

# NPDA

National Paediatric  
Diabetes Audit

 **RCPCH Audits**

## Parents and Carers Report 2016-2017

**Published 2018**



**HQIP**

Healthcare Quality  
Improvement Partnership

 **RCPCH**

Royal College of  
Paediatrics and Child Health  
*Leading the way in Children's Health*

# Parents 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 2016-17 there were just over 2800 new diagnoses).

Just over 95% of children and young people with diabetes have Type 1 diabetes, and 5% have Type 2 diabetes or other rare forms of diabetes.

# Overview



The National Paediatric Diabetes Audit (NPDA) takes place annually in England and Wales.

The clinic that you attend is asked to submit information about the care they provide to all of their patients to the NPDA. The aim is to provide information that leads to improved quality of care for those children and young people affected by diabetes.

The NPDA publish a report every year about the information they receive from clinics. This booklet provides a summary for parents and carers of the findings from the 2016-2017 audit year. It looks at whether children and young people were receiving the recommended diabetes-related health checks, how many had developed or were at greater risk of developing diabetes-related complications, and how many were reaching blood glucose targets.

On page 28, you will find a glossary of key words and terms used in diabetes care. These words and terms have been used within the report, so you may find it helpful to browse through the glossary if you come across anything in the report that you are unfamiliar with. In general, the terms used are ones you will have already come across.

# Health checks 2016-17



The NPDA 'Care Processes and Outcomes' Report 2016-2017 provides information about the key health checks that your child should receive.

In 2017, 173 paediatric diabetes clinics in England and Wales were audited, with information provided for over 29,100 children and young people under 25 years-old with diabetes.

# What care should my child receive?

There are several health checks that the National Institute for Health and Care Excellence (NICE) guidance recommends should be performed at least once annually for children and young people with diabetes.

## Type 1

The NPDA describes seven of these to be 'key' annual checks for children and young people with Type 1 diabetes in the report:

Health Check	When?
<b>HbA1c</b> A measure of blood glucose levels	At diagnosis, then every three months*
<b>Height and weight (BMI)</b> A check for healthy growth	At diagnosis, then every three months*
<b>Blood pressure</b> A check for high blood pressure	At 12 years-old, then annually*
<b>Urinary albumin</b> A check for kidney damage	At 12 years-old, then annually*
<b>Thyroid</b> A check for thyroid disease	At diagnosis, then annually*
<b>Eye screening</b> A check for eye disease	At 12 years-old, then annually*
<b>Foot examination</b> A check for damage to nerves or blood vessels	At 12 years-old, then annually*

## Type 2

The NPDA describes the following as key health checks for Type 2 diabetes in the report:

Health Check	When?
<b>HbA1c</b> A measure of blood glucose levels	At diagnosis, then every three months*
<b>Height and weight (BMI)</b> A check for healthy growth	At diagnosis, then every three months*
<b>Blood pressure</b> A check for high blood pressure	At diagnosis, then annually*
<b>Urinary albumin</b> A check for kidney damage	At diagnosis, then annually*
<b>Thyroid</b> A check for thyroid disease	At diagnosis, then annually*
<b>Eye screening</b> A check for eye disease	At 12 years-old, then annually*
<b>Foot examination</b> A check for damage to nerves or blood vessels	At 12 years-old, then annually*

**\*Your diabetes clinic may choose to do this check more often or start screening at a younger age.**



In addition to the seven key health checks, your clinic should also:

- **Screen for coeliac disease** at diagnosis, as children and young people with Type 1 diabetes have higher rates of this autoimmune disease.

*Type 1*

- **Ask about smoking**, so that support for reducing or quitting smoking can be offered if necessary.

*Type 1 & Type 2*

- **Complete a psychological screening assessment** since problems such as anxiety and depression can be more common in children and young people with diabetes.

*Type 1 & Type 2*

- **Offer a structured education programme** to help children, young people and their parents and carers, to manage their diabetes confidently.

*Type 1 & Type 2*

The next audit (2017-18) will report on a wider range of other health checks and specialist appointments that your clinic should provide.

