

***RCPCH Audits**

Annual report 2019-20 Care processes and outcomes







Front cover Image by Emilia Smith, winner NPDA Cover Art Competition

National Paediatric Diabetes Audit (NPDA) National report 2019/20:

Care processes and outcomes

Citation: National Paediatric Diabetes Audit Annual Report 2019-20: Care Processes and Outcomes. London: Royal College of Paediatrics and Child Health, 2021.

© Healthcare Quality Improvement Partnership 2021

1. Foreword

I am delighted to introduce this 2019/20 National Paediatric Diabetes Audit (NPDA) report; the tenth to be published by the Royal College of Paediatrics and Child Health, and the 17th since the audit's inception. The report highlights the care and outcomes of children and young people living with diabetes in England and Wales in 2019/20. It covers incidence and prevalence, diabetes-related outcomes and complications, use of diabetes-related technologies, compliance with health care checks recommended by the National Institute for Health and Care Excellence (NICE), and recommendations for improvements in care.

This year has been tough for everyone and at one point the production of the annual report seemed uncertain. The final data submission window for the 2019/20 audit began on the 1st April 2020, when the first wave of the COVID-19 pandemic was peaking, and the NHS was in a state of extreme flux. In some parts of the country, members of the paediatric workforce were relocated to support colleagues working in acute adult medicine, paediatric diabetes teams were grappling with new ways of supporting their families and discovering new concepts such as working remotely. Mandatory participation in national clinical audits, including the NPDA was suspended. Despite these challenges, it is commendable that 96% of paediatric diabetes teams in England and Wales were able, and chose, to submit data for the 2019/20 audit year. This is testament to the dedication of the paediatric diabetes care. I would urge all units to submit data for 2020/21, a year unlike any other, but one from which to use data to learn from, and to shape future services.

Overall, since 2012/13, the NPDA has shown impressive national improvements in HbAlc outcomes and rates of completion of health checks fuelled by a more coordinated national, regional and local approach to diabetes management. Despite the results contained in this 2019/20 report looking similar to 2018/19, this still represents overall improvement, and I am aware of the fantastic work of the ongoing National Diabetes Quality Programme. Furthermore, we should not be disheartened by these results, as international comparisons with other European countries also show dramatic improvements in one year followed with a plateauing the next year. To quote Martin Luther King Jr 'if you can't fly then run, if you can't run then walk, if you can't walk then crawl, but whatever you do you have to keep moving forward'. The NPDA continues to move forward.

This report continues to show worrying insights into differences in outcomes related to social deprivation and ethnicity. Those living in more deprived areas continue to lag behind those in the least deprived areas and minority ethnic children and young people are less likely to achieve lower HbAlc targets or be using a diabetes technology that could support their management, even after accounting for other patient factors. In the year where the 'Black Lives Matter' movement has raised the profile of ethnic inequalities across society, this report provides additional impetus for action to reduce disparities in care outcomes across different ethnicities. Barriers to achieving excellent outcomes amongst those children and young people living in more deprived areas and of Black ethnicity must be identified and mitigated if we are to see significant further overall national progress.

There continues to be a worrying trend for higher numbers of children and young people with Type 2 diabetes being cared for by paediatric diabetes services. Whilst still a rare disease amongst children and young people, rising numbers indicate that this is related to the rise in obesity in England and Wales which requires ongoing attention.

With the pandemic and associated lockdowns ongoing at the time of writing, we are yet to fully quantify their impact on child health and outcomes, including those reported here. It will be incumbent on all of us, when we emerge from the worst of it, to help assess the damage, use our voice to advocate for policies that help repair the damage and address the pre-existing threats to child health evidenced within this report.

I would like to thank all those involved in writing the report and developing its recommendations, including the NPDA Project Board, Methodology and Dataset Group, the audit team, and Clinical Lead, Professor Justin Warner. I would like to thank the paediatric diabetes teams across England and Wales for their support for the audit in this uniquely challenging year, and for their ongoing efforts to make improvements in their local services.

Professor Russell Viner

President, Royal College of Paediatrics and Child Health

2. 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/m2. 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.

HbAlc (Glycated haemoglobin) – The term HbAlc refers to glycated haemoglobin. By measuring glycated haemoglobin (HbAlc), clinicians are able to get an overall picture of what our average blood sugar levels have been over a period of weeks/ months. For people with diabetes this is important as the higher the HbAlc, the greater the risk of developing diabetes-related complications. (Diabetes.co.uk)

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.

