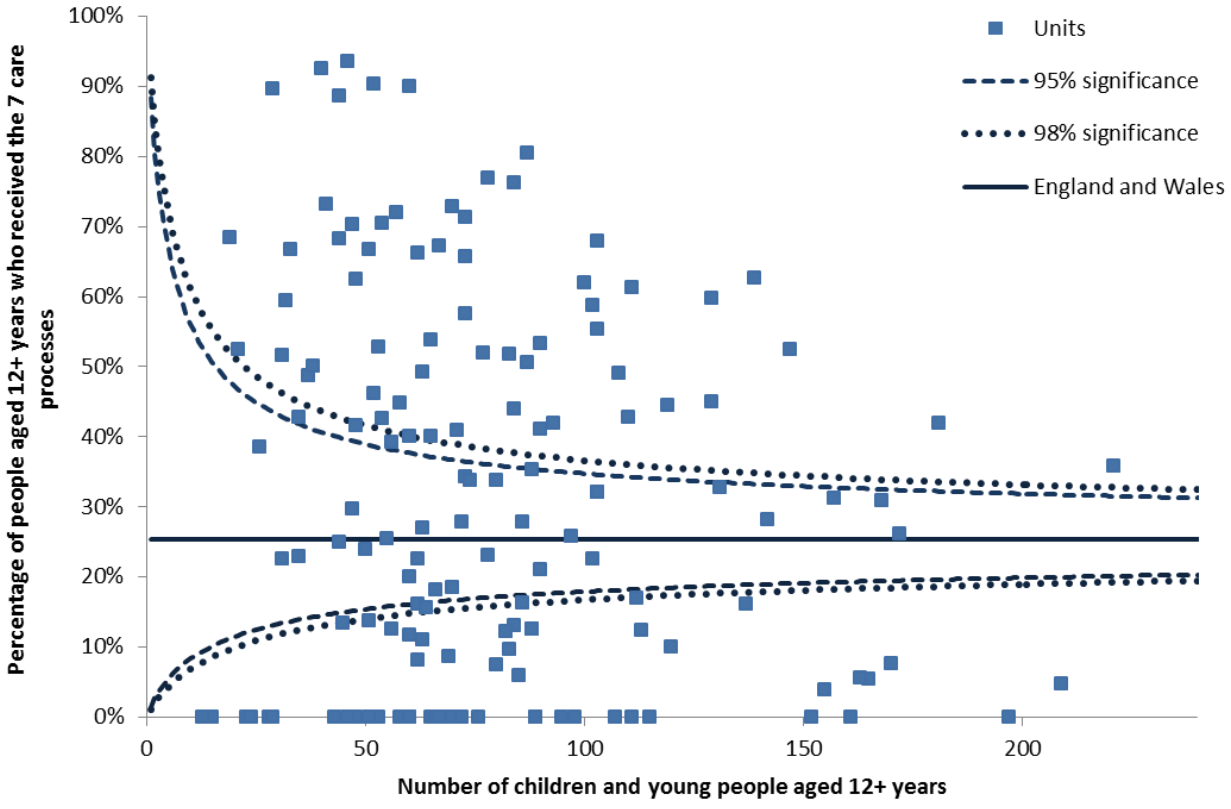
Guidelines specify a starting age of 12 years for commencing all care processes with the exception of HbA1c, which should be recorded in children and young people of all ages. Results for 2014/15 and comparison to previous years are shown in Table 3.

Table 3: Percentage of children and young people recorded as receiving care processes by year of audit

	2010-11	2011-12	2012-13	2013-14	2014-15
HbA1c (all ages)	92.8	89.3	97.6	98.3	98.7
BMI (aged 12+)	75.3	64.7	87.9	94.0	94.2
Blood Pressure (aged 12+)	62.7	67.7	77.3	80.2	82.9
Urinary Albumin (aged 12+)	40.3	40.7	49.5	48.8	52.4
Cholesterol (aged 12+)	34.9	44.4	52.7	54.2	60.8
Eye screening (aged 12+)	35.8	36.9	49.7	51.9	64.9
Foot examination (aged 12+)	31.9	34.4	39.5	45.7	55.4
All seven processes (aged 12+)	5.8	6.7	12.1	16.1	25.4

Figure 3 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. Individual PDU level reports have been published alongside this report to highlight unit level performance.

Figure 3: Percentage of young people aged 12 years and older who had all seven care processes by unit, 2014/15



4.2 Completion of the health checks (care processes) smoking, thyroid disease screening, coeliac disease screening and psychological assessment

The audit also collects data on four additional health checks[4]:

- smoking status for those aged 12 years and older (smoking for cardiovascular risk)
- thyroid function screening for those with Type 1 diabetes (blood test for thyroid disease risk)
- coeliac disease screening for those with Type 1 diabetes (blood test for coeliac disease risk)
- psychological assessment (assessment for psychological risk)

Results are shown in Table 4.

Table 4: Percentage of children and young people receiving the individual care processes of smoking status, thyroid and coeliac disease screening and psychological assessment by country and region, 2014/15

	Smoking status recorded (aged 12+ years)	Thyroid Function (Type 1 only)	Screening for coeliac disease (Type 1 only)	Psychological assessment
England and Wales	55.7%	71.0%	58.4%	56.5%
England	55.1%	70.3%	57.2%	56.1%
Wales	68.7%	84.7%	79.5%	64.5%
East of England	43.8%	64.1%	59.7%	57.4%
East Midlands	68.5%	84.4%	70.9%	79.3%
London and South East	60.4%	59.8%	45.6%	50.0%
North East	61.5%	72.9%	40.2%	17.8%
North West	65.0%	81.4%	57.2%	58.3%
South Central	48.9%	75.3%	73.3%	75.3%
South West	34.5%	72.5%	62.3%	60.8%
West Midlands	59.2%	73.8%	59.1%	50.3%
Yorkshire and The Humber	50.7%	65.7%	62.5%	60.2%

[4] NICE CG-15, (2004) recommended children and young people with Type 1 diabetes should be offered screening for thyroid disease at diagnosis and annually thereafter, and screening for coeliac disease at diagnosis only. However, the guidance or coeliac disease screening changed in June 2009 where previously the recommendation was to screen at diagnosis and three yearly thereafter. Many PDUs continue to screen on an annual basis and there is anecdotal evidence that cases of coeliac disease are recognised through this additional screening. The NPDA recognise the publication of new NICE guidance (NG18- NICE, 2015) for children and young people with diabetes published in August 2015 after the 2014/15 data collection period.

The NICE guidance on screening for thyroid and coeliac disease makes particular reference to screening at diagnosis of Type 1 diabetes. Table 5 shows the recorded screening of those with Type 1 diabetes diagnosed in the audit period.

Table 5: Percentage of children and young people diagnosed with Type 1 diabetes during the audit year undergoing screening for thyroid and coeliac disease, 2014/15

	Thyroid function (Type 1 only)	Screening for coeliac disease (Type 1 only)
England and Wales	57.3%	55.8%
England	56.5%	55.1%
Wales	72.7%	69.5%
East of England	59.2%	61.7%
East Midlands	55.2%	59.8%
London and South East	54.5%	46.6%
North East	62.7%	50.6%
North West	62.2%	57.3%
South Central	52.0%	53.3%
South West	49.7%	62.9%
West Midlands	47.5%	46.8%
Yorkshire and The Humber	65.8%	63.6%

5. Outcomes of care

The collection of audit results on outcome measures is an important part of monitoring diabetes control and care. 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 not only covers HbA1c measurements which are recommended as the best indicator of long-term diabetes control, but also other indicators of small vessel (microvascular) disease, large vessel (macrovascular) disease including cardiovascular risk, and autoimmune disease.

5.1 Summary of findings

- There has been an improvement in diabetes control as measured by HbA1c in England and Wales over the last two years. While there is no national target for mean HbA1c, the national mean HbA1c for children and young people with all types of diabetes has fallen from 71.6 mmol/mol in 2013/14 to 70.1 mmol/mol in 2014/15.

- The percentage of children and young people achieving excellent diabetes control (HbA1c less than 58 mmol/mol) has increased from 15.8% in 2012/13, 18.4% in 2013/14, to 23.5% for children and young people with all types of diabetes (22.0% for those with Type 1 diabetes) in 2014/15.

- The percentage with a very high HbA1c (greater than 80 mmol/mol), has decreased from 25.9% in 2012/13, 23.9% in 2013/14 to 21.3% for children with all types of diabetes (21.5% in those with Type 1 diabetes) in 2014/15.

- Better control is achieved in the first year following diagnosis of Type 1 diabetes (mean HbA1c 66.4 mmol/mol) compared to the longer term (76.4 mmol/mol after 10-14 years).

- Children and young people with Type 1 diabetes living in the most deprived areas have worse outcomes in terms of HbA1c, with a mean HbA1c of 73.7 mmol/mol compared to a mean of 67.2 mmol/mol for those living in the least deprived areas.

- 11.6% of children and young people with diabetes show increased risk of developing kidney disease in the future and 12.8% show early signs of increased risk of blindness.

- 15.9% of children and young people with Type 1 diabetes aged between 0-11 years, and 20.7% aged 12 years and over, are obese. A large number of young people with Type 1 diabetes have high blood pressure (27.1%). Hyperlipidaemia (high blood cholesterol concentration) is also evident in childhood diabetes, with 21.8% of young people aged 12 years and over having a total cholesterol above the cut off limit of 5.0 mmol/l.

Recommendation

MDTs should aim for all children and young people to remain within the HbA1c target set by NICE (individualised for the child) from diagnosis and endeavour to improve the blood glucose levels of children and young people that are currently above target with emphasis on self-management education and psychological support. Particular attention needs to be given to the vulnerable sub-group with persistent high HbA1c levels and appropriate engagement, education and psychosocial support is paramount.

5.2 HbA1c and treatment regimen

5.2.1 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. NICE recommends a treatment target level below 58 mmol/mol (NICE, 2004) with a level >80mmol/mol carrying considerable increased risk of both microvascular diabetic complications (eye disease and kidney disease) and cardiovascular disease[5]. 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 intensification therapy achieving good diabetes control in childhood tracks into continued good control as adults and a lower risk of developing vascular complications in the future.

Average HbA1c and the proportion of children and young people meeting specific HbA1c targets varies 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 only include data on those with Type 1 diabetes.

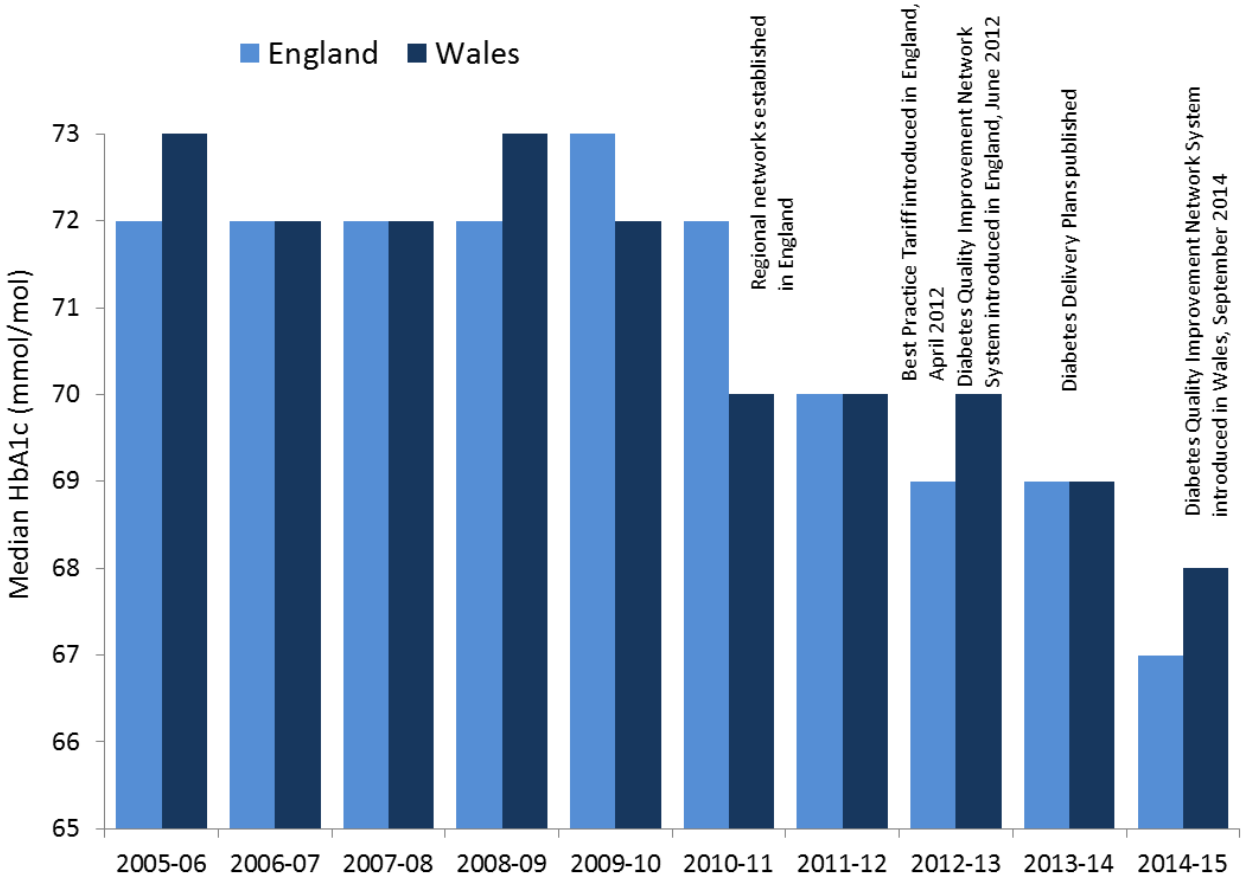
The mean and median HbA1c of children and young people with all types of diabetes in England and Wales receiving care in a PDU were 70.1 and 66.5 mmol/mol respectively (Table 6). For the fifth consecutive year there has been a fall in the median HbA1c levels for England and Wales (Figure 4).

Table 6: HbA1c for all children and young people with all types of diabetes and one or more valid HbA1c measurements by country and region, 2014/15

	No. of children & young people	Mean (mmol/mol)	Standard deviation (mmol/mol)	Median (mmol/mol)	IQR (mmol/mol)
England and Wales	27,012	70.1	18.5	66.5	19.5
England	25,652	70.0	18.5	66.5	19.5
Wales	1,374	72.2	18.7	68.3	19.2
East of England	3,022	71.4	18.4	67.5	19.4
East Midlands	1,838	67.7	16.7	65.0	17.5
London and South East	5,791	70.4	19.1	67.0	20.1
North East	1,576	71.0	17.4	67.5	18
North West	3,347	69.9	18.6	66.0	19
South Central	2,102	66.6	17.2	63.9	17
South West	2,493	69.2	18.0	66.0	19
West Midlands	2,896	71.5	19.5	67.2	20
Yorkshire and The Humber	2,710	70.4	18.7	67.0	20.6

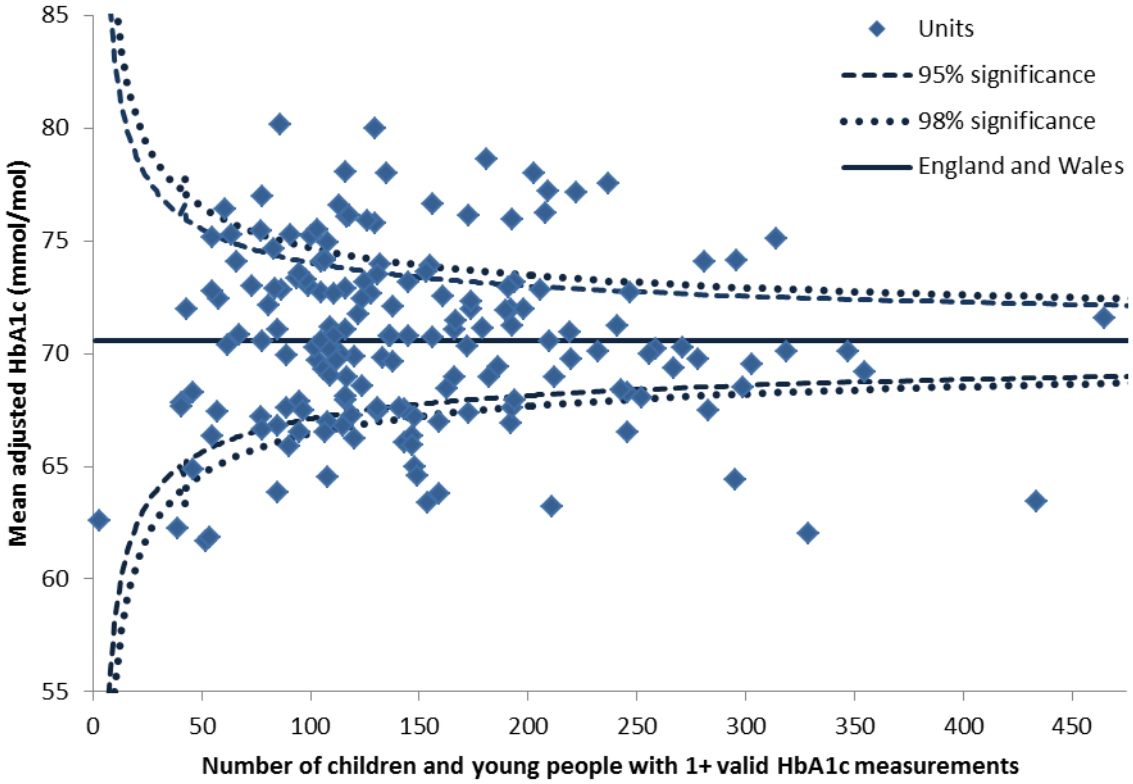
[5] New NICE guidance (NG18, published August 2015) has introduced stricter targets of below 48mmol/mol and asks hospitals to report those achieving a level of 53 mmol/mol or below. Although these recommendations were not published until after the end of the current audit period, the percentage of those achieving the new targets have been reported to allow measures for reference and to enable comparisons over time in future audits.