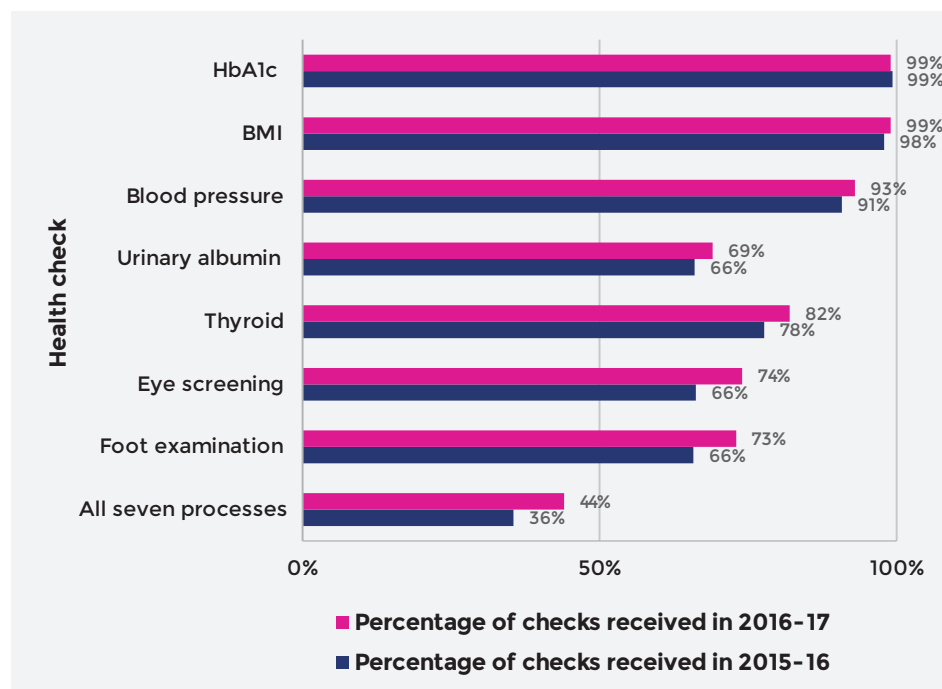


# Completion of health checks

## Type 1 diabetes

The NPDA investigated how many children and young people with Type 1 diabetes received their seven key health checks (as described on page 5).

The percentages of children and young people with Type 1 diabetes in England and Wales who received each key health check in this audit year (2016-17) are shown below, with the results from 2015-16 for comparison:





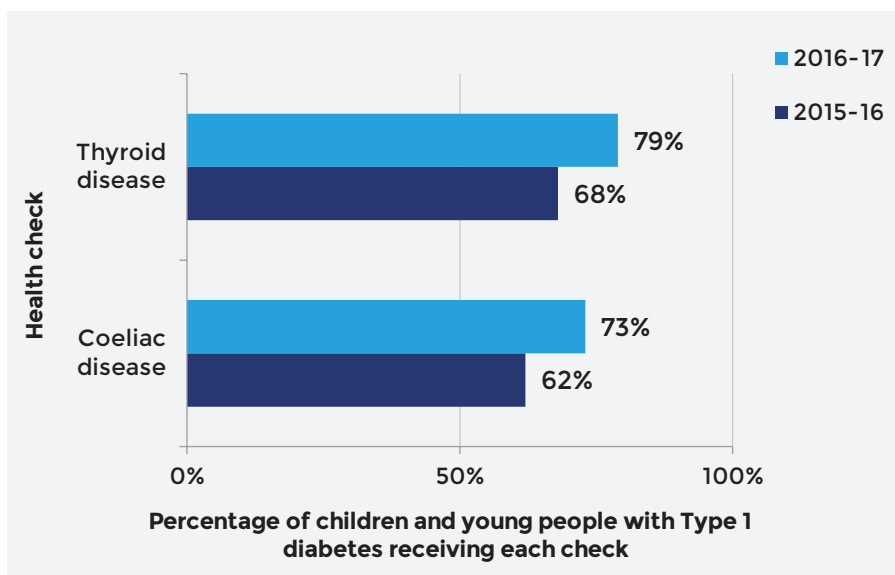
There is improvement in numbers of completed checks between 2015-16 to 2016-17. These checks are important to detect any problems associated with diabetes so that advice can be provided if anything is detected.

Ask your diabetes clinic about your child receiving these key health checks. It is also important that the results of these checks are recorded by your clinic and submitted to the NPDA, otherwise no one will know if they have been done.

## Other checks

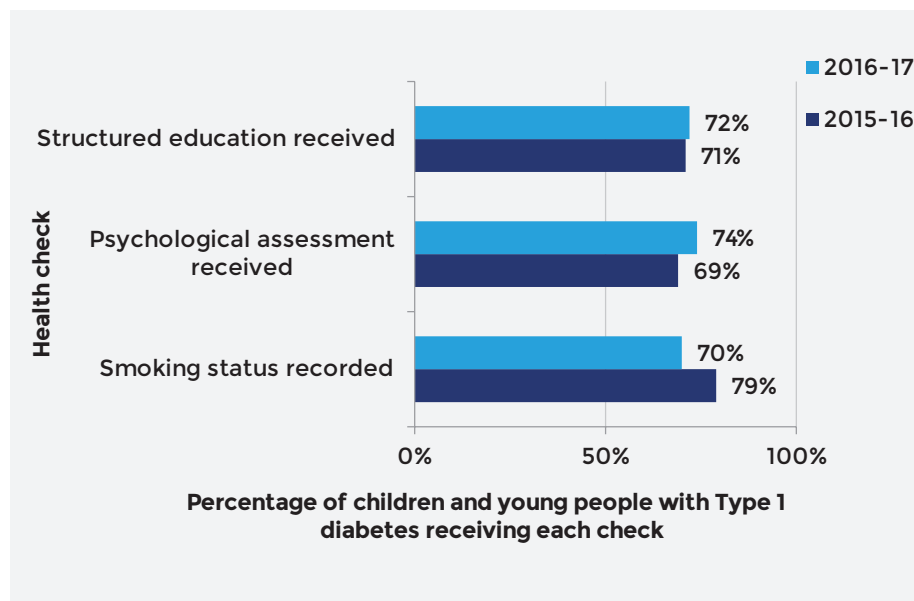
### Thyroid and coeliac disease

Around three-quarters of children and young people newly diagnosed with Type 1 diabetes received screening for thyroid and coeliac disease in 2016-17 to see if they also had these associated autoimmune conditions. Results from 2015-16 are shown for comparison.



## Smoking, psychological screening and structured education

Percentages of children and young people with Type 1 diabetes receiving structured education, psychological and smoking checks in 2016-17 compared to 2015-16 are shown below:



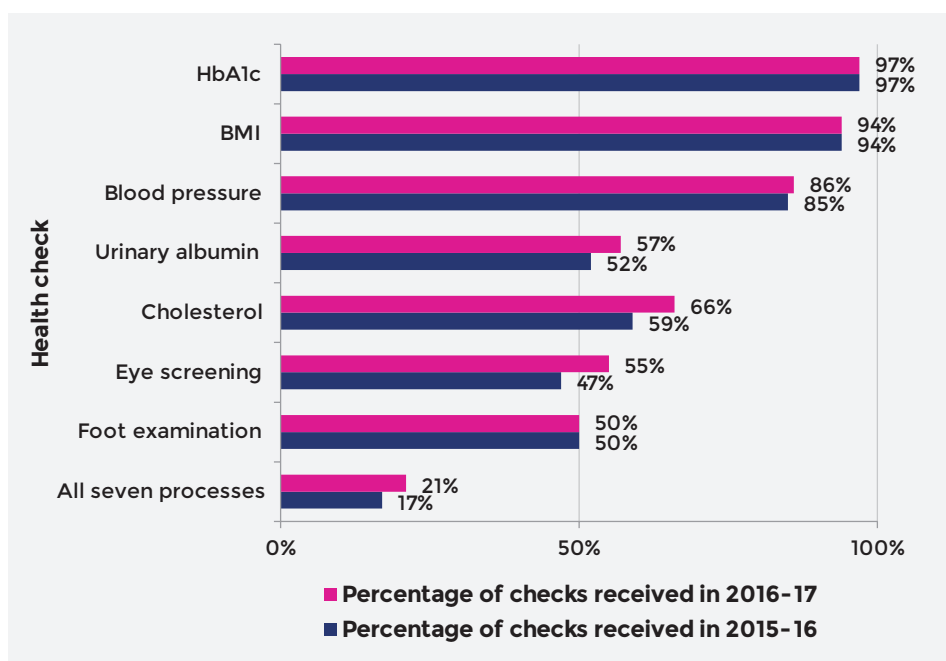
# Completion of health checks

## Type 2 diabetes

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The NPDA investigated how many children and young people with Type 2 diabetes received their seven key health checks (as described on page 6).

The percentages of children and young people with Type 2 diabetes in England and Wales who received each key health check in this audit year (2016-17) are shown below, with the results from 2015-16 for comparison:

