

# Annual report 2020-21: Care processes and outcomes



# National Paediatric Diabetes Audit (NPDA) National report 2020/21:

Care processes and outcomes

# Contents

<b>1.</b>	<b>Foreword</b>	<b>4</b>			
<b>2.</b>	<b>Introduction to the National Paediatric Diabetes Audit</b>	<b>5</b>			
<b>3.</b>	<b>Background to the audit</b>	<b>6</b>			
<b>4.</b>	<b>Commissioners of the NPDA</b>	<b>7</b>			
<b>5.</b>	<b>Scope of the 2020/21 NPDA report</b>	<b>8</b>			
5.1	Key audit questions	8			
<b>6.</b>	<b>Key messages</b>	<b>9</b>			
<b>7.</b>	<b>Recommendations</b>	<b>12</b>			
	Case study 1: Improving take up and recording of retinal screening	13			
	Case study 2: Adapting to restrictions on face to face care with drive through clinics	13			
<b>8.</b>	<b>Summary of results</b>	<b>14</b>			
8.1	Overall National HbA1c results	14			
8.2	Key findings: Type 1 diabetes	14			
8.2.1	Incidence, prevalence, and patient characteristics	14			
8.2.2	Completion of health checks	14			
8.2.3	Blood glucose diabetes control targets (HbA1c)	15			
8.2.4	Microvascular complications	15			
8.2.5	Macrovascular complications	15			
8.2.6	Outcomes of psychological assessment	16			
8.2.7	Hospital admissions	16			
8.2.8	Treatment regimen	16			
8.2.9	Continuous blood glucose monitoring	17			
8.2.10	Thyroid and coeliac disease	17			
8.3	Key findings: Type 2 diabetes	17			
8.3.1	Incidence, prevalence, and patient characteristics	17			
8.3.2	Completion of health checks	18			
8.3.3	Blood glucose diabetes control targets (HbA1c)	18			
8.3.4	Microvascular complications	18			
8.3.5	Macrovascular complications and risk factors	18			
8.3.6	Outcomes of psychological assessment	18			
8.3.7	Treatment regimen	18			
<b>9.</b>	<b>NPDA resources to support the use of the audit results for quality improvement</b>	<b>19</b>			
9.1	Reviewing results	19			
9.2	Communicating results and planning improvements as a team	20			
9.3	Engaging families in improving care	21			
9.4	Other NPDA publications	20			
<b>10.</b>	<b>Conclusion</b>	<b>22</b>			
<b>11.</b>	<b>Glossary</b>	<b>23</b>			
<b>12.</b>	<b>Acknowledgements</b>	<b>25</b>			

# 1. Foreword

I am delighted to introduce this 2020/21 National Paediatric Diabetes Audit (NPDA) report; the eleventh to be published by the Royal College of Paediatrics and Child Health, and the 18th 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 2020/21. 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 report covers the first year of the COVID-19 pandemic; a year where the day to day lives of children and young people were transformed by lockdowns and school closures, and healthcare including paediatric diabetes care faced unprecedented disruption and a shift towards remote consultations.

The impact of disruption to care is evident in the health check completion rates achieved during this year, which this report shows to be lower than in previous audit years. However, there is still much to celebrate within this report, including lower national average HbA1c than in previous years, increases in the use of diabetes related technologies within all ethnic and socio-economic groups, and a participation rate of 100% amongst paediatric diabetes teams in England and Wales, despite suspension of mandatory participation in national clinical audits during the same time. Participation by all teams, despite the challenges of delivering, recording, and submitting details of care delivered and outcomes achieved, is a testament to the commitment to data driven improvement within the paediatric diabetes clinical community.

The rising incidence of Type 1 diabetes within the audit year evidenced within this report, on the other hand, provides cause for concern. Whilst audit data cannot be used to determine the cause of the spike in incidence observed across the 2020/21 audit year, it must provide impetus for research into these causes, and paediatric diabetes units must be resourced properly to provide the best possible care at onset of diabetes within the context of rising numbers and higher caseloads.

The continuing trend for year on year increases in the numbers of children and young people with Type 2 diabetes receiving care from paediatric diabetes teams, also evidenced within this report, shows that national efforts to reduce childhood obesity and associated complications have so far not had the impact required. Type 2 diabetes in the young is an aggressive form of the condition, and this report coupled with the NPDA spotlight audit on Type 2 diabetes published late in 2021 suggest that more support is required to prevent or delay the onset of this condition for those living in the most deprived areas of the country who are most at risk, and in supporting those with the condition to achieve its remission.

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, and for their ongoing efforts to make improvements in their local services.



**Professor Camilla Kingdon**  
**President, Royal College of Paediatrics and Child Health**

## 2. 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 18 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 by the Healthcare Inspectorate Wales in 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 six 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, Prigge et al., 2021).

### 3. 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).

## 4. 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 [www.hqip.org.uk/national-programmes](http://www.hqip.org.uk/national-programmes).

## 5. Scope of the 2020/21 NPDA report

This 2020/21 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 2020 through to 31st March 2021, aged 0 – 24 on the first day of the audit period.

The period covered by this audit year corresponds to the first year of the COVID-19 pandemic. During this year, in-person paediatric diabetes clinics were suspended for months at a time, and some families were reluctant to come to clinic once restrictions were eased. Despite the challenges associated with delivering and recording care in the 2020/21 audit year, 100% of all paediatric diabetes teams submitted data for all patients receiving care from their services in the audit year.

### 5.1 Key audit questions

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

- Are numbers of children and young people with Type 1 and Type 2 diabetes receiving care from PDUs increasing?
- 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?