Figure 4: Change in median HbA1c for children and young people with all types of diabetes in England and Wales 2005/06 to 2014/15 with associated NHS policy and/or paediatric diabetes delivery structural changes



There is considerable variability across England and Wales in the mean HbA1c for children and young people with Type 1 diabetes achieved by PDUs providing care after adjustment for case-mix (Appendix 1 for methodology). Figure 5 shows the mean adjusted HbA1c for each PDU in England and Wales.

Figure 5: Funnel plot of mean adjusted HbA1c for children and young people with Type 1 diabetes by PDU, 2014/15



The percentage of all children and young people with diabetes achieving HbA1c targets is shown in Table 7. There is considerable variability across England and Wales in the achievement of the treatment targets in patients with Type 1 diabetes after case-mix adjustment (Figures 6 and 7, refer to Appendix 1 for methodology for case-mix adjustment).

Table 7: New NICE HbA1c targets for children and young people with all types of diabetes by country and region, 2014/15

	≤48 mmol/mol	≤53 mmol/mol	<58 mmol/ mol	≥69 mmol/mol	> 75 mmol/mol	> 80 mmol/ mol
England and Wales	6.4%	13.2%	23.5%	42.2%	28.8%	21.3%
England	6.5%	13.4%	23.8%	41.9%	28.6%	21.1%
Wales	4.4%	10.1%	17.8%	47.5%	32.4%	24.2%
East of England	5.2%	10.7%	21.0%	45.2%	31.3%	23.5%
East Midlands	7.1%	15.3%	26.2%	37.0%	23.1%	16.7%
London and South East	6.7%	14.0%	24.3%	43.5%	29.9%	22.0%
North East	4.6%	10.6%	19.5%	44.1%	30.1%	21.7%
North West	6.2%	13.3%	23.6%	41.0%	27.9%	20.7%
South Central	9.2%	16.7%	29.2%	33.4%	21.0%	15.1%
South West	6.9%	14.4%	24.4%	40.1%	27.4%	19.9%
West Midlands	6.0%	11.6%	21.3%	45.0%	31.5%	23.7%
Yorkshire and The Humber	6.6%	13.7%	24.6%	43.2%	30.0%	22.6%

Figure 6: Funnel plot of adjusted HbA1c less than 58 mmol/mol by PDU for children and young people with Type 1 diabetes by PDU, 2014/15

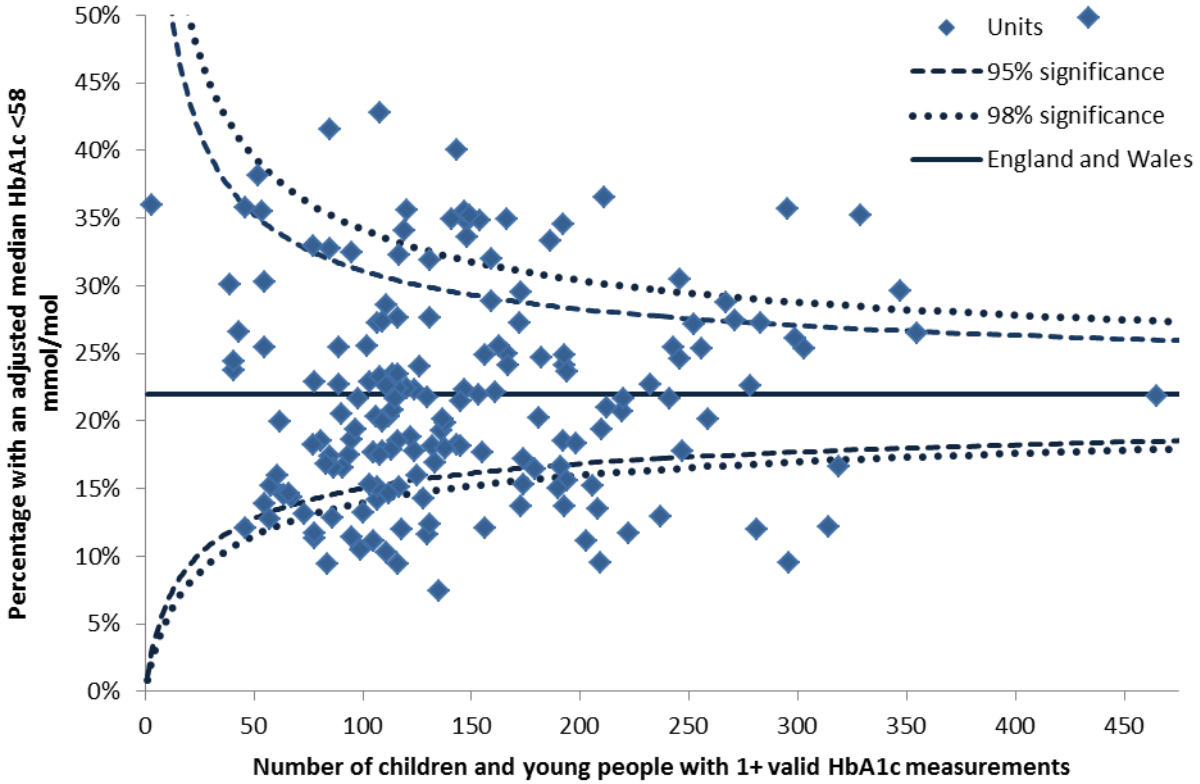
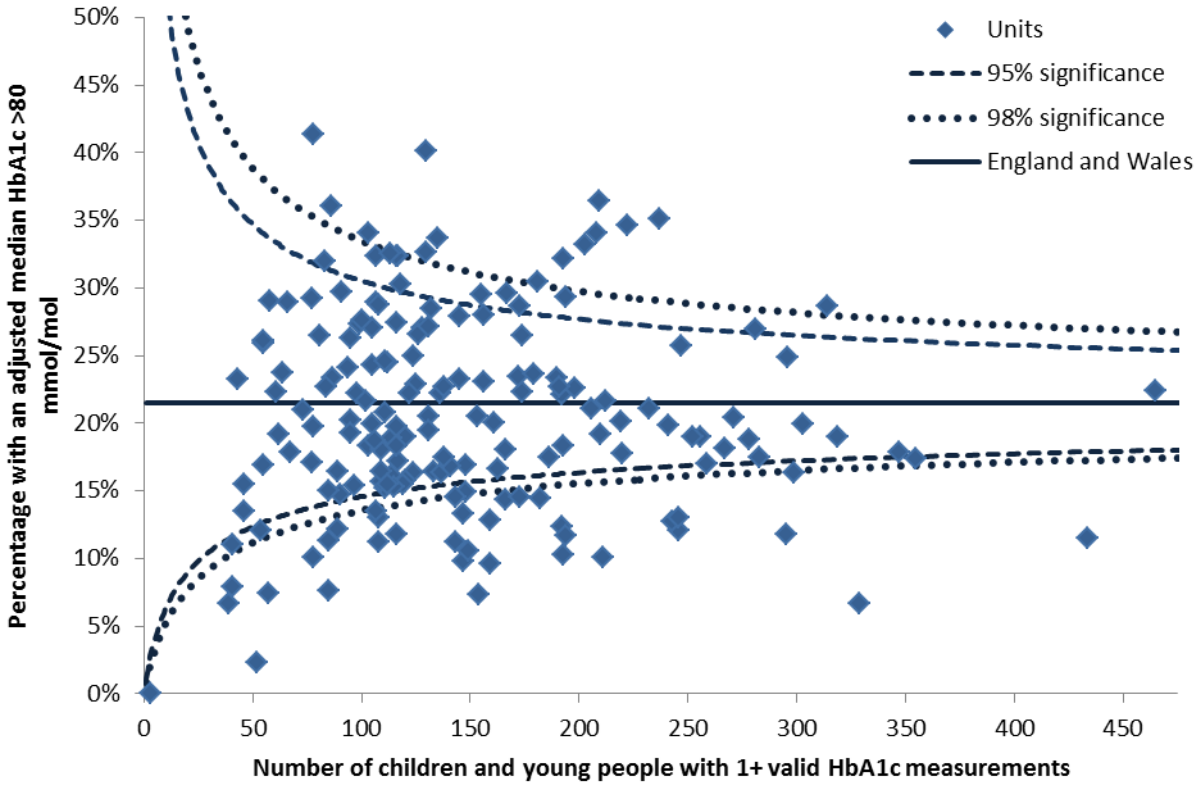


Figure 7: Funnel plot of adjusted HbA1c greater than 80 mmol/mol by PDU for children and young people with Type 1 diabetes, 2014/15



Mean HbA1c rises with duration of Type 1 diabetes (Figure 8), with a decline in the percent achieving <58mmol/mol and rise in those with greater than 80mmol/mol (Figure 9). This may well reflect increasing age as borne out by Figure 10, which shows older children tend to have poorer control.

