

National Paediatric Diabetes Audit

Parent and Carers Report 2015-16

Commissioned by the
Healthcare Quality Improvement Partnership

Managed by the
Royal College of Paediatrics and Child Health



National Paediatric Diabetes Audit: Parent and Carers Report

Diabetes mellitus (diabetes) is a condition where the amount of glucose in your blood is too high because the body cannot use it properly.

Type 1 diabetes affects around 2 per 1000 children in England and Wales (in 2015-16 there were just over 2800 new cases).

96% of children and young people with diabetes have **Type 1** diabetes, whereas 4% have **Type 2** diabetes or other rare forms of diabetes.

Overview

The **National Paediatric Diabetes Audit (NPDA)** is performed annually in England and Wales. The clinic that you attend is asked to submit information about your child's diabetes care. The sole aim is to provide information that leads to improved quality of care for those children and young people affected by diabetes.

This report provides a summary for parents and carers of the findings of two national reports produced by the NPDA this year.

The **NPDA Care Processes (healthcare checks) and Outcomes report** looks at whether children and young people are receiving the recommended diabetes-related health checks, how many are reaching blood glucose targets, and how many have developed or are at greater risk of developing diabetes-related complications.

The **NPDA Hospital Admissions report** describes the numbers and reasons behind diabetes-related hospital admissions, and is produced every three years.



National Paediatric Diabetes Audit: Health checks 2015-16

This section summarises the key findings from the NPDA Care Processes and Outcomes report, which looked at the quality of care received by children and young people with diabetes in all clinics in England and Wales, and their outcomes.

The audit is useful for parents and carers as it provides information about the key healthcare checks that your child should receive and important information about clinic outcomes such as average HbA1c.

In 2016, 173 diabetes clinics in England and Wales were audited, with information provided for over 28,400 children and young people under 25 years-old.

Type 1 diabetes

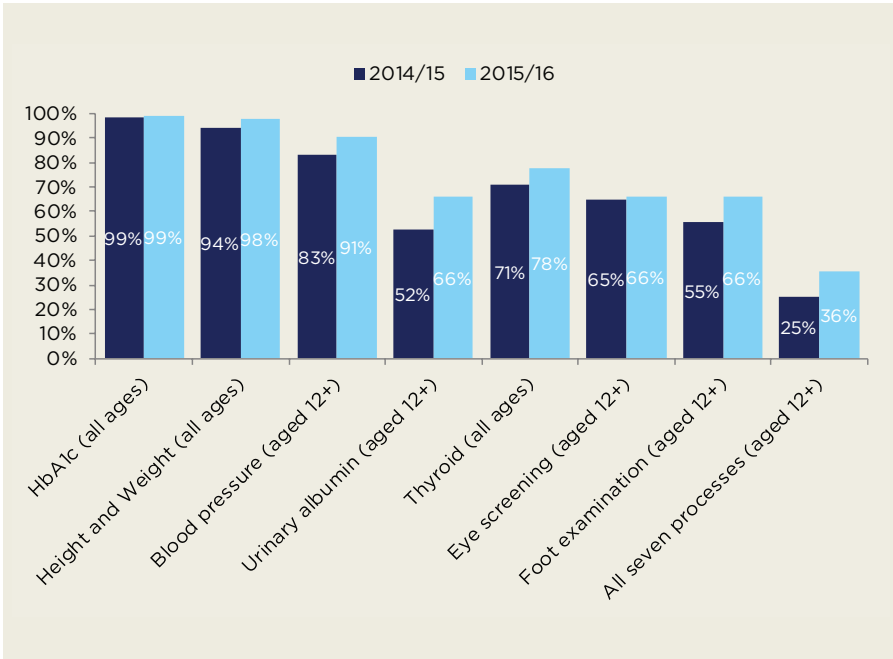
Completion of health checks

The NPDA investigated how many children and young people with Type 1 diabetes received the key health checks in this audit year (2015-16) which include the following:

1. **HbA1c** (a measure of blood glucose levels)
2. **Height and weight** (a check for healthy growth)
3. **Blood pressure** – a check for hypertension (high blood pressure)
4. **Urinary albumin** – a check for kidney damage
5. **Thyroid** – a check for thyroid function (thyroid disease)
6. **Eye screening** – a check for eye disease (retinopathy)
7. **Foot examination** – a check for damage to nerves or blood vessels (neuropathy)