Key health checks – Seven health checks for children with Type 1 or Type 2 diabetes recommended for annual completion by NICE guidance (NG18, 2015) that monitor diabetes management and screen for diabetes-related complications.

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.

Micro/macro albuminuria – as kidney disease progresses, more albumin leaks into the urine, a condition called microalbuminuria or proteinuria. As the amount of albumin in the urine increases, the kidneys' ability to filter the blood decreases.

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.

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. Retinopathy can cause blindness if left undiagnosed and untreated.

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.

3. Introduction to the National Paediatric Diabetes Audit

The NPDA is delivered by the Royal College of Paediatrics and Child Health (RCPCH) and has been reporting for 17 years. Data is submitted by healthcare professionals in Paediatric Diabetes Units (PDUs) in England and Wales about the care received by the children and young people with diabetes using their service. The effectiveness of diabetes care is measured against NICE guidelines (NG18, NICE 2015) and includes treatment targets, health checks, patient education, psychological wellbeing, and assessment of diabetes related complications including acute hospital admissions, all of which are vital to monitoring and improving the long-term health and wellbeing of children and young people with diabetes.

The NPDA is designed to measure and motivate change at local, regional network and national levels across England and Wales. It also has a role in assuring patient safety, as data from the audit are used to inform hospital inspections by the Care Quality Commission (CQC) in England and in Wales by the Healthcare Inspectorate 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.

In the last five years, NPDA outcome data have also been benchmarked against certain other European, North American and Australasian countries, providing insights into areas where international comparisons can drive improvements (McKnight et al., 2015; Maahs et al., 2015; Sherr et al., 2016; Anderzen et al., 2020).

4. Background to the audit

Diabetes mellitus occurs when blood glucose levels are elevated because the body is unable to metabolise it. The UK has the highest number of children and young people aged 0-14 with Type 1 diabetes in Europe (International Diabetes Federation, 2019). Complications associated with suboptimal diabetes management include damage to small and large blood vessels and nerves which over time can result in blindness, kidney failure, heart disease, stroke, and amputations. With good diabetes care and blood glucose management, the risks of complications are reduced, enabling children and young people to enjoy a healthy and longer life.

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

5. Commissioners of the NPDA

The RCPCH is commissioned by the Healthcare Quality Improvement Partnership (HQIP) to deliver the NPDA as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies <u>www. hqip.org.uk/national-programmes</u>

6. Scope of the 2019/20 NPDA report

This 2019/20 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 2019 through to 31st March 2020, aged 0 – 24 on the first day of the audit period.

The NPDA achieved a participation rate of 100% of paediatric diabetes units in England and Wales from 2011/12 until the 2018/19 audit year. Challenges associated with the COVID-19 pandemic meant that seven out of the 173 paediatric diabetes teams in England and Wales did not submit data for 2019/20.

A comparison was made to the 2018/19 audit where the data was complete (<u>see Appendix 2</u>) to ascertain whether the data submitted by the 166 PDUs in 2019/20 was representative of all children and young peopled with diabetes being managed within a PDU.

Analysis showed that the patient cohort for each audit year were similar in terms of demographics and outcomes, and that the 2019/20 sample was broadly representative of the wider population of children and young people being managed within a paediatric diabetes unit.

6.1 Key audit questions

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

- What proportion of children and young people with diabetes are reported to be receiving key age-specific processes of diabetes care, as recommended by NICE?
- How many children and young people 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?
- Are there inequalities in care and outcomes between PDUs, regional networks, or between different patient groups?

6.2 Full audit results

An associated Appendix 1 to this publication provides full details of the tables of results and analyses that inform the key findings and recommendations set out within this report and can be found at: https://www.rcpch.ac.uk/resources/npda-annual-reports#downloadBox

7. Key messages

- 1. Paediatric diabetes teams have demonstrated laudable commitment to data driven quality improvement by succeeding in submitting their 2019/20 datasets during the first wave of the COVID-19 pandemic, despite severe disruption to services.
- 2. National median HbAlc (a measure of blood glucose control) remained constant at 61.5 mmol/ mol between 2018/19 and 2019/20 following several years of year on year decreases (improvement) in the national median.