Figure 8: Mean HbA1c for children and young people with Type 1 diabetes by duration of diabetes, 2014/15

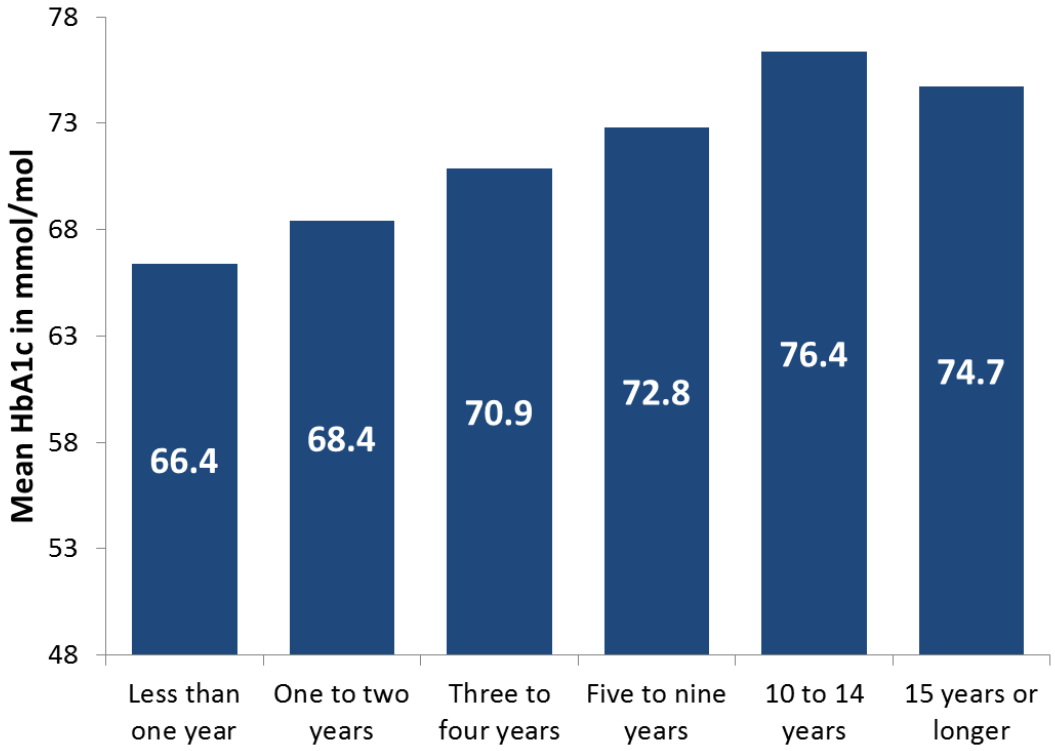
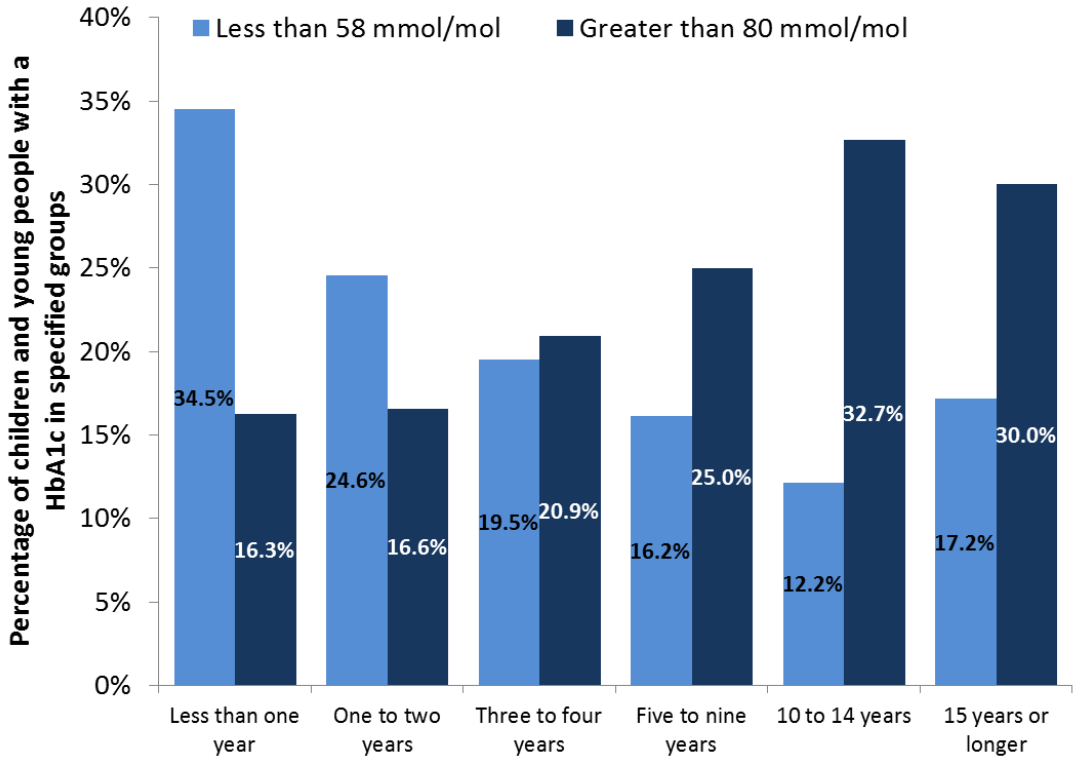


Figure 9: Percentage of children and young people with Type 1 diabetes with HbA1c in specified groups by duration of diabetes, 2014/15



Younger children with Type 1 diabetes tend to achieve better control than older children and young people (Figure 10), which is also reflected in the target achievement (Figure 11).

Figure 10: Mean HbA1c for children and young people with Type 1 diabetes by age and sex, 2014/15

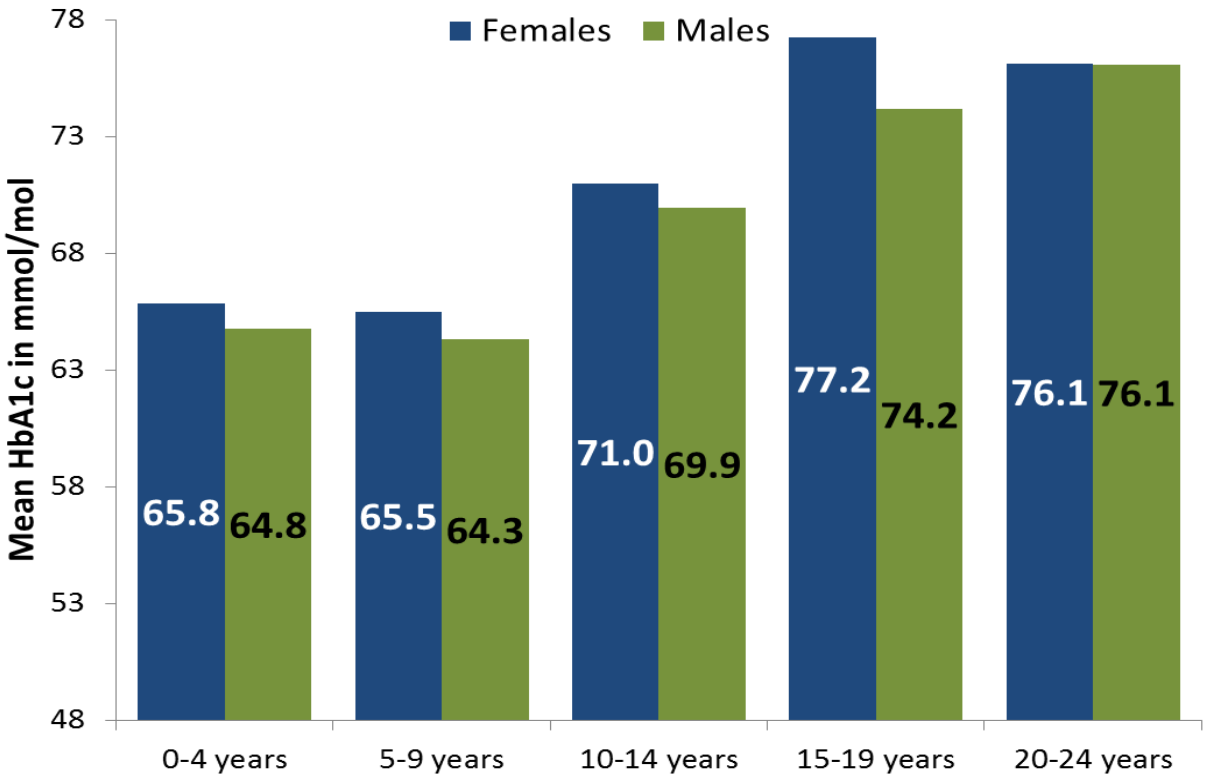
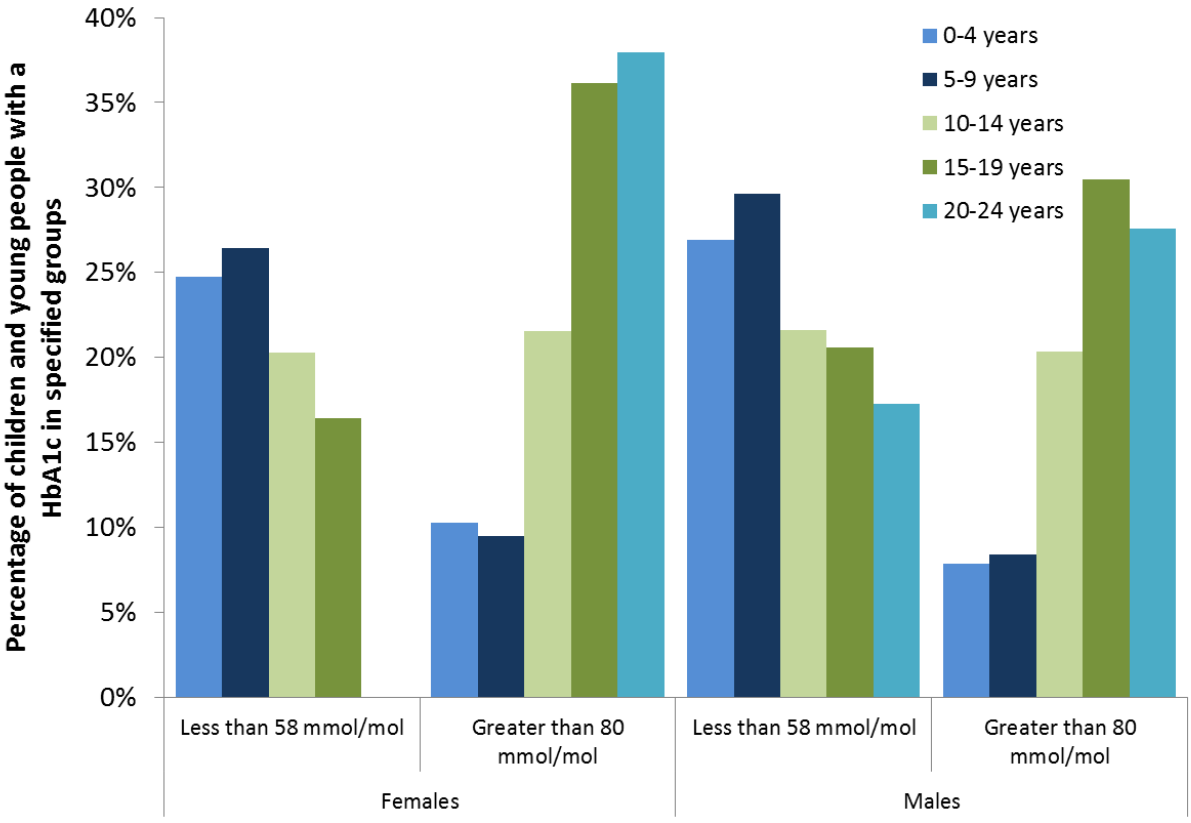