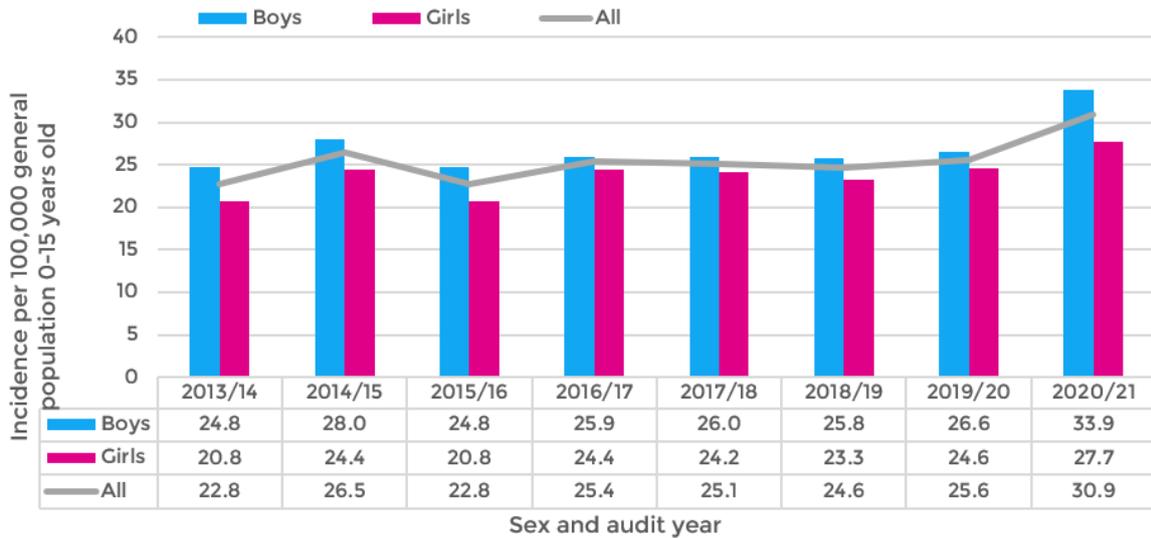
### 5.2 Full audit results

Appendix 1 to this publication provides full details of the results and analyses informing the key findings and recommendations set out within this report, and can be found on the annual reports page of the NPDA website: <https://www.rcpch.ac.uk/resources/npda-annual-reports>

## 6. Key messages

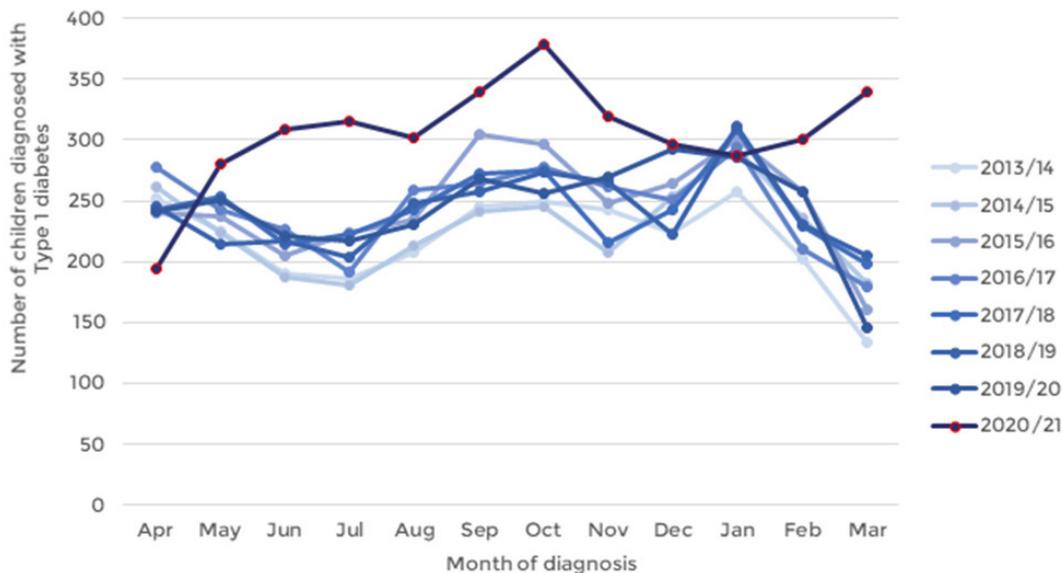


1. Paediatric diabetes teams should be commended for achieving 100% participation in the 2020/21 NPDA, despite all the challenges associated with delivering, recording, and submitting details of care provided during the contemporaneous COVID-19 pandemic.
2. Incidence of Type 1 diabetes increased significantly in 2020/21 amongst those aged 0-15, from 25.6 new cases per 100,000 in 2019/20 to 30.9 in 2020/21 – an increase of 20.7% ( $p < 0.001$ ).



**Figure 1:** Incidence of Type 1 diabetes per 100,000 general population among children aged 0-15 years by sex, 2013/14 to 2020/21

3. There were 3,662 children and young people newly diagnosed with Type 1 diabetes receiving care from paediatric diabetes units in 2020/21. This is 789 more than the average number newly diagnosed and being managed in a PDU between 2013/14-2019/20. This increase was over four times the size of the average caseload for PDUs in 2020/21. The consistent seasonal pattern of new cases of Type 1 diabetes observed in previous audit years was also disrupted in 2020/21.