The percentages of children and young people with diabetes in England and Wales who received each key health check are shown below:



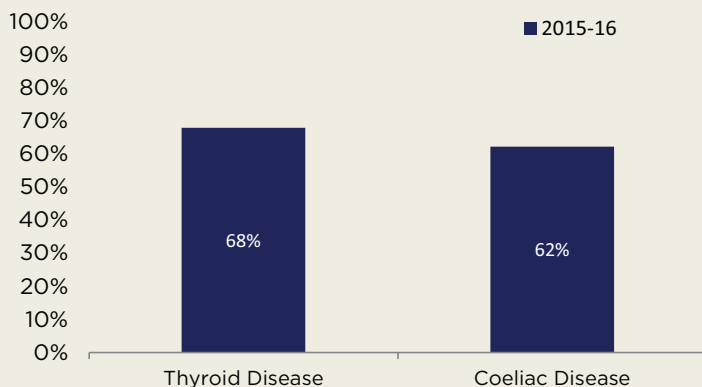
This is an encouraging improvement in the numbers completing the checks from 2014-15 to 2015-16. These checks are important to detect any problems associated with diabetes and to provide advice if anything is detected.

Ask your diabetes clinic about your child receiving these key health checks. It is extremely important that you attend your clinic to have these checks recorded.

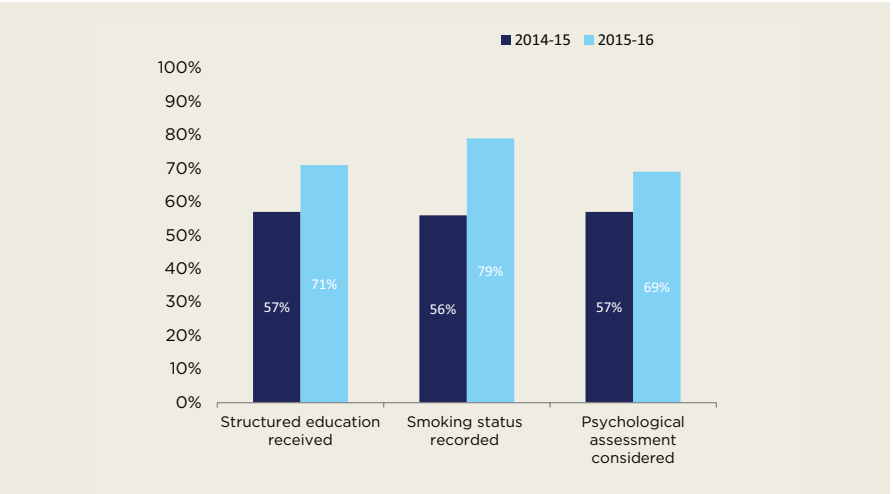
There are **further important checks** your clinic should perform which include:

1. **Thyroid** (annually) and **Coeliac disease** screening at diagnosis of Type 1 diabetes.
2. **Asking about smoking** is important so that support for reducing or quitting smoking can be offered if necessary.
3. **A psychological screening assessment** since problems such as depression and eating disorders are more common.
4. **The availability of a structured education programme** to help children, young people and their parents to look after the diabetes confidently.

Percentages of children and young people who received screening for thyroid and coeliac disease at diagnosis of Type 1 diabetes in 2015-2016:



Percentages of children and young people with Type 1 diabetes receiving other checks in 2015-16 compared to 2014-15:



What does this mean?

- ✧ Not all children and young people with diabetes are being checked every year for the warning signs associated with the risk of developing diabetes complications.
- ✧ Parents and carers should ask their diabetes team about their child's completion of the key health checks as part of an annual assessment. Finding problems early can reduce the risk of further complications later.
- ✧ Parents and carers should ask their clinic for age-appropriate, structured education to support their child's management of their diabetes if they have not been offered this.