Figure 11: Percentage of children and young people with Type 1 diabetes with HbA1c in specified groups by age and sex, 2014/15



Children and young people with Type 1 diabetes living in the most deprived areas have poorer diabetes control (Figure 12), which is also reflected in the target achievement (Figure 13).

Figure 12: Mean HbA1c for children and young people with Type 1 diabetes by deprivation quintile, 2014/15

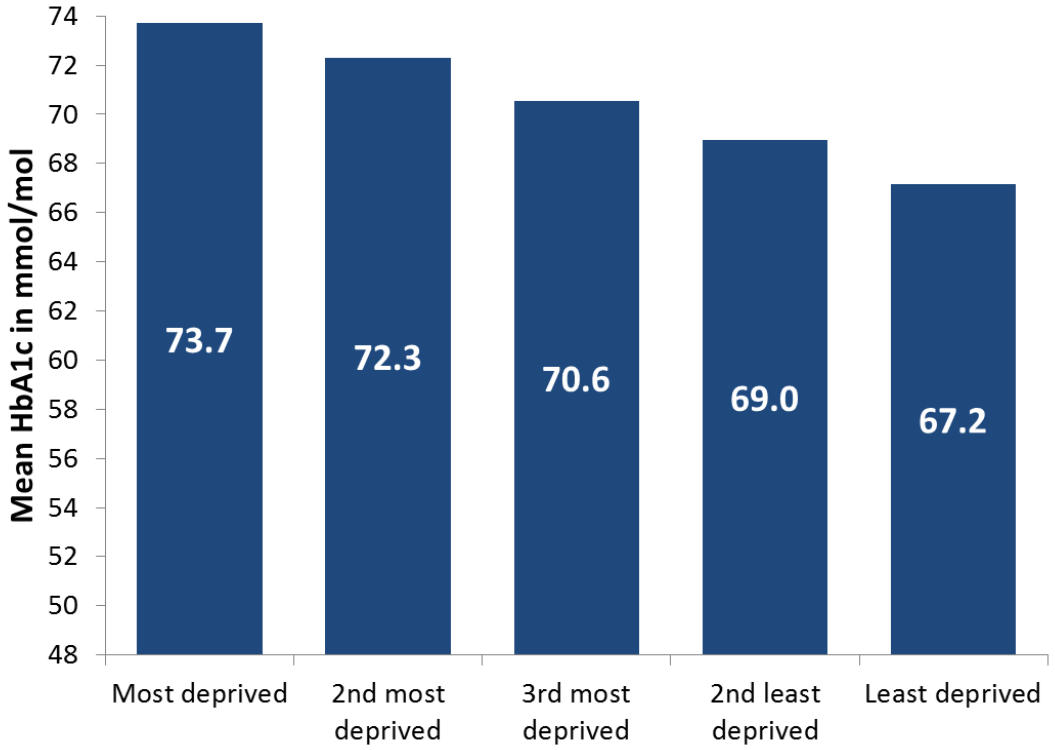
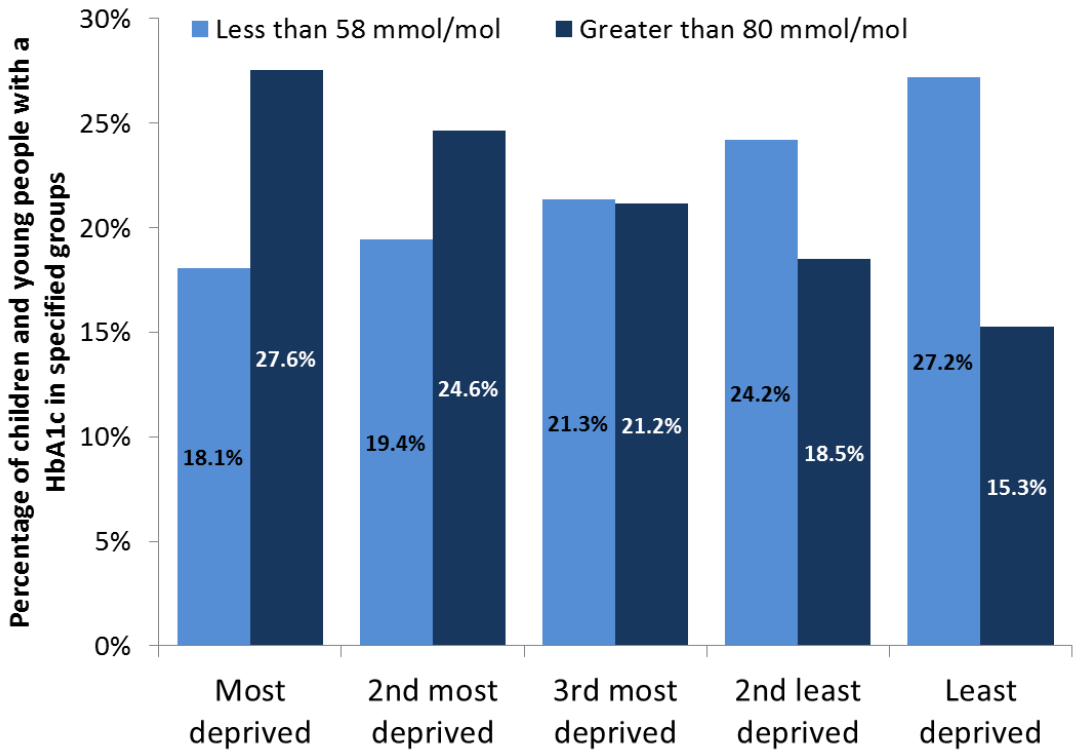


Figure 13: Percentage of children and young people with Type 1 diabetes with HbA1c targets by deprivation quintile, 2014/15



5.2.2 Treatment regimen

There is variability in insulin treatment regimen across England and Wales (Table 8) with insulin pump usage being greater in younger age groups and in the least deprived areas (Tables 9 and 10).

Table 8: Treatment regimen for children and young people with Type 1 diabetes by country and region, 2014/15

	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	3.3%	5.5%	3.6%	57.4%	22.9%	0.1%	0.5%	6.6%
England	3.4%	5.5%	3.6%	57.3%	22.7%	0.1%	0.6%	6.8%
Wales	1.3%	5.8%	2.9%	60.0%	26.7%	*	*	3.2%
East of England	0.5%	4.9%	4.7%	53.4%	21.4%	*	0.4%	14.5%
East Midlands	2.8%	3.8%	1.0%	60.0%	30.5%	0.0%	0.8%	1.1%
London and South East	4.1%	5.8%	7.3%	58.1%	16.2%	0.1%	0.6%	7.8%
North East	2.7%	10.7%	6.8%	48.1%	29.9%	0.0%	0.3%	7.8%
North West	9.7%	8.0%	2.2%	55.1%	17.4%	0.0%	1.0%	6.6%
South Central	1.9%	3.5%	2.1%	65.1%	25.5%	0.0%	*	1.9%
South West	0.5%	5.1%	0.9%	55.8%	19.5%	0.0%	0.4%	17.7%
West Midlands	3.4%	5.5%	3.0%	60.8%	24.6%	0.0%	0.8%	2.0%
Yorkshire and the Humber	2.4%	2.2%	1.2%	57.5%	33.8%	0.3%	0.5%	2.1%

* indicates a number less than 5 which has been suppressed

Table 9: Treatment regimen for children and young people with Type 1 diabetes by age, 2014/15

	Multiple daily injections	Insulin pump therapy
0 – 4 years	58.1%	29.7%
5 – 9 years	62.8%	26.4%
10 – 14 years	67.2%	23.6%
15 – 19 years	70.0%	18.5%

Table 10: Treatment regimen for children and young people with Type 1 diabetes by deprivation quintile, 2014/15

	Multiple daily injections	Insulin pump therapy
Most deprived	71.2%	18.4%
2nd most deprived	69.4%	21.6%
3rd most deprived	66.7%	23.7%
2nd least deprived	63.4%	25.1%
Least deprived	61.5%	26.3%

5.3 Small vessel (microvascular) disease

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

Diabetes remains the leading cause of renal failure and the second most common cause of lower limb amputation (International Diabetes Federation, 2013). The new NICE guideline (NG18), published August 2015, states that diabetes foot problems result in the most common form of non-traumatic limb amputation. Furthermore, current research demonstrates that for a child diagnosed with Type 1 diabetes, the expected loss of life expectancy is 10-12 years (Livingstone, 2015). However with good diabetes care, many of the complications can be minimised.

5.3.1 Kidney disease

Increased risk of kidney disease is indicated by the presence of either micro- or macro-albuminuria (Table 11).

Table 11: Albuminuria results for all young people with diabetes aged 12 years and older by country and region, 2014/15

	Normoalbuminuria	Microalbuminuria or Macroalbuminuria
England and Wales	88.3%	11.6%
England	88.7%	11.3%
Wales	83.6%	16.4%
East of England	88.6%	11.4%
East Midlands	91.4%	8.6%
London and South East	86.7%	13.3%
North East	88.9%	11.1%
North West	88.1%	11.9%
South Central	91.2%	8.8%
South West	86.4%	13.6%
West Midlands	89.9%	10.1%
Yorkshire and The Humber	89.9%	9.8%

The risk of kidney disease increases with age (Table 12) and with deprivation (Table 13).

Table 12: Albuminuria results for all young people with diabetes aged 12 years and older by age, 2014/15

	Microalbuminuria or Macroalbuminuria
12 years	9.9%
13 years	11.1%
14 years	12.3%
15 years	11.1%
16 years	12.8%
17 years	13.2%
18 years	10.2%

Table 13: Albuminuria results for all young people with diabetes aged 12 years and older by deprivation quintile, 2014/15

	Microalbuminuria or Macroalbuminuria
Most deprived	15.2%
2nd most deprived	11.2%
3rd most deprived	10.4%
2nd least deprived	11.3%
Least deprived	10.2%

5.3.2 Eye disease

Increased risk of eye disease is indicated by the abnormal eye screening (Table 14).

Table 14: Results of eye screening for all young people with diabetes aged 12 years and older, 2014/15

	Normal	Abnormal	Missing eye screening data
England and Wales	70.2%	12.8%	17.0%
England	70.9%	13.0%	16.2%
Wales	59.1%	10.5%	30.4%
East of England	73.5%	13.4%	13.1%
East Midlands	70.2%	11.4%	18.4%
London and South East	69.0%	11.0%	20.1%
North East	81.0%	17.0%	2.0%
North West	68.5%	14.2%	17.3%
South Central	74.6%	10.5%	14.8%
South West	73.8%	14.5%	11.8%
West Midlands	63.9%	13.6%	22.6%
Yorkshire and The Humber	70.9%	14.0%	15.1%

Prevalence of the risk of eye disease increases with age (Table 15) but there is no clear association with deprivation (Table 16).

Table 15: Abnormal eye screening results for all young people with diabetes aged 12 years and older by age, 2014/15

	Abnormal
12 years	6.4%
13 years	10.1%
14 years	10.9%
15 years	12.5%
16 years	14.8%
17 years	19.0%
18 years	23.9%

Table 16: Abnormal eye screening results for all young people with diabetes aged 12 years and older by deprivation quintile, 2014/15

	Abnormal
Most deprived	12.8%
2nd most deprived	13.5%
3rd most deprived	13.4%
2nd least deprived	11.6%
Least deprived	13.0%

5.4 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 which include high blood pressure, abnormal lipid levels, high body mass index and smoking.

5.4.1 Blood Pressure and cholesterol

High blood pressure and/or raised blood cholesterol increases lifetime risk of cardiovascular disease including strokes and heart disease. Maintaining normal blood pressure and cholesterol within target reduces this risk. 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). Results are shown in Table 17.

Table 17: Blood pressure and total cholesterol targets for all young people aged 12 years and older with Type 1 diabetes by country and region, 2014/15

	'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	26.9%	10.9%	34.9%	25.0%	5.6%	27.1%	37.2%	78.2%
England	27.1%	10.9%	35.0%	25.3%	5.6%	27.4%	37.2%	78.0%
Wales	24.1%	9.6%	31.7%	20.0%	5.4%	22.1%	38.5%	81.9%
East of England	26.5%	11.1%	35.4%	27.0%	6.2%	29.4%	37.5%	81.4%
East Midlands	26.3%	12.2%	35.6%	29.7%	6.6%	31.7%	40.5%	79.1%
London and South East	27.9%	10.4%	35.3%	24.1%	3.4%	25.2%	35.7%	75.5%
North East	23.3%	4.5%	27.3%	22.6%	2.3%	22.9%	38.9%	77.8%
North West	28.4%	8.8%	35.1%	26.3%	5.4%	28.7%	35.5%	73.5%
South Central	24.7%	12.5%	33.4%	22.8%	5.7%	25.5%	39.7%	84.3%
South West	27.5%	11.4%	35.6%	27.1%	6.2%	29.9%	38.7%	78.8%
West Midlands	28.3%	12.4%	37.1%	24.6%	7.5%	27.4%	37.8%	78.8%
Yorkshire and The Humber	26.3%	13.0%	35.3%	24.3%	7.2%	27.5%	34.3%	77.3%

5.4.2 Body Mass Index

Increased levels of Body Mass Index (BMI, weight/height^2) increase 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 and 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

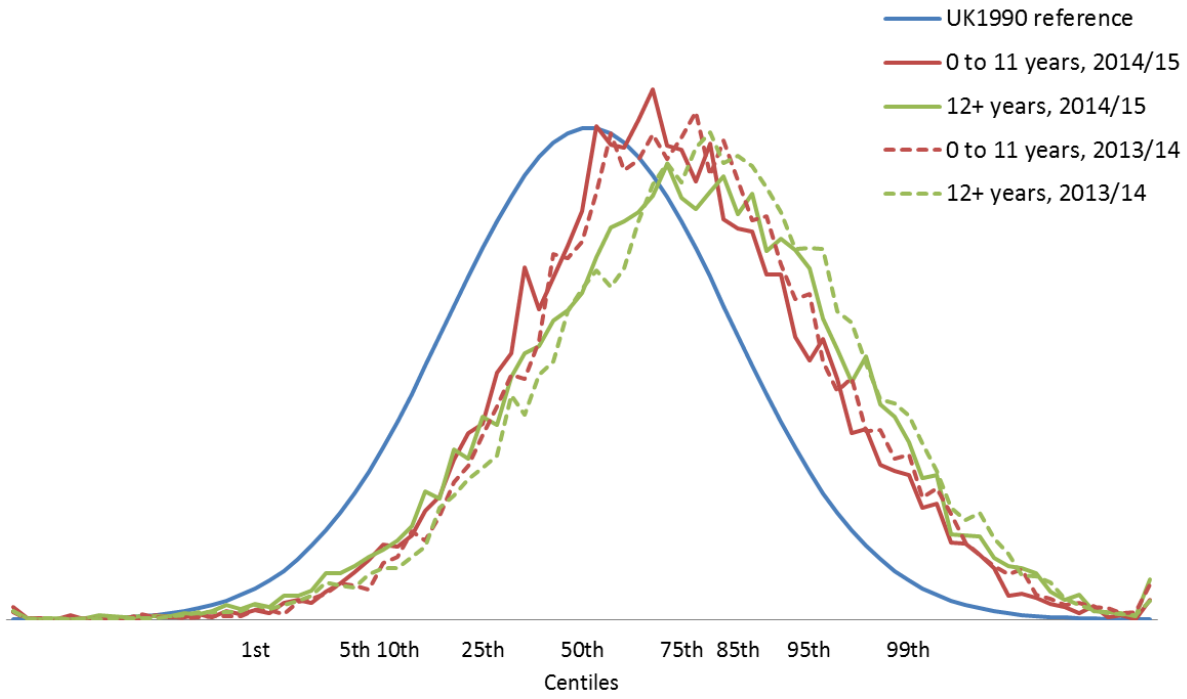
Comparisons can be made with the National Child Measurement Programme in England (2013/14 and the Child Measurement Programme in Wales (2013/14). These programmes measure the height and weight of all children in Reception class (aged 4 to 5 years old) in both countries and Year 6 (aged 10 to 11 years old) in England. For 2014/15, in England 31.6% (similar to 32.3% in 2013/14) of children aged 4 to 5 years old with Type 1 diabetes are overweight or obese compared to 22.5% in the Child Measurement Programme. A similar pattern is found in Wales where 44.4% (increase from 35.7% 2013/14) of children with Type 1 diabetes aged 4-5 years are overweight or obese compared to 26.5% within the Child Measurement Programme. Amongst children aged 10 to 11 years old with Type 1 diabetes the prevalence of overweight and obesity was 32.9% (reduction from 40.2% 2013/14) compared to 33.5% in the 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.