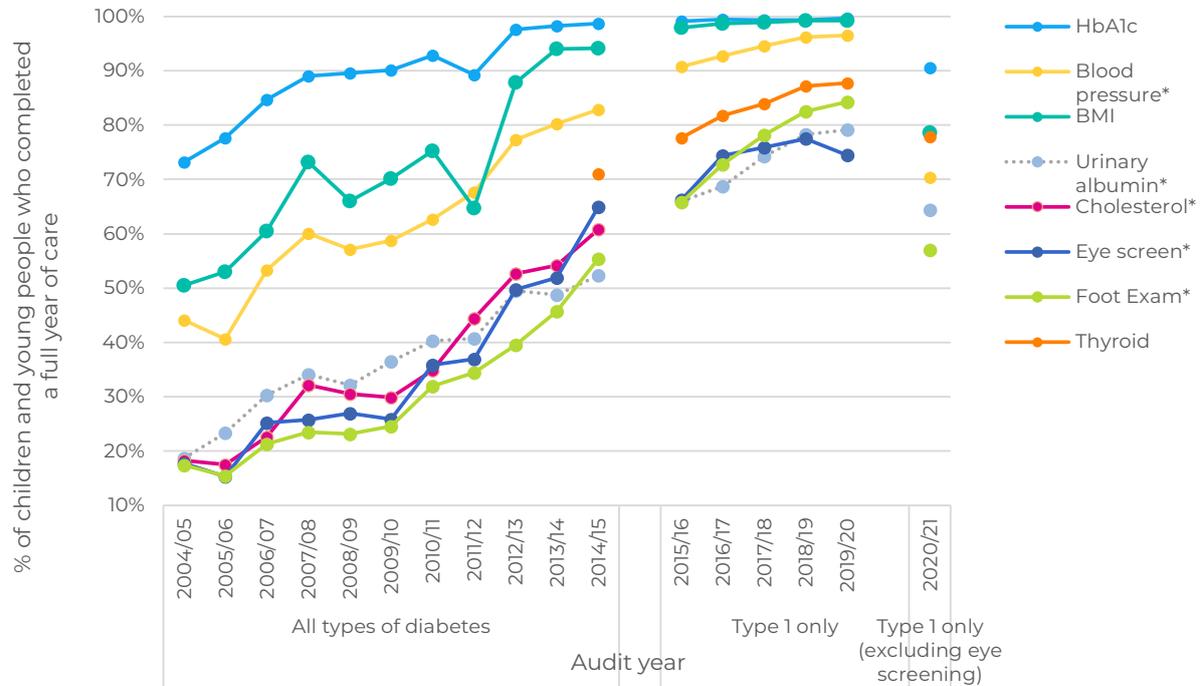


**Figure 2:** Number of new cases of Type 1 diabetes amongst children and young people receiving care from a PDU by month, 2013/14-2020/21

4. Numbers of children and young people with Type 2 diabetes being managed within a PDU increased from 866 in 2019/20 to 973 in 2020/21, with the numbers diagnosed within the audit year having increased from 201 in 2019/20 to 230 in 2020/21.

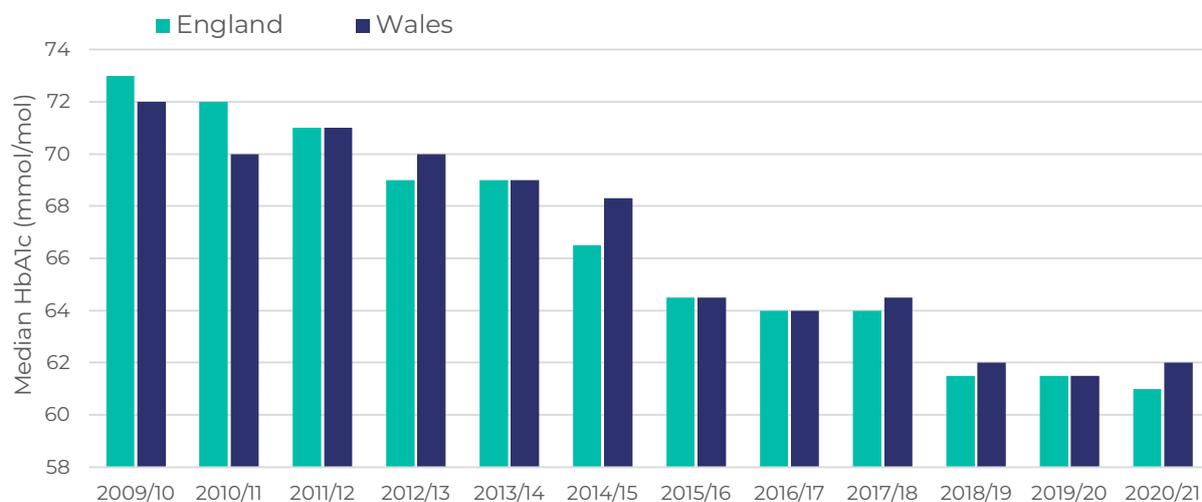


5. The impact of the pandemic on paediatric diabetes care can be seen in lower completion rates of all recommended health checks and the smaller percentage of children and young people starting insulin pump therapy if diagnosed in 2020/21, compared to previous years.



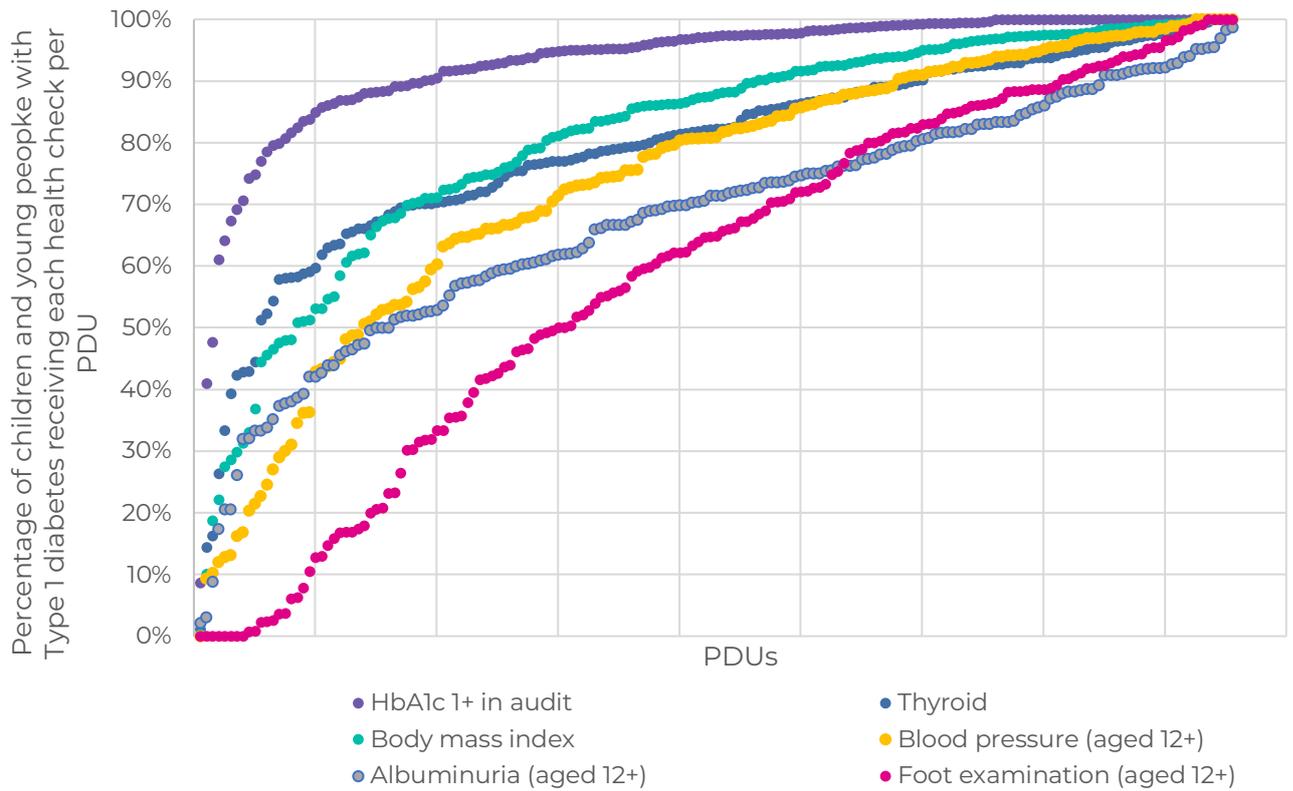
**Figure 3:** Percentage of children and young people with Type 1 diabetes who completed a full year of care recorded as receiving individual health checks, 2004/05 to 2020/21

6. National median HbA1c (a measure of blood glucose control) reduced from 61.5 mmol/mol to 61.0mmol/mol between 2019/20 and 2020/21 following several years of year on year decreases (improvement) in the national median (combining results from PDUs in England and Wales).



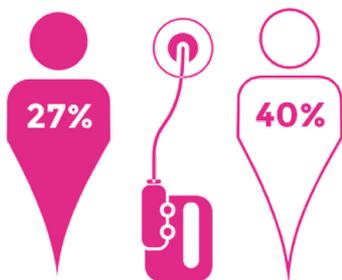
**Figure 4:** Median HbA1c for children and young people with all types of diabetes in England and Wales 2009/10 to 2020/21

7. There was wide variation in the completion rates of all key annual health checks at PDU level, with some achieving close to 100% and others achieving less than 10%.



**Figure 5:** Percentage of children and young people with Type 1 diabetes receiving each key health check by PDU, 2020/21

8. There was an increase in use of real time continuous glucose monitors (rtCGM) from 19.4% in 2019/20 to 27.9% in 2020/21, with increases observed across all deprivation quintiles and ethnic groups. The highest percentage increase between the audit years was amongst Black children and young people with Type 1 diabetes, from 11.7% in 2019/20 to 21.9% in 2020/21 – an increase of 87.2%. However, 21.9% was still the lowest percentage out of all ethnic groups, with those of mixed ethnicity having the highest rate of usage, at 29.3%.



9. Lower use of insulin pumps was associated with ethnic minority status, with Black children and young people having the lowest use (27.4%) compared to 40.2% of White children. Higher use of insulin pumps was associated with living in a less deprived area, with 44.0% of those in the least deprived areas using a pump compared to 32.5% in the most deprived areas.

## 7. Recommendations

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

1. Commission and fund, local and regional services, taking into account local demographic and socioeconomic factors and inequities in outcomes highlighted by this report.

### Trusts and Health Boards should:

2. Ensure PDUs have appropriate staffing levels in paediatric multi-disciplinary teams (MDT) to provide excellent care to young patients with diabetes in the context of increasing numbers of children and young people with diabetes being diagnosed and managed within PDUs.

This must include:

- Dedicated admin and IT support for recording good quality data
  - Provision for all children and young people for whom multiple daily insulin injections are not appropriate to use an insulin pump from diagnosis, and to be trained and able to do so
3. Ensure that alternative arrangements for delivering and recording routine paediatric care are in place when in person hospital visits are suspended.
  4. Support paediatric diabetes services to reset, restore and recover following disruption to services caused by the COVID-19 pandemic, with reference to [RCPCH principles](#) for doing so.
  5. Ensure that parents and patients have access to appropriate psychological support as required and in line with NICE guidance.

### Paediatric diabetes teams and hospital commissioners should:

6. Ensure that a real time continuous glucose monitor is available to all children and young people with diabetes who wish to use one, supported by an education programme to ensure optimal use.

### Paediatric diabetes teams should:

7. Review their annual NPDA results as a team within a month of receipt, and work together to identify priorities for on-going quality improvement activities.
8. 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 HbA1c 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 at their next clinic appointment.
9. Ensure that they produce consistent messages about glucose and HbA1c targets and have a mechanism to ensure all team members are aware of and are communicating the same targets to their families.

## Case study 1: Improving take up and recording of retinal screening

In 2018/19 the paediatric Diabetes team at the University Hospitals Coventry and Warwickshire NHS Trust were a negative outlier for retinal screening, with a completion rate of 56.3%. This was due to a process change meaning that we no longer had access to the external screening provider's database, due to data protection restrictions.

To overcome this challenge, we got in touch with the retinal screening provider to find out about how their process works and came up with a solution. We now send an updated active patient list to the team every three months and when a patient on that list has had retinal screening, we are sent a copy of their results letter electronically via email. The patient list we send is also populated with the date last attended or did not attend (DNA), and any future appointments booked. This means that we can also remind patients of their upcoming appointment when they are in clinic.

We also utilise Diamond (a diabetes-specific electronic patient record system) to add notes to the clinic episode of those who have missed retinal screening appointments, this then prompts the consultant to remind the patient to book their screening when they attend clinic. At the end of the audit year a letter and information leaflets are sent to patients who did not attend screening, reminding them of the importance of these appointments. A copy of this letter is also sent to the GP.

Following these changes our retinal screening completion rate went up to 75% in 2019/20, which was above the regional and national average of 69% and 74%.

Laura Bambrick

Paediatric Diabetes Specialist Administrator  
**University Hospitals Coventry and Warwickshire NHS Trust**

## Case study 2: Adapting to restrictions on face to face care with drive through clinics

During lockdown in 2020, the Grimsby Paediatric Diabetes team held drive-through HbA1c testing which was very successful and enabled us to keep contact with our families.

The patient/parent drove up to the front of the clinic, with the children usually bringing their testing kit. We approached the car in our PPE, and the child did the finger prick after cleaning their finger. If they didn't have wipes, we provided wet and dry cotton wool. The child held their arm out of the window, we took the blood sample for the HbA1c analyser and then, using a wipeable cuff, we also took their blood pressure.

Patients requiring profile changes did the same thing and passed the devices out to us. We took the device in an antiseptic wipe, cleaned the devices, changed our PPE and then reset the pump and returned it.

Rebecca Bennett

Paediatric Diabetes Specialist Nurse  
**Northern Lincolnshire and Goole NHS Foundation Trust**

## 8. Summary of results

### 8.1 Overall National HbA1c results

- The national median HbA1c for children and young people with all types of diabetes fell from 61.5mmol/mol in 2019/20 to 61.0 mmol/mol in 2020/21.



### 8.2 Key findings: Type 1 diabetes

#### 8.2.1 Incidence, prevalence, and patient characteristics<sup>1</sup>

- There were 29,892 children and young people with Type 1 diabetes receiving care from a PDU in 2020/21, making up 94.6% of the audit cohort.
- In 2020/21 there were 3,662 children and young people newly diagnosed with Type 1 diabetes, of whom 3,526 (96.3%) were aged 0-15 years old. This is 789 more than the average number newly diagnosed and being managed in a PDU between 2013/14-2019/20 (2873). For comparison, the mean number of children and young people with all types of diabetes being managed within a PDU in 2020/21 was 185.
- The consistent seasonal pattern of new cases of Type 1 diabetes observed in previous years was disrupted in 2020/21, however the reason for this is unknown.
- Incidence of Type 1 diabetes increased significantly in 2020/21 amongst those aged 0-15, from 25.6 new cases per 100,000 in 2019/20 to 30.9 in 2020/21 – an increase of 20.7%.
- The increase from 2019/20 to 2020/21 was higher amongst boys, amongst whom there was a 27.4% increase, compared to a 12.6% increase in girls.
- The estimated prevalence rate of Type 1 diabetes in England and Wales was 204.5 per 100,000 of the general population. It was higher among boys (208.3 per 100,000) compared to girls (200.4 per 100,000).



#### 8.2.2 Completion of health checks

- After years of annual improvement, the completion rates of all key annual health checks decreased between 2019/20 and 2020/21.
- The percentage of children and young people with diabetes aged 12 and above receiving all six key health checks was 40.5%.
- Following changes to guidance on screening frequency in 2020, the percentage of those age 12 and above with Type 1 diabetes receiving retinal screening decreased from 74.5% in 2019/20 to 24.3% in 2020/21. Of those with results in both years, 49.1% with an abnormal result in 2019/20 received a screen in 2020/21.
- Less than a fifth (14.9%) of children and young people with Type 1 diabetes had four or more measurements recorded in 2020/21, down from 54.1% in 2019/20, and a quarter (26.0%) only had one HbA1c recorded in the audit year.



<sup>1</sup> The NPDA and the [National Diabetes Audit \(NDA\)](#) have undertaken a quality assurance exercise around case ascertainment of new cases of Type 1 diabetes. The NPDA collects data on children and young people with diabetes from PDUs where care is provided whereas the NDA collects data from the General Practice Extraction Service (GPES) covering whole populations. Although there are slight differences in the number of new cases from these two data sources, the increasing incidence is demonstrated in both, thus validating the data for audit and QI purposes.

- Four fifths (82.6%) of children and young people with Type 1 diabetes were offered an additional dietetic appointment outside of multidisciplinary team meetings, compared to 89.0% in 2019/20. The percentage of appointments attended decreased with age and duration of diabetes, from 56.3% of those four years old or younger, to 44.5% in the group aged 15 or older.
- Completion rates of psychological assessment, flu vaccine recommendation, 'sick day rules' advice and blood ketone testing advice all decreased from 2019/20 to 2020/21, with the percentage receiving psychological screening decreasing most, from 84.4% in 2019/20 to 71.6% in 2020/21.
- Rates of screening for thyroid and coeliac diseases at diagnosis of Type 1 diabetes increased from 85.2% and 81.3% in 2019/20 to 86.6% and 83.8% in 2020/21, respectively.
- The percentage of children and young people receiving Level 3 carbohydrate counting advice at diagnosis of Type 1 diabetes remained stable between 2019/21 and 2020/21, with 82.5% receiving this in 2019/20 and 82.1% in 2020/21.

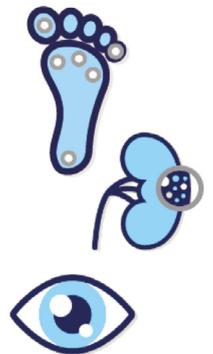
### 8.2.3 Blood glucose diabetes control targets (HbA1c)

- The national mean and median HbA1c for children and young people with Type 1 diabetes decreased from 65.0 and 62.0 mmol/mol in 2019/20 to 64.2 and 61.0 mmol/mol, respectively in 2020/21.
- A tenth (11.8%) of children and young people with Type 1 diabetes had an HbA1c equal to or lower than 48 mmol/mol, and 37.9% had an HbA1c lower than 58 mmol/mol.
- Higher HbA1c was associated with female sex, Black, mixed or Asian ethnicity, longer duration of diabetes, living in a deprived area, and adolescence.



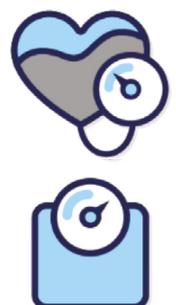
### 8.2.4 Microvascular complications

- A tenth (10.3%) of children and young people with Type 1 diabetes had micro- or macro- albuminuria.
- There was little variation in the presence of albuminuria by duration of diabetes, age, or deprivation, although the presence of albuminuria was associated with poorer HbA1c outcomes, and boys had higher prevalence at most ages.
- The percentage of children and young people with Type 1 diabetes with an abnormal eye screen increased from 12.0% in 2019/20 to 16.9% in 2020/21, possibly because services were asked to prioritise those with known retinopathy.
- Of those with retinal results recorded in 2019/20 and 2020/21, a tenth (10.3%) with a normal result in 2019/20 were found to have retinopathy in 2020/21, whilst two fifths (42.4%) of those with retinopathy in 2019/20 had a normal result in 2020/21.



### 8.2.5 Macrovascular complications

- Nearly one third of young people (31%) with Type 1 diabetes had high blood pressure (hypertension) in 2020/21; an increase compared to the figure reported in 2019/20 (26.7%).
- A fifth (19.8%) of those with Type 1 diabetes had a total blood cholesterol of 5mmol/l or higher.



- In England, 40.4% of children aged 4 to 5 years old with Type 1 diabetes were overweight or obese (an increase from 32.5% in 2019/20) - higher than the 27.7% in the National Child Measurement Programme for England 2020/21.
- The prevalence of overweight and obesity in children aged 10 to 11 years old with Type 1 diabetes in England 2020/21 was 42.1% (an increase from 38.7% in 2019/20) compared to 40.9% of the wider cohort within the National Child Measurement Programme for England 2020/21.
- In Wales, 57.2% of children with Type 1 diabetes aged 4 to 5 years were overweight or obese (an increase from 47.2% in 2019/20) - more than double the 26.9% recorded in the Child Measurement Programme for Wales in 2018/19 (the latest data available).
- Overweight and obesity were associated with higher deprivation. Girls aged under 12 were less likely to be overweight or obese compared to boys, whereas this trend was reversed in girls and boys aged 12 and above.

### 8.2.6 Outcomes of psychological assessment



- Almost a half (46.5%) of children and young people with Type 1 diabetes were assessed as requiring additional psychological or Child and Adolescent Mental Health Services (CAMHS) support outside of multi-disciplinary team (MDT) clinics, an increase from 43.9% in 2019/20.
- The percentages of younger boys and girls assessed as requiring additional psychological support were similar up to age 12. Rates diverged thereafter, as more adolescent girls were recorded as requiring additional support compared to adolescent boys.
- Children and young people with Type 1 diabetes who required additional psychological support were more likely to have an HbA1c in the higher target range compared to those who did not require additional psychological support.

### 8.2.7 Hospital admissions



- In 2020/21, 165 out of 171 PDUs submitted admissions data, up from 155 in 2019/20.
- A quarter (25.8%) of the children and young people diagnosed within the audit year receiving care from PDUs submitting admissions data in 2020/21 had DKA at diagnosis of Type 1 diabetes, an increase from 22.9% in 2019/20.

### 8.2.8 Treatment regimen



- The percentage of children and young people with Type 1 diabetes using an insulin pump was 38.5% - unchanged from 2020/21.
- Insulin pump usage decreased with duration of diabetes, with 86.1% of those in their first year of diagnosis of Type 1 diabetes using insulin injections, compared to less than half (48.9%) of those after five to nine years post diagnosis.
- The percentage of those using insulin pumps in the first year of Type 1 diabetes reduced by almost a half, from 24.8% in 2019/20 to 13.9% in 2020/21.
- Lower use of insulin pumps was associated with ethnic minority status, with Black children and young people having the lowest use (27.4%) compared to 40.2% of White children. Higher use of insulin pumps was associated with living in a less deprived area, with 44.0% of those in the least deprived areas using a pump compared to 32.5% in the most deprived areas.

## 8.2.9 Continuous blood glucose monitoring

- Use of real time continuous glucose monitors (rtCGM) with alarms amongst children and young people with Type 1 diabetes increased markedly between 2019/20 and 2020/21, with 27.9% using one in 2020/21 compared to 19.4% in 2019/20.
- Increased use was found across all deprivation quintiles and ethnic groups, with the highest percentage increase between the audit years being amongst Black children and young people with Type 1 diabetes, from 11.7% in 2019/20 to 21.9% in 2020/21 - an increase of 87.2%. However, 21.9% was still the lowest percentage out of all ethnic groups, with those of mixed ethnicity having the highest rate of usage, at 29.3%.
- Children and young people with Type 1 diabetes living in the least deprived areas were more likely to be using rtCGM compared to those living in the most deprived areas, although the percentage increase between the audit years was highest amongst those living in the most deprived areas, with a 70.0% increase in use between 2019/20 and 2020/21.
- Children and young people with Type 1 diabetes using rtCGM were more likely to achieve lower HbA1c targets compared to those who were not using rtCGM.



## 8.2.10 Thyroid and coeliac disease

- One in 20 (5.2%) of children and young people in England and Wales with Type 1 diabetes had been recommended a gluten-free diet, indicative of coeliac disease; and 2.7% were receiving treatment for thyroid disease.
- The prevalence of thyroid disease was twice as high amongst girls (3.7%) compared to boys (1.8%) with Type 1 diabetes.
- The prevalence of coeliac disease was one and a half times higher amongst girls (6.5%) compared to boys (4.1%) with Type 1 diabetes.
- The prevalence of coeliac disease was highest amongst White children and young people with Type 1 diabetes, while the prevalence of thyroid disease was highest amongst Asian children and young people with Type 1 diabetes.



## 8.3 Key findings: Type 2 diabetes

### 8.3.1 Incidence, prevalence, and patient characteristics

- The audit found 973 children and young people with Type 2 diabetes being cared for in a PDU, of whom 230 (23.6%) were newly diagnosed within the audit year
- There was an increase of 107 (12.4%) compared to the total number reported in 2019/20.
- 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.



### 8.3.2 Completion of health checks

- The completion rates of all recommended health checks for Type 2 diabetes decreased between 2019/20 and 2020/21.
- Only a quarter (24.1%) of those with a complete year of care and Type 2 diabetes received all six key recommended health checks in the audit year
- The percentage of those with a complete year of care receiving four or more HbA1c measurements during the audit year decreased from 33.0% in 2019/20 to 10.7% in 2020/21.



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

- The mean and median HbA1c of children and young people with Type 2 diabetes in England and Wales receiving care in a PDU in 2020/21 were 61.0 and 53.0 mmol/mol, increases from 58.6 and 51 mmol/mol, respectively, in 2019/20.
- Two fifths (40.9%) were achieving the recommended target of lower or equal to 48 mmol/mol, a decrease from 44.3% in 2019/20.
- Higher HbA1c was associated with longer duration of diabetes, Black ethnicity, and living in a more deprived area.



### 8.3.4 Microvascular complications

- Albuminuria was present in 23.4% of children and young people with Type 2 diabetes – over twice that recorded for young people with Type 1 diabetes (10.3%) – indicating that children and young people with Type 2 diabetes are at greater risk of kidney disease.
- A small number (3.5%) of young people with Type 2 diabetes aged 12 years and above had an abnormal retinopathy screening result. The rate of retinopathy found amongst young people with Type 1 diabetes was 16.9% by comparison.



### 8.3.5 Macrovascular complications and risk factors

- Half (49.3%) of children and young people with Type 2 diabetes had high blood pressure
- Almost a third (28.0%) met or exceeded the higher target for total blood cholesterol ( $\geq 5$  mmol/l).
- The majority (84.6%) of those with Type 2 diabetes were obese.



### 8.3.6 Outcomes of psychological assessment

- Over half (59.5%) of children and young people with Type 2 diabetes were assessed as requiring additional psychological support.



### 8.3.7 Treatment regimen

- A tenth (11.4%) of children and young people with Type 2 diabetes were managing their diabetes through diet alone, and half (48.1%) were using dietary management in combination with blood glucose lowering medication.
- A fifth (23.2%) were using insulin injections with other blood glucose lowering medication.

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

## 9.1 Reviewing results

Figure 1: Radar plot showing unit, region and national performance on the six key health checks, % achieving an HbA1c of below 58 mmol/mol and % achieving an HbA1c of below 80 mmol/mol

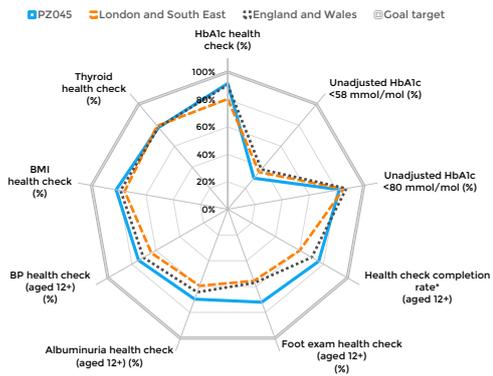
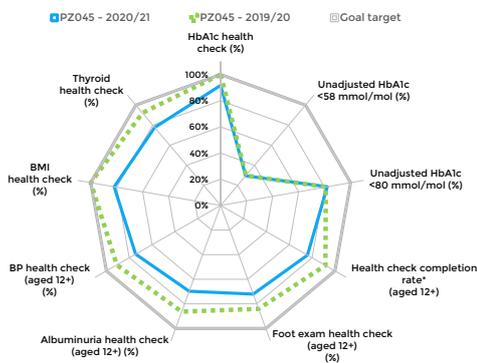


Figure 2: Radar plot showing unit performance in 2019/20 and 2020/21 on the six key health checks, % achieving an HbA1c of below 58 mmol/mol and % achieving an HbA1c of below 80 mmol/mol



This section includes a summary of the additional recommended health check data collected by the NPDA.

Figure 11: Percentage of children and young people with Type 1 diabetes with a complete year of care who received additional health checks

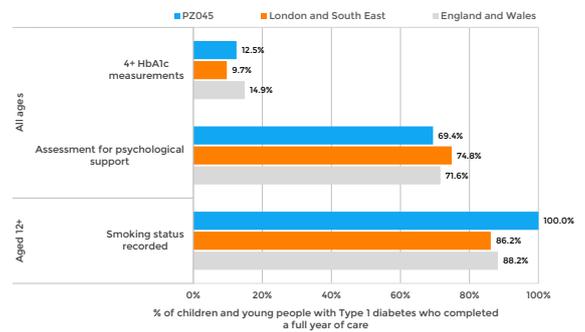
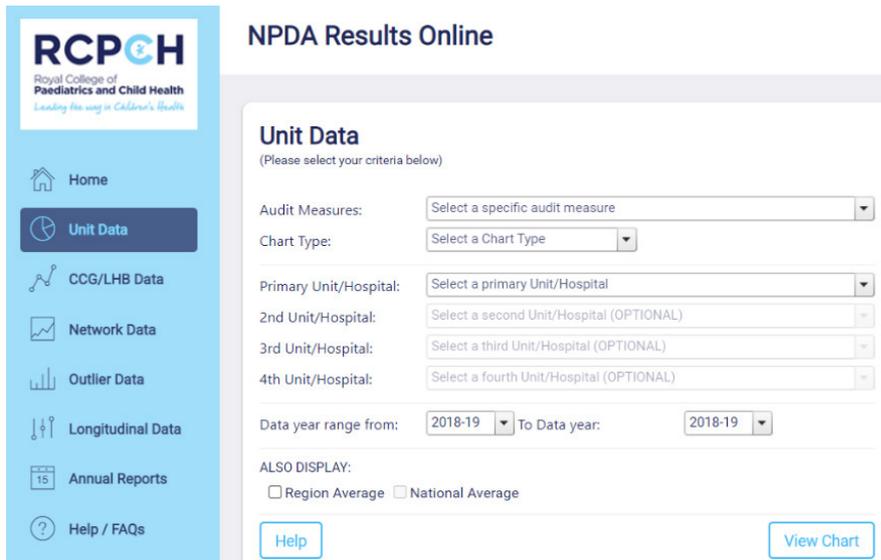


Figure 12: Percentage of children and young people with Type 1 diabetes with a complete year of care who were offered an additional dietetic appointment, who attended an additional dietetic appointment, and the proportion who were offered and subsequently attended an appointment (take-up rate)



\*When interpreting this result, please note that a low take-up rate is not reflective of underperformance on this metric. Patients may choose not to take up or attend the additional dietetic appointment offered to them, if they feel the dietetic support they are already receiving is sufficient for their needs.

- Comprehensive [PDU level reports](#) 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, [NPDA Results Online](#). Results for specific measures can be compared across each reporting level, and between audit years.
- The NPDA also provides [Excel files](#) of each audit years results presented at PDU, regional, CCG, and STP level on the NPDA website.

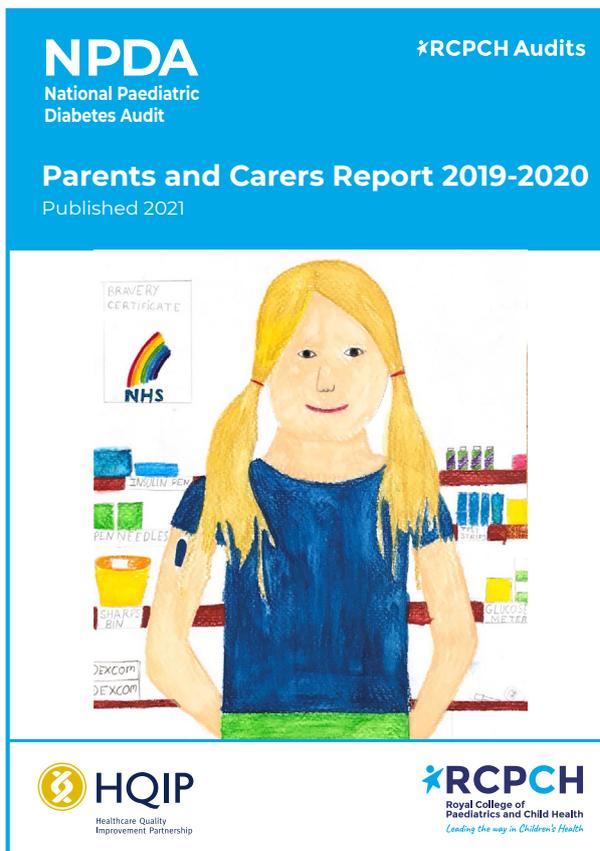
## 9.2 Communicating results and planning improvements as a team

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.

## 9.3 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 [clinic posters](#) showing PDU performance against key audit measures and national and regional results.
- [Animations](#) explaining the function of the audit, and key results and messages arising from the audit.



## 9.4 Other NPDA publications

In addition to the core annual report on health checks and outcomes of children and young people with diabetes, the NPDA has also produced a range of reports on other aspects of paediatric diabetes care including:

- In depth [spotlight reports](#) on the:
  - Care and outcomes of children and young people with Type 2 diabetes
  - The workforce in paediatric diabetes units
  - Use of diabetes related technologies in children and young people with diabetes
- [Patient and parent experience](#)
- [Diabetes related hospital admissions](#)

## 10. Conclusion

The 2020/21 audit year was unprecedented in terms of increased incidence of Type 1 diabetes, and in terms of the impact of the COVID-19 pandemic on routine paediatric diabetes care. This impact is seen in the lower rates of health check completion, and the smaller numbers of children and young people diagnosed with Type 1 diabetes in 2020/21 starting insulin pump therapy in this audit year.

However, despite the unique pressures and restrictions faced by PDUs in 2020/21, there is much to celebrate in this report. Whilst the trend for year on year improvements in health check completion seen in previous audit years was reversed, the trend for lower year on year national median HbA1c amongst children and young people with diabetes continued; and whilst inequalities in use of insulin pump and real time continuous glucose monitors persisted, there is evidence that the gaps in use between different ethnic groups and those living in the least and most deprived areas is closing.

It must also be celebrated that every single PDU in England and Wales participated in the NPDA for this year despite the challenges associated with delivering, recording and submitting details of care provided, and with participation not mandated during this period. This commitment to data driven improvement amongst the paediatric diabetes clinical community has made this report possible, which now must provide an impetus to reset, restore and recover excellent service to all children and young people with diabetes and their families.

# 11. Glossary

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

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

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

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

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

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

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

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

**HbA1c (Glycated haemoglobin)** – The term HbA1c refers to glycated haemoglobin. By measuring glycated haemoglobin (HbA1c), 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 HbA1c, 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.

## 12. Acknowledgements

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