Figure 1: Median HbAlc for children and young people with all types of diabetes in England and Wales 2009/10 to 2019/20

- 3. Considerable variation in HbAlc target outcomes amongst children and young people with Type I diabetes persists between PDUs even after case-mix adjustment.
- 4. The completion rates of all recommended health checks for Type 1 diabetes increased between 2018/19 and 2019/20, except for eye screening.



* health checks completed on children and young people aged 12 or older

Figure 2: Percentage of children and young people who completed a full year of care recorded as receiving individual health checks, 2004/05 to 2019/20

- 8. The proportion of children and young people with Type 1 diabetes who were assessed as requiring additional psychological or CAMHS support outside of MDT clinics increased from 39.1% in 2018/19 to 43.9% in 2019/20.
- 9. One fifth (19.4%) of children and young people with Type 1 diabetes were using a real-time continuous glucose monitor (rtCGM). Children using this technology were found to be more likely to be meeting lower HbA1c targets.



Figure 3: Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by rtCGM usage, 2019/20

- 7. Increased use of rtCGM was associated with living in less deprived areas and White ethnicity, with those in the most deprived areas and Black children and young people least likely to be using this technology.
- 8. Those living in more deprived areas were found to have a higher risk of retinopathy, albuminuria, needing additional psychological support, and higher HbAlc levels.

8. Recommendations

Hospital commissioners, NHS Regional Offices, Regional Partnership Boards, NHS England and NHS Wales should:

- 1. Read this report alongside the unit level reports within their area to benchmark outcomes both locally and nationally.
- 2. Note the inequities in outcomes highlighted by this report and fund care based on case mix in terms of language, ethnicity and deprivation.

Trusts and Health Boards should:

- 3. Ensure PDUs have appropriate staffing levels in the paediatric multi-disciplinary teams (MDT) to provide excellent quality care to young patients with diabetes. This must include dedicated admin support and IT support to record good quality data.
- 4. Ensure that parents and patients have access to appropriate psychological support as required and in line with NICE guidance.

Paediatric diabetes teams and commissioners should:

- 5. Ensure that technologies such as pumps and rtCGM are:
 - · Considered in concordance with NICE guidance and,
 - Education programmes are available to support their use.

Paediatric diabetes teams should:

- 6. Review their NPDA results, in a timely way, within a team meeting and work together to identify priorities for on-going quality improvement activities.
- 7. Regularly upload data collected as part of routine diabetes care (monthly) by members of the paediatric diabetes (MDT) into the NPDA data capture system. Data uploaded should be:
 - · Checked for completeness and quality.
 - Used to monitor performance against HbAlc and health check completion targets throughout the audit year.
 - Used to identify patients at risk of missing key health checks by the end of the audit year, so that they may be followed up their next clinic appointment.
- 8. Ensure consistent messages about glucose and HbAlc targets and have a mechanism to ensure all team members are aware of and communicating the same target to their families.
- 9. Ensure that all families attending their diabetes service are made aware of the recommended annual health checks for diabetes.
- 10. Take steps to improve engagement with children and young people with Type 2 diabetes to ensure that the NICE-recommended health checks for this cohort are carried out annually.

9. Summary of results

9.1 Overall National HbAlc results

In 2019/20 the mean HbAlc was 64.5 mmol/mol, while the median HbAlc was 61.5 mmol/mol.

9.2 Key findings: Type 1 diabetes

9.2.1 Incidence, prevalence, and patient characteristics

- In 2019/20, data for 27,653 children and young people with Type 1 diabetes (52.3% male, 47.7% female) were reported to the NPDA in England and Wales.
- The prevalence of Type 1 diabetes in children and young people aged 0 to 15 years old in England and Wales was estimated to be 198.3 per 100,000 of the general population; it is slightly higher among boys (199.0 per 100,000) compared to girls (197.6 per 100,000).
- There were at least 2,799 children and young people aged 0 to 15 years old newly diagnosed with Type 1 diabetes in England and Wales in 2019/20, with an estimated incidence of 25.6 per 100,000 general population within this age group. Incidence varies by age group among boys and girls.
- There were proportionately more children and young people with Type 1 diabetes living in the most deprived quintile areas (23.0%), which is consistent with the distribution of the general population aged 0-19 years old in England and Wales.

9.2.2 Completion of health checks

- The completion rates of all recommended health checks for Type 1 diabetes increased between 2018/19 and 2019/20, except for eye screening.
- The percentage of children and young people with Type I diabetes receiving level 3 carbohydrate-counting education within 14 days of diagnosis increased from 75.6% in 2018/19 to 82.5% in 2019/20.
- The percentage of children and young people with Type 1 diabetes receiving flu vaccination, sick day rules advice and blood ketone testing increased with respect to 2018/19.
- The percentage of those aged 12 and above with a complete year of care receiving all seven recommended health checks for Type 1 diabetes decreased from 55.2% in 2018/19 to 54.4% in 2019/20.
- The percentage of those with a complete year of care receiving four or more HbAlc measurements during the audit year decreased from 57.5% in 2018/19 to 53.1% in 2019/20.
- The percentage of children and young people with Type I diabetes receiving screening for coeliac disease and thyroid disease within 90 days of diagnosis in 2019/20 remained in excess of 80% and was similar to the previous year (83% vs 81% for coeliac disease and 89% vs 85% for thyroid disease for 2018/19 and 2019/20 respectively).





• The percentage of those with a complete year of care receiving psychological assessment decreased from 85.7% in 2018/19 to 84.4% in 2019/20.

9.2.3 Blood glucose diabetes control targets (HbA1c)

- The national mean and median HbA1c were 65.0 and 62.0 mmol/mol respectively. These results were consistent with those recorded in 2018/19.
- Higher average HbAlc was associated with female sex, longer duration of diagnosis, living in a more deprived area, adolescence and Black, mixed and Asian ethnicity.

9.2.4 Microvascular complications

- Albuminuria was found in 11.1% of young people aged 12 years and above with Type 1 diabetes.
- There was little variation in the presence of albuminuria by duration of diabetes, age or sex.
- The presence of albuminuria was associated with poorer HbAlc outcomes.
- Abnormal eye screening was found in 12.0% of young people aged 12 and above with Type 1 diabetes.
- The risk of abnormal eye screening increased with age and duration of diabetes and was highest amongst adolescent females.

9.2.5 Macrovascular complications

- High blood pressure (hypertension) was found in 26.7% of young people aged 12 years and older with Type 1 diabetes, as defined by systolic or diastolic blood pressure.
- One fifth (18.9%) of young people aged 12 years and older with Type 1 diabetes had a total blood cholesterol level exceeding the target of 5 mmol/l.
- 17.5% of children aged 0 to 11 years with Type 1 diabetes were overweight, and 18.6% were obese. In young people aged 12 years and above 18.4% were overweight and 24.3% obese.
- In England, 32.5% of children aged 4 to 5 years old with diabetes were overweight or obese (a decrease from 35.9% in 2018/19) compared to 23.0% in the National Child Measurement Programme for England.
- In Wales, 47.2% of children with diabetes aged 4 to 5 years were overweight or obese (an increase from 37.7% in 2018/19) compared to 26.3% in the Child Measurement Programme for Wales in 2017/18.
- The prevalence of overweight and obesity amongst children aged 10 to 11 years old with diabetes in England was 38.7% (an increase from 37.1% in 2018/19) compared to 35.1% of the wider cohort within the National Child Measurement Programme for England.
- A higher proportion of girls aged 12 years and above were overweight or obese compared to boys of the same age with Type 1 diabetes.
- The proportion of children and young people who were overweight or obese were higher in the most deprived quintiles than the least deprived.







9.2.6 Outcomes of psychological assessment

- The proportion of children and young people with Type I diabetes who were assessed as requiring additional psychological or Child and Adolescent Mental Health Services (CAMHS) support outside of multi-disciplinary team (MDT) clinics increased from 39.1% in 2018/19 to 43.9% in 2019/20.
- Nearly two thirds (61.8%) of children and young people with Type 1 diabetes in Wales were assessed as requiring additional psychological support.
- Amongst children and young people with Type 1 diabetes, there was a higher proportion of adolescent girls recorded as requiring additional psychological support compared to adolescent boys.
- The percentage of children and young people with Type 1 diabetes assessed as requiring additional psychological support was highest amongst those who were recently diagnosed.
- Children and young people with Type 1 diabetes who were recorded as requiring additional psychological support were more likely to have higher HbA1c.

9.2.7 Hospital admissions

- The number of units submitting admissions data decreased from 168 in 2018/19 to 155 in 2019/20.
- Data quality and completeness needs to improve further before PDU submitted admission data can be considered representative of admission trends in England and Wales.

9.2.8 Treatment regimen

- Over one third (38.0%) of children and young people with Type 1 diabetes were using an insulin pump.
- Usage of insulin pumps to deliver insulin therapy in Type 1 diabetes has increased in all age groups since 2014/15.
- Increased usage of pump therapy was associated with female sex, younger age, living in the least deprived areas and White ethnicity.
- Over a third (39.8%) of White children and young people with Type I diabetes were using an insulin pump compared to 26.7% of Black children and young people with diabetes.
- In the least deprived areas, 44.3% of children and young people with diabetes were using an insulin pump, compared to 31.7% in the most deprived areas.
- The gap between pump usage amongst children and young people with Type 1 diabetes living in the most and least deprived areas has widened with time, from 18.4% versus 26.3% (a difference of 7.9 percentage points) in 2014/15, to 31.7% versus 44.3% (a difference of 12.6 percentage points) in 2019/20. However, the discrepancy reduced from 13.4 percentage points in 2018/19.

9.2.9 Continuous blood glucose monitoring

- Almost a fifth (19.4%) of children and young people with Type 1 diabetes were using a real time continuous glucose monitor with alarms (rtCGM).
- Almost half of all children with Type 1 diabetes aged 0-4 were using an rtCGM, compared to 11% of 15-19 year olds.









- One fifth (20.2%) of White children and young people with Type 1 diabetes were using an rtCGM compared to 15.1% of Asian and 11.7% of Black children and young people with diabetes.
- In the most deprived areas, 14.0% of children and young people with diabetes were using an rtCGM, compared to 25.2% in the least deprived areas.
- Children and young people with Type 1 diabetes using rtCGM with alarms were more likely to be using insulin pump therapy than insulin injections.
- Combined pump and rtCGM usage amongst children and young people with Type I diabetes was most strongly associated with achievement of lower HbAIc target outcomes.

9.2.10 Thyroid and coeliac disease

- One in 20 (5.8%) of children and young people in England and Wales with Type I diabetes had been recommended a gluten-free diet, indicative of coeliac disease; and 3.1% were receiving treatment for thyroid disease.
- Prevalence of coeliac disease was higher amongst girls with Type 1 diabetes (7.0%) compared to boys (4.7%).
- There were twice as many girls with Type I diabetes and thyroid disease (4.3%) compared to boys (2.0%).
- The prevalence of coeliac disease was higher amongst children and young people with Type 1 diabetes living in the least deprived areas, and within White and Asian ethnic groups.

9.3 Key findings: Type 2 diabetes

9.3.1 Incidence, prevalence, and patient characteristics

- There were 866 children and young people with Type 2 diabetes reported to the audit, of whom 201 (23.2%) were newly diagnosed within the audit year.
- There have been year on year increases in the numbers of children and young people with Type 2 diabetes being managed within a PDU since 2012/13, with the percentage of the total NPDA sample doubling from 1.3 to 3.0% in this period.
- Higher risk of Type 2 diabetes was found in girls, those of non-white ethnicity, and those living in the most deprived areas, consistent with previous NPDA findings.

9.3.2 Completion of health checks

- The completion rates of all recommended health checks for Type 2 diabetes decreased between 2018/19 and 2019/20, except for urinary albumin which remained constant.
- The percentage of those aged 12 and above with a complete year of care receiving all seven key checks decreased from 30.9% in 2018/19 to 26.7% in 2019/20.
- The percentage of those with a complete year of care receiving four or more HbAlc measurements during the audit year decreased from 34.9% in 2018/19 to 33.0% in 2019/20.







9.3.3 Blood glucose diabetes control targets (HbAlc)

- The mean and median HbAlc of children and young people with Type 2 diabetes in England and Wales receiving care in a PDU in 2019/20 were 58.6 and 51.0 mmol/mol.
- The national mean increased by 1.2 mmol/mol and the national median increased by 0.5 mmol/mol between 2018/19 and 2019/20.
- Similarly to Type I diabetes, higher average HbAlc was seen in those children and young people of a female sex, with a longer duration of diagnosis, living in a more deprived area and Black, mixed and Asian ethnicity.

9.3.4 Microvascular complications

- Albuminuria was found in 25.7% of children and young people with Type 2 diabetes; more than twice the rate observed in those with Type 1 diabetes, indicating that children and young people with Type 2 diabetes are at greater risk of kidney disease.
- Abnormal eye screening results were found in 6.1% of young people with Type 2 diabetes; half the rate recorded amongst young people with Type 1 diabetes.