Table 18: Body mass index categories for children and young people with Type 1 diabetes by country and region, 2014/15

	% 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	1.6%	65.5%	16.5%	15.9%	0.5%	2.5%	57.4%	19.0%	20.7%	0.5%
England	1.6%	65.7%	16.4%	15.7%	0.5%	2.5%	57.5%	18.9%	20.6%	0.5%
Wales	0.9%	61.6%	17.8%	18.7%	0.9%	2.7%	55.3%	19.7%	22.2%	0.1%
East of England	1.5%	68.0%	14.2%	14.8%	1.4%	2.2%	59.6%	18.3%	18.3%	1.5%
East Midlands	2.0%	66.6%	17.3%	14.1%	0.0%	2.3%	56.1%	18.7%	22.9%	0.0%
London and South East	2.0%	66.8%	15.8%	15.0%	0.5%	2.8%	60.8%	17.3%	18.4%	0.7%
North East	1.6%	62.5%	17.3%	16.9%	1.8%	2.3%	51.9%	19.2%	25.8%	0.7%
North West	1.4%	63.1%	18.4%	16.7%	0.5%	2.3%	54.7%	19.9%	22.4%	0.7%
South Central	1.4%	68.8%	14.7%	14.9%	0.1%	2.1%	58.3%	20.4%	18.8%	0.4%
South West	1.4%	63.8%	17.9%	16.9%	0.0%	1.9%	58.6%	20.0%	19.1%	0.3%
West Midlands	1.6%	62.8%	18.8%	16.5%	0.3%	2.7%	57.2%	18.4%	21.6%	0.1%
Yorkshire and The Humber	1.4%	68.4%	13.8%	16.1%	0.3%	3.0%	55.0%	19.8%	22.1%	0.1%

Figure 14 shows the distribution of BMI for 0-11 years and those aged 12 years and over with Type 1 diabetes in comparison to the 1990 standards. A clear shift to the right can be seen demonstrating increased levels of being overweight and obese.

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

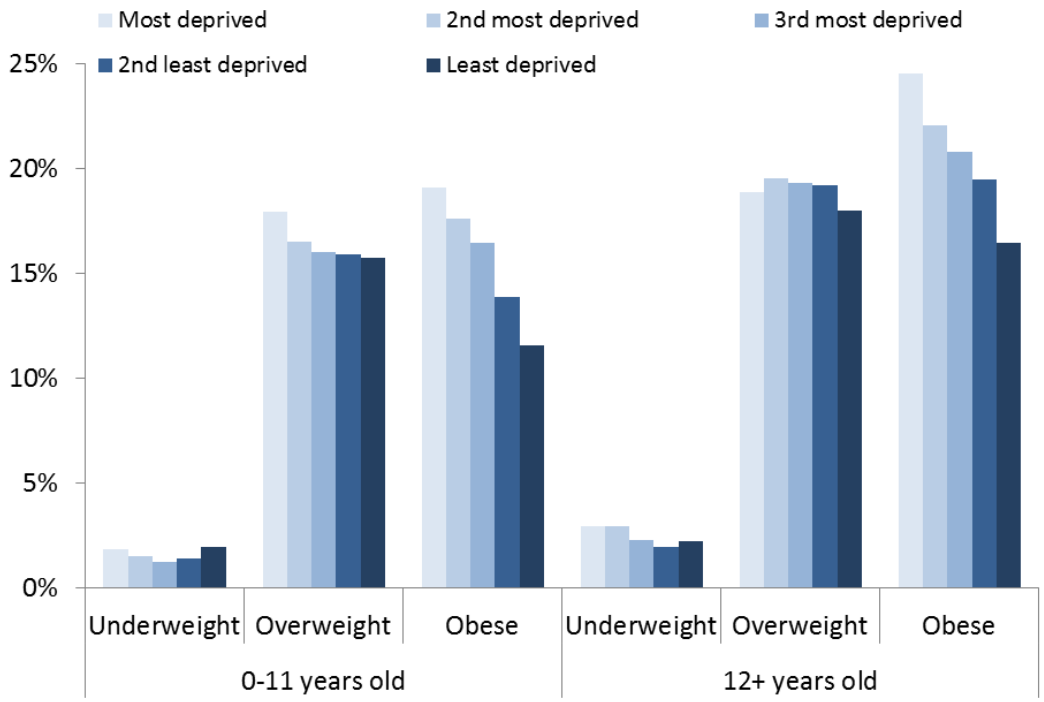


Similar to the background population there is a clear deprivation gradient for being overweight and/or obese in children and young people with diabetes (Table 19, Figure 15).

Table 19: Body mass index categories for children and young people with Type 1 diabetes by deprivation, 2014/15

	% 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	1.8%	60.6%	17.9%	19.1%	0.6%	2.9%	53.4%	18.9%	24.6%	0.2%
2nd most deprived	1.5%	64.0%	16.5%	17.6%	0.4%	2.9%	54.7%	19.5%	22.1%	0.8%
3rd most deprived	1.3%	65.6%	16.0%	16.5%	0.7%	2.3%	57.2%	19.3%	20.8%	0.4%
2nd least deprived	1.4%	68.4%	15.9%	13.9%	0.5%	2.0%	58.8%	19.2%	19.5%	0.5%
Least deprived	2.0%	70.2%	15.7%	11.6%	0.5%	2.2%	62.7%	18.0%	16.4%	0.7%

Figure 15: Percentage of children and young people with Type 1 diabetes within each body mass index category by deprivation quintile



5.5 Smoking

Smoking in young people with diabetes is detrimental to outcomes and raises the risk of future complications, and the association is strongest in Type 1 diabetic patients (Eliasson, 2003). The adverse effect of smoking in any population suggests the need for education (Table 20).

Table 20: Smoking status of all young people aged 12 years and older with diabetes by country and region, 2014/15

	% with smoking status recorded who were never smokers	% with smoking status recorded who were former smokers	% with smoking status who were current smokers
England and Wales	95.1%	0.9%	4.0%
England	95.1%	0.8%	4.1%
Wales	95.6%	2.1%	2.3%
East of England	94.3%	0.8%	4.9%
East Midlands	92.1%	*	7.7%
London and South East	97.1%	0.5%	2.4%
North East	95.7%	0.8%	3.5%
North West	95.1%	0.9%	3.9%
South Central	95.8%	0.8%	3.3%
South West	93.3%	*	6.3%
West Midlands	95.1%	1.4%	3.4%
Yorkshire and The Humber	93.1%	1.9%	5.1%

* indicates a number less than 5 which has been suppressed

5.6 Other auto-immune conditions

Of the children and young people who had a valid measurement of thyroid function 3.2% have thyroid disease and 4.7% of children who had been screened for coeliac disease were following a gluten-free diet indicative of coeliac disease in England and Wales (Table 21).

Table 21: Thyroid and coeliac disease in children and young people with Type 1 diabetes, 2014/15

	On thyroxine for hypothyroidism or anti-thyroid medication for hyperthyroidism	On gluten free diet
England and Wales	3.2%	4.7%
England	3.2%	4.7%
Wales	4.0%	5.1%
East of England	3.4%	6.5%
East Midlands	5.2%	7.1%
London and South East	2.8%	2.6%
North East	2.5%	3.7%
North West	2.4%	4.1%
South Central	2.7%	5.3%
South West	3.4%	3.3%
West Midlands	3.4%	5.3%
Yorkshire and The Humber	3.8%	5.3%

Note: the data presented above is limited to those individuals with Type 1 diabetes with a valid thyroid function measurement or those with an observation date for a gluten-free diet in the audit period.

6. Self-Management: 'Structured patient education'

Summary

Managing blood glucose levels and daily diabetes care is a challenging balancing act for children, young people and parents. The pressure impacts on daily living such as school life and activities, relationships, emotions, health and well-being, yet only half of children and young people have access to Structured Patient Education Programmes.

Recommendation

Regional diabetes networks should explore options for developing regional and national structured patient education programmes. Such initiatives will avoid such 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 and in a family centred way (Waldron & Campbell, 2014). Programmes should be designed by experienced diabetes educators (Campbell & Waldron, 2013), and be given at diagnosis and then through the life stages of the child and family. Care must also be taken to evaluate the programmes and review them regularly to ensure that they are meeting the needs of the children and families.

Structured Patient Education Programmes are recommended by NICE as part of the ongoing management of children and young people with diabetes. 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.'*

Across England and Wales 58.1% of children and young people with Type 1 diabetes and 39.7% of those with Type 2 diabetes were recorded as receiving structured patient education between April 2014 and March 2015 (Table 22).

Table 22: Percentage of children and young people documented as having received structured patient education in the audit period by country and region, 2014/15

	Type 1 diabetes	Type 2 diabetes	All types of diabetes
England and Wales	58.1%	39.7%	57.4%
England	58.9%	40.8%	58.2%
Wales	43.1%	13.3%	42.8%
East of England	61.7%	78.3%	61.5%
East Midlands	65.3%	56.3%	64.8%
London and South East	48.4%	40.3%	48.1%
North East	76.1%	58.8%	75.7%
North West	64.6%	37.8%	63.4%
South Central	63.7%	25.0%	62.9%
South West	39.5%	12.5%	38.8%
West Midlands	52.5%	32.9%	51.4%
Yorkshire and The Humber	78.3%	47.4%	77.5%

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, the presence of psychologists and the development of psychological support for children, young people and families has expanded enormously (Binney & Roswess-Bruce, 2015; Roswess-Bruce & Binney, 2016). However, further work needs to be done to develop national agreement on the best way to use expert psychologists in the clinical setting (Binney & Roswess-Bruce, 2015; Roswess-Bruce & Binney, 2016).

Data collected on the use of Child and Adolescent Mental Health Services (CAMHS) and psychological support was poor, with data missing for nearly half (43.5%) of children and young people with diabetes (Table 23). Better quality data is required before the NPDA can make further comment on psychological support.

Table 23: Use of Child and Adolescent Mental Health Services and psychological support by country and region, 2014/15

	No referral required	Referred and seen	Referred but no evidence of being seen	Missing data
England and Wales	38.7%	16.6%	1.2%	43.5%
England	37.8%	17.1%	1.2%	43.9%
Wales	55.7%	6.9%	1.9%	35.5%
East of England	28.5%	27.9%	0.9%	42.6%
East Midlands	42.7%	35.2%	1.3%	20.7%
London and South East	33.9%	15.2%	0.9%	50.0%
North East	12.8%	4.1%	0.9%	82.2%
North West	42.7%	14.1%	1.5%	41.7%
South Central	57.7%	16.7%	1.0%	24.7%
South West	43.6%	15.1%	2.1%	39.2%
West Midlands	39.4%	10.0%	0.8%	49.7%
Yorkshire and The Humber	41.3%	17.4%	1.5%	39.8%

8. Conclusion

The 12th annual NPDA report (2014/15) has demonstrated continued improvement in outcomes for children and young people with diabetes. The rate of improvement seen in England and Wales has exceeded that seen in some other European countries, and it is extremely rewarding for clinicians, healthcare professionals, patients and commissioners to see positive results starting to emerge after the time and financial investment spent trying to improve diabetes care for children.

There have been many changes in the landscape for paediatric diabetes over the last five years including the establishment of managed networks and the Peer Review Programme. Furthermore, the publication of service delivery plans in England and Wales and the Best Practice Tariff in England have enabled Trusts and Health Boards delivering care to improve the quality of service they provide. The investment is paying off with continued quality improvement, as evidenced within this report. However, there is more work to be done to reduce the variability in outcomes seen across the two nations and ongoing improvements are still required to ensure that all children and young people with diabetes in England and Wales receive all the recommended health checks and support necessary for achieving and maintaining good diabetes control.

The NPDA calls on everyone involved in the provision of paediatric diabetes care to sustain the effort underpinning the improvements seen, and to strive for further progress. Commissioners must ensure paediatric diabetes units have the resources in place in order to provide high quality care for all children, regardless of postcode, and hold providers to account to ensure that the Best Practice Tariff is used to best effect. Healthcare professionals providing guidance to children and young people with diabetes and their families are urged to share best practice to drive up standards, and patients and parents/carers are encouraged to engage with their provider units to support them to deliver the best possible care.

9. 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 disorders.

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 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 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 gluten being omitted 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 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 that 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.

10. List of Tables

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14. Appendix I – Details of the case mix adjustment for HbA1c

N.B. Full details of the analysis methodology and details of definitions of inclusion/exclusion criteria for each care process can be found in the Technical Document at www.rcpch.ac.uk/npda.

HbA1c varies by demographic and social characteristics. It is therefore appropriate to adjust the figures for each PDU to take account of the characteristics of their patients or case-mix. The case-mix adjustments applied to the 2014/15 data include patient characteristics measured in the audit that are outside the influence of the PDUs and which may influence HbA1c measurements. These are age, sex, duration of diabetes and deprivation as measured by quintiles of the Indices of Multiple Deprivation 2015 in England and the Welsh Indices of Multiple Deprivation 2014 in Wales. The case-mix adjustment applied in previous years also included ethnic group. Data quality issues have prevented the use of data on ethnic group in 2014/15. This means direct comparisons between the case-mix adjusted figures for 2014/15 and previous years cannot be confidently made.

An expected Hba1c is calculated for each patient based their characteristics (age, sex, duration of diabetes and deprivation quintile) using the regression equation established from the whole dataset shown in Appendix 1 Table 1. An individualised adjusted HbA1c is then calculated as:

Case-mix adjusted HbA1c = (Observed HbA1c/Expected HbA1c) x Total cohort mean HbA1c.

Appendix 1 Table 1: Adjustment factors for calculating mean HbA1c by PDU, 2014/15

		Co-efficient	95 CI	p
Constant		53.42	52.58-54.26	<0.001
Age	Per year of age	0.92	0.87-0.98	<0.001
Sex	Female	-	-	-
	Male	-1.51	-1.09-1.94	<0.001
Duration	Per year of diabetes duration	0.32	0.26-0.39	<0.001
Deprivation	Most deprived	7.12	6.46-7.79	<0.001
	2nd most deprived	5.46	4.78-6.14	<0.001
	3rd most deprived	3.31	2.63-3.99	<0.001
	2nd least deprived	1.89	1.21-2.56	<0.001
	Least deprived	-	-	-

The model only explains 7.9% of the variation in mean HbA1c. This means that 92.1% of the variation in mean HbA1c is due to other factors that have not been included in the model such as ethnicity, clinic structure, resource and the nature of the care provided[6].

In a similar manner 'case mix' adjustment can be made for the treatment targets for percentage of children and young people with an HbA1c less than 58 mmol/mol and greater than 80 mmol/mol. Appendix 1 Table 2 shows the multivariate analysis for each treatment target. As the factors included in the case mix adjustment (age, sex, duration of diabetes and deprivation) only explain a very small percentage of the variation in achieving these targets by PDUs the vast majority of the variation is due to other factors such as clinic structure and the nature of the care provided.

Appendix 1 Table 2: Adjustment factors for HbA1c targets, 2014/15

		HbA1c less than 58 mmol/mol			HbA1c greater than 80		
		Odds ratio	95 CI	p	Odds ratio	95 CI	p
Age	Per year of age	0.99	0.98-1.00	0.003	1.18	1.17-1.19	<0.001
Sex	Male	-	-	-	-	-	-
	Female	0.88	0.82-0.93	<0.001	1.18	1.11-1.25	<0.001
Duration	Per year of diabetes duration	0.90	0.89-0.91	<0.001	1.01	1.00-1.02	0.024
Deprivation	Most deprived	0.56	0.51-0.61	<0.001	2.40	2.18-2.66	<0.001
	2nd most deprived	0.63	0.57-0.69	<0.001	1.99	1.79-2.20	<0.001
	3rd most deprived	0.73	0.67-0.80	<0.001	1.52	1.37-1.69	<0.001
	2nd least deprived	0.84	0.77-0.92	<0.001	1.30	1.17-1.45	<0.001
	Least deprived	-	-	-	-	-	-

The model to predict having an HbA1c less than 58 mmol/mol explains 5.0% of the variation and the model to predict having an HbA1c greater than 80 mmol/mol explains 11.3% of the variation.[7]

[6] The co-efficients give the values used to calculate the 'expected' mean HbA1c for each child and young person with diabetes. For example, a 10 year old male who had had diabetes for two years and lived in the 2nd most deprived quintile of neighbourhoods would have an expected mean HbA1c of 53.42 + (0.92*10)+(-1.51)+(0.32*2)+(5.46) or 68.7mmol/mol. Across a PDU the expected mean HbA1c values can be compared to the actual HbA1c achieved by children and young people. The ratio of observed versus expected mean values is used to calculate the case mix adjusted HbA1c for each PDU. $R^2$for the regression model is 0.077.

[7] Binary regression models were created to adjust the percentage of children and young people with Type 1 diabetes with a HbA1c within certain ranges (less than 58mmol/mol and more than 80mmol/mol). This model calculates the odds of having an Hba1c in each of the specified groups. For example the odds of a female having a HbA1c of more than 80mmol/mol compared to a male 1.18 to 1. For each additional year of diabetes duration the odds of having an HbA1c of more than 80mmol/mol increase by 1.01. These odds have been converted into the probability that a child or young person would have an HbA1c within the specified range. For each PDU the sum of the probabilities of having an HbA1c in the specified range is compared to the actual number of children and young people with an HbA1c in the specified range is used to calculate the adjusted percentage.

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