HbA1c

HbA1c

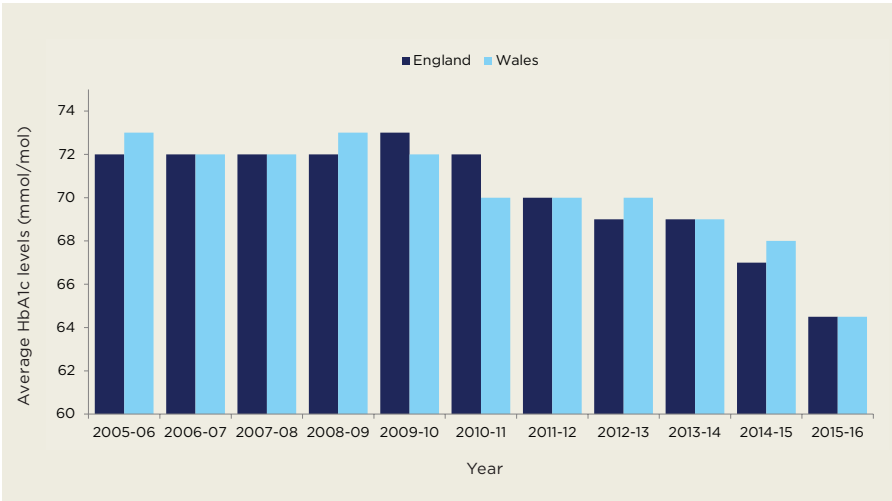
- ✧ HbA1c is an indicator of blood glucose levels over the preceding six to eight weeks.
- ✧ It is recommended that people with Type 1 diabetes should aim for a target HbA1c of **48 mmol/mol (6.5%)** or lower
- ✧ An HbA1c level above **75 mmol/mol (9%)** is considered to show very high blood glucose levels, and is associated with an increased risk of developing diabetes-related complications.

A number of factors play a part in **improving and maintaining good HbA1c levels**, including:

- **regular testing** of blood glucose,
- keeping a **routine, carbohydrate counting** and adjusting **insulin doses**,
- exercise and continued diabetes **education**.



The national average HbA1c has fallen over recent years for children and young people with all types of diabetes, demonstrating improved management of diabetes:



This is good news and a credit to all the hard work that has been carried out to drive improvements in diabetes care in children and young people over the last six years.

However, **there is variability across different clinics and networks** with some achieving better HbA1c than others. **Higher average HbA1c levels were also found amongst older children and those living in more socially deprived areas of the country.**

More information about these differences can be found in the main NPDA 2015-16 report or in the individual paediatric diabetes clinic reports, available on the NPDA website:

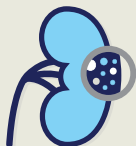
www.rcpch.ac.uk/npda.

Complications of Type 1 diabetes



Eye disease

Early signs of increased risk of blindness were found in **13.8%** of young people (12 years and over).



Albuminuria

(warning sign for kidney disease)

Found in **9.7%** of young people (12 years and over).



Smoking

3.1% of children and young people who were asked said they were a smoker.



High cholesterol

Found in **21.8%** of young people (12 years and over).



High blood pressure

Found in **26.3%** of young people (12 years and over).



Overweight

16.5% of 0-11 year olds and **20.8%** of those aged 12 and above were found to be overweight.



HbA1c

6.5% of children and young people had an HbA1c level below 48 mmol/mol and **24.5%** had a level exceeding 75 mmol/mol.

What does this mean?

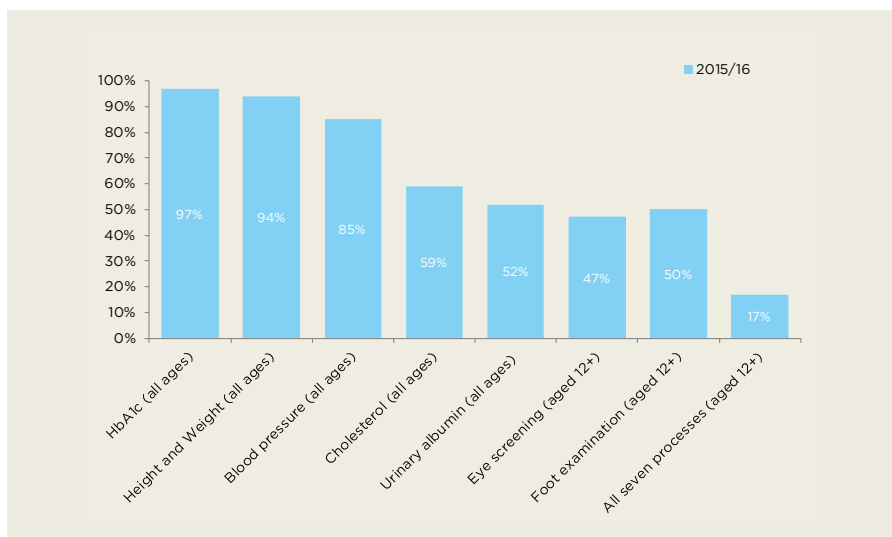
- ✧ Children and young people with diabetes and their families need to ensure optimal blood glucose levels to reduce the risk of developing complications.
- ✧ Parents and carers should speak to their diabetes clinic about the results of the screening investigations and discuss plans to reduce the risk of developing complications.



Type 2 diabetes

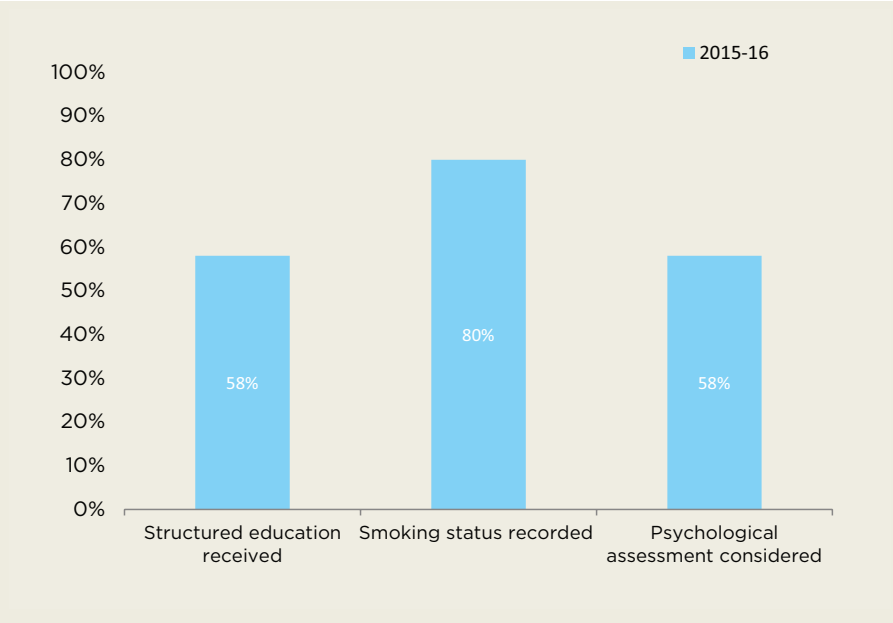
Completion of health checks

The percentages of children and young people with Type 2 diabetes in England and Wales who received each key health check in 2015-16 are shown below:



Completion of other health checks

The percentage of children and young people with Type 2 diabetes that are receiving other health checks are shown below:



HbA1c

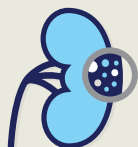
The average HbA1c level in children and young people with Type 2 diabetes was **51 mmol/mol** compared to **65 mmol/mol** for those with Type 1.

Complications for Type 2 diabetes



Eye disease

Early signs of increased risk of blindness were found in **5.4%** of young people (12 years and over).



Albuminuria

(warning sign for kidney disease)

Found in **14.5%** of young people (12 years and over).



Smoking

2.1% of children and young people who were asked said they were a smoker.



High cholesterol

Found in **26%** of young people (12 years and over).



High blood pressure

Found in **40.4%** of young people (12 years and over).



Overweight

78.5% of children and young people were found to be overweight.



Foot examination

Foot complications are not recorded by the NPDA but **50%** of young people had their feet checked.

Key conclusions

- ✧ There have been significant improvements in the care of children and young people with diabetes, as demonstrated by increased completion of health checks and improved national average HbA1c
- ✧ Parents and carers of children and young people with diabetes should talk to their diabetes clinics about receiving and discussing the results of healthcare checks, suitable for their age.
- ✧ Parents and carers should work with their diabetes team to achieve the best HbA1c level possible for their child by aiming for blood glucose levels within targets set by their clinic.
- ✧ Ongoing support for children and young people with diabetes is important. This should include structured educational packages, psychological assessment and ongoing support, and blood glucose target setting to reduce the risk of long term complications.

Further NPDA reading

Please visit www.rcpch.ac.uk/npda to view or download:

- The full national NPDA report for 2015-16
- Individual reports summarizing the performance of each paediatric diabetes unit participating in the audit
- Individual Patient and Parent Experience Measure (PREM) reports for all participating units. These include feedback from patients and patients about their experiences of using these services.

National Paediatric Diabetes Audit: Hospital Admissions Report 2012-2015

This section summarises the key findings from the NPDA Hospital Admissions report, which looked at the **numbers and reasons behind diabetes-related hospital admissions between April 2012-March 2015**.

The results are based on information about admissions collected by your local hospital and diabetes team.

The report focused on:

- **Diabetic Ketoacidosis (DKA)**
- **Hypoglycaemia**
- **Other admissions not related to DKA or hypoglycaemia.**

What are DKA, Hypoglycaemia and Other diabetes-related causes?

DKA results from lack of insulin which leads to the development of ketones causing acidosis. It is often associated with high blood glucose levels as the body cannot use glucose when insulin levels are low.

Hypoglycaemia means 'low blood glucose levels' – less than **4 mmol/l**. This is too low to provide enough energy for your body's activities.

Summary of key findings for all hospital admissions in children and young people with all types of diabetes

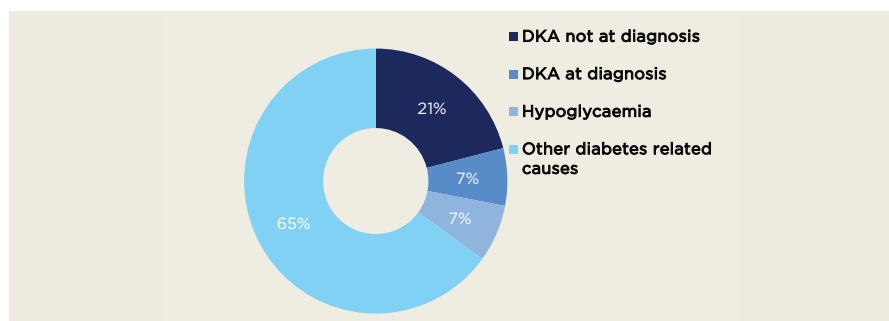
There were 30,714 diabetes-related admissions of children and young people between 2012 and 2015

- The rate of diabetes-related admissions across three audit years was stable, and did not decrease despite national improvements in diabetes control and increased completion of health checks seen over the past few years
- Certain patient groups had higher rates of admission including females, those in their teenage years and those living in a deprived area.

Hospital admissions in children and young people with Type 1 diabetes

Nearly 1/4 of all children and young people with Type 1 diabetes were admitted for diabetes-related reasons at least once within each audit year between 2012 and 2015.

The cause of these admissions throughout the three audit years for England and Wales were:



DKA among children and young people with Type 1 diabetes

DKA at diagnosis occurred in **23% of new cases of Type 1 diabetes** throughout the audit period.

For those admitted with **DKA not associated with diagnosis of diabetes**:

- Those with an HbA1c over **80mmol/mol** were 12 times more likely to have a DKA admission compared to those with an HbA1c below **58mmol/mol**.
- There was a small increased risk of admission for DKA for those on insulin pump therapy. Knowledge of this is important as insulin pump usage increases. This should be discussed with your care provider at the beginning of pump therapy.

Hypoglycaemia admissions among children and young people with Type 1 diabetes

- About **2%** of all children and young people with Type 1 diabetes had an admission with hypoglycaemia.
- There was an increased risk of admission for those with an HbA1c between **58 – 80 mmol/mol** compared to those less than **58 mmol/mol**.
- Children and young people living in the least deprived areas have a lower risk of admission with hypoglycaemia compared to those in the most deprived areas.

Other diabetes-related admissions among children and young people with Type 1 diabetes

- Around **65%** of all diabetes-related admissions of children and young people were for 'other diabetes related causes', with roughly half of these being for stabilisation of diabetes.



Who is most at risk of admission?

There are many factors that affect the rates of admission. In order to separate out the impact of each of these, a statistical test was applied to find out which were associated with higher risk. The table below shows which patient factors were found to increase the risk of admission for DKA not at diagnosis, hypoglycaemia, and other diabetes-related causes amongst children and young people with Type 1 diabetes.

Characteristics	DKA not at diagnosis	Hypoglycaemia	Other diabetes admissions
Females compared to males	✱		✱
Those living in deprived areas compared to those in the least deprived areas	✱	✱	✱
Those aged under 5 years of age	✱	✱	
Those aged over 5 years of age			✱
Those with HbA1c above 80 mmol/mol)	✱	✱	✱
Those with increased duration of diabetes (more than one year)	✱	✱	✱
Those using insulin pumps compared to those on insulin injections	✱		✱

Your diabetes clinic can help you avoid admissions by:

- ✧ Providing self-management education during times of illness ('sick day rules') and avoiding or treating hypoglycaemia.
- ✧ Providing 24-hour access to specialist diabetes advice.
- ✧ Providing an individualised care plan to achieve the best possible HbA1c.

Check your clinic's performance

The NPDA has developed an online reporting tool - **NPDA Results Online** - to make it easier for parents, young people with diabetes and clinicians to compare the care provided by their clinic to others in the region or country.

NPDA Results Online allows users to:

- ✧ View and download an annual summary report for their clinic.
- ✧ View and compare the results for specific NPDA audit measures such as HbA1c outcomes, Eye Screening completion and Structured Education provision.

Access data from your clinic

Visit the NPDA results website:

<http://npda-results.rcpch.ac.uk>

The logo for the Royal College of Paediatrics and Child Health (RCPCH). It features the letters 'RCPCH' in a bold, sans-serif font. The 'C' is stylized with a blue circle around it, containing a white silhouette of a child running.

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Home



Annual Reports



Unit Data



CCG/LHB Data



Network Data



Outlier Data



Help / FAQs

The homepage has background information about the NPDA and access to the National Report.

Annual reports are available for all clinics from 2014-15 to 2015-16 .

Performance against individual audit measures can be viewed from 2014-15 to 2015-16 for individual clinics, regions and CCGs/LHBs.

You can view how your care provider performs against others.

For more information on how to use NPDA Results Online please visit the NPDA website where you can download a user-guide.

Glossary

- **Body Mass Index (BMI)**
A measure of someone's size based on their weight and height. It is used to determine if someone is a healthy weight for their height.
- **Cholesterol**
A fatty substance which is vital for the normal functioning of the body. Excessively high levels of cholesterol can have an effect on health.
- **Coeliac disease**
An autoimmune disease (meaning that the immune system mistakenly attacks healthy tissue in the body) caused by the gut's reaction to gluten.
- **Glucose**
A blood sugar which acts as a major source of energy for the body.
- **Healthcare Quality Improvement Partnership (HQIP)**
An independent established organisation to promote quality in healthcare, to increase the impact that clinical audit has on healthcare quality improvement.
- **Key healthcare checks**
These are the various measures that health care professionals should take as part of looking after those with diabetes.
- **Ketones**
Poisonous chemicals produced when the body breaks down fat for energy instead of glucose due to a lack of insulin.

- **NICE**

The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care.

- **Structured Education Programme**

A programme of self-management education, tailored to the child or young person's and their family's needs, both at the time of 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 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.

Other resources

If you have questions about you or your child's care please speak to your healthcare provider and diabetes team.

More information about diabetes management, support and clinical audit can be found at the following websites:

- The Association of UK Dieticians: **www.bda.uk.com**
- Children with Diabetes: **www.childrenwithdiabetesuk.org**
- Children and Young People's Diabetes Network: **www.cypdiabetesnetwork.nhs.uk**
- Diabetes (type 1 and type 2) in children and young people: diagnosis and management: **<https://www.nice.org.uk/guidance/ng18>**
- Diabetes UK: **www.diabetes.org.uk**
- Families with Diabetes: **www.familieswithdiabetes.co.uk**
- Health Quality Improvement Partnership: **www.hqip.org.uk**
- Juvenile Diabetes Research Foundation: **www.jdrf.org.uk**
- Type 1 diabetes education: **www.type1diabetestraining.co.uk**
- Young person's diabetic support service: **www.upbete.co.uk**
- NHS Digital: **www.digital.nhs.uk**
- Association of Children's Diabetes Clinicians: **www.a-c-d-c.org**

Fair processing

Written consent is not required for submission of patient data to the audit, however patients have the ability to opt out of having their data submitted and should speak to their diabetes team if they do not want to be included.

Disclaimer

All images within this report are being used for illustrative purposes only. Any person depicted in the content is a model, has no affiliation or connection with the RCPCH, or any aspect of physical healthcare.

Notes

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