9.3.5 Macrovascular complications and risk factors

- Hypertension (defined by either systolic or diastolic blood pressure) was found in 44.3% of children and young people with Type 2 diabetes, almost double that seen in Type 1 diabetes.
- Over a quarter (28.8%) of young people aged 12 years and older with Type 2 diabetes had a total blood cholesterol level exceeding the target of 5 mmol/l.
- Most (84.2%) of children and young people with Type 2 diabetes were obese.

9.3.6 Outcomes of psychological assessment

• Over half (53.6%) of children and young people with Type 2 diabetes were assessed as requiring additional psychological or CAMHS support outside of MDT clinics; an increase from 45.5% in 2018/19.

9.3.7 Treatment regimen

 More than half (57.7%) of children and young people with Type 2 diabetes were managing their diabetes with dietary management alone or with diet and blood glucose lowering medication.









10. NPDA resources to support the use of the audit results for quality improvement

10.1 Reviewing results

• Comprehensive <u>PDU level reports</u> comparing performance between audit years and against regional and national averages are available to download from via a pdf generator on the NPDA website.



• Unit, regional, and CCG level results are available for comparison on the NPDA's interactive reporting web tool, <u>NPDA Results Online</u>. Results for specific measures can be compared across each reporting level, and between audit years.

NPDA National report 2019/20: Care processes and outcomes

RCPCH	NPDA Results Online		
Royal College of Paediatrics and Child Health Leading His ung in Caldron's Health	Linit Data		
Home	(Please select your criteria b	elow)	
🕑 Unit Data	Audit Measures:	Select a specific audit measure	-
	Chart Type:	Select a Chart Type	
N CCG/LHB Data	Primary Unit/Hospital:	Select a primary Unit/Hospital	•
Naturark Data	2nd Unit/Hospital:	Select a second Unit/Hospital (OPTIONAL)	
	3rd Unit/Hospital:	Select a third Unit/Hospital (OPTIONAL)	
Ullier Data	4th Unit/Hospital:	Select a fourth Unit/Hospital (OPTIONAL)	
$ \dot{a} $ Longitudinal Data	Data year range from:	2018-19 🔻 To Data year: 2018-19 👻	
15 Annual Reports	ALSO DISPLAY:	National Average	
? Help / FAQs	Help	View	Chart

• The NPDA also provides <u>Excel files</u> of each audit years results presented at PDU, regional, CCG, and STP level on the NPDA website.

10.2 Communicating results and planning improvements as a team

Team work is essential for successful, sustained quality improvement activity, and so the NPDA has developed a slide deck for clinical leads to use to present their results to their teams, identify areas of achievement and for improvement, and raise awareness of the audit's key findings and recommendations. The slide deck contains links to resources to support quality improvement, including case studies and presentations from NPDA annual conferences.



10.3 Engaging families in improving care

We believe that quality improvement activities are most successful when clinical teams and service users work together, so our parent and patient focussed outputs are designed to empower them to recognise good care and meaningfully collaborate with clinicians to support required improvements where identified. For this core, care process and outcome audit, these include:

- Parent and carer versions of the report in English and Welsh
- Bespoke <u>clinic posters</u> showing PDU performance against key audit measures and national and regional results.
- <u>Animations</u> explaining the function of the audit, and key results and messages arising from the audit.

Examples shown relate to the 2018/19 and updated versions will be produced for the 2019/20 report.



11. Conclusion

In a uniquely challenging year, paediatric diabetes teams have demonstrated continued commitment to data-driven improvement by participating in the NPDA 2019/20 data process. This report demonstrates the maintenance of improvements made year on year over the past seven years, both in terms of diabetes related outcomes, and the provision of recommended health checks for those with Type 1 diabetes.

However, this report also shows that there remains much to do to reduce inequalities in outcomes associated with deprivation, ethnicity, and age, in the use of technologies that can support children and young people to achieve the best HbAlc possible, and in terms of risk of Type 2 diabetes. Further, health check completion amongst those with Type 2 diabetes worsened. Teams must continue to work together with the children and young people that they care for, their families and healthcare commissioners to identify and tackle barriers to achieving excellent outcomes. Ongoing national, regional and local quality improvement activities must focus on reducing variation in care and outcomes between patients and PDUs.

12. Acknowledgements

Report Editors

- Ms Saira Pons Perez, NPDA Analyst, RCPCH
- Professor Justin Warner, Clinical Lead, RCPCH and Consultant in Paediatric Endocrinology and Diabetes, Cardiff and Vale University Health Board
- Ms Holly Robinson, NPDA Manager, RCPCH
- Ms Karina Green, NPDA Coordinator, RCPCH

Quantitative Analysis

• Ms Saira Pons Perez, NPDA Analyst, RCPCH

National Paediatric Diabetes Audit Clinical Lead

• Professor Justin Warner, Clinical Lead, RCPCH and Consultant in Paediatric Endocrinology and Diabetes, Cardiff and Vale University Health Board

Project Management

• Ms Holly Robinson, NPDA Manager, RCPCH

Project Support

- Ms Karina Green, NPDA Coordinator, RCPCH
- Mr Simon Duncan, Audit Administrator, RCPCH
- Mr Tom Keiller, Administrative Assistant, RCPCH
- Mr Calvin Down, Clinical Standards Programme Manager, RCPCH
- Ms Adele Picken, Information Governance Manager, RCPCH

National Paediatric Diabetes Audit Project Board

- Professor Nick Bishop, Vice President for Science and Research, RCPCH (Chair)
- Dr Fiona Campbell, Consultant Paediatric Diabetologist, Leeds Teaching Hospitals NHS Trust
- Professor Justin Warner, Clinical Lead, RCPCH and Consultant in Paediatric Endocrinology and Diabetes, Cardiff and Vale University Health Board
- Dr Kemi Lokulo-Sodipe, Specialty Registrar in Paediatrics, Southampton Children's Hospital
- Ms Rachel Harris, Paediatric Diabetes Specialist Nurse, Cardiff and Vale University Health Board
- Ms Kate Cullen, Parent Representative
- Mr Simon Lewthwaite, Parent Representative
- Dr Neil Hopper, Consultant Paediatrician, South Tyneside And Sunderland NHS Foundation Trust
- Dr Mark Deakin, Consultant Paediatrician, Alder Hey Children's Hospital NHS Foundation Trust

National Paediatric Diabetes Audit Methodology and Dataset Working Group

- · Dr Fiona Campbell, Leeds Teaching Hospitals NHS Trust (Chair)
- Dr Nivedita Aswani, Consultant in General Paediatrics and Diabetes, Derby Hospitals NHS Foundation Trust
- Dr Bill (William) Lamb, Consultant Paediatric Diabetologist
- Professor Justin Warner, Consultant in Paediatric Endocrinology and Diabetes, Cardiff and Vale University Health Board
- Ms Francesca Annan, Dietitian, Clinical Specialist Paediatric/Adolescent Diabetes Dietitian, University College London Hospital Foundation Trust
- Dr Halina Flannery, Clinical Psychologist, University College London Hospital NHS Foundation Trust
- Ms Kate Fazakerley, Parent Representative
- · Dr Alex De Costa, Specialty Registrar in Paediatrics, Queen Mary University
- Ms Kate Cullen, Parent Representative
- Mr Simon Lewthwaite, Parent Representative
- Ms Rachel Harris, Paediatric Diabetes Specialist Nurse, Cardiff and Vale University Health Board
- Ms Nicky Moor, Paediatric Diabetes Specialist Nurse, Barts and the London NHS Trust
- Dr Neil Hopper, Consultant Paediatrician, South Tyneside And Sunderland NHS Foundation Trust
- · Dr Mark Deakin, Consultant Paediatrician, Alder Hey Children's Hospital NHS Foundation Trust
- Dr Evelien Gevers, Consultant Paediatrician, Barts and the London NHS Trust

HQIP Support

- Ms Vivien Dunne, Project Manager, NCAPOP, Healthcare Quality Improvement Partnership
- Dr Sasha Hewitt, Associate Director, NCAPOP, Healthcare Quality Improvement Partnership
- Ms Emma Skipper, Associate Director, NCAPOP, Healthcare Quality Improvement Partnership

National Paediatric Diabetes Audit (NPDA)

Annual report 2019-20 Care processes and outcomes

Published by RCPCH May 2021



Healthcare Quality Improvement Partnership (HQIP) Dawson House, 5 Jewry Street, London EC3N 2EX



Royal College of Paediatrics and Child Health 5-11 Theobalds Road, London, WC1X 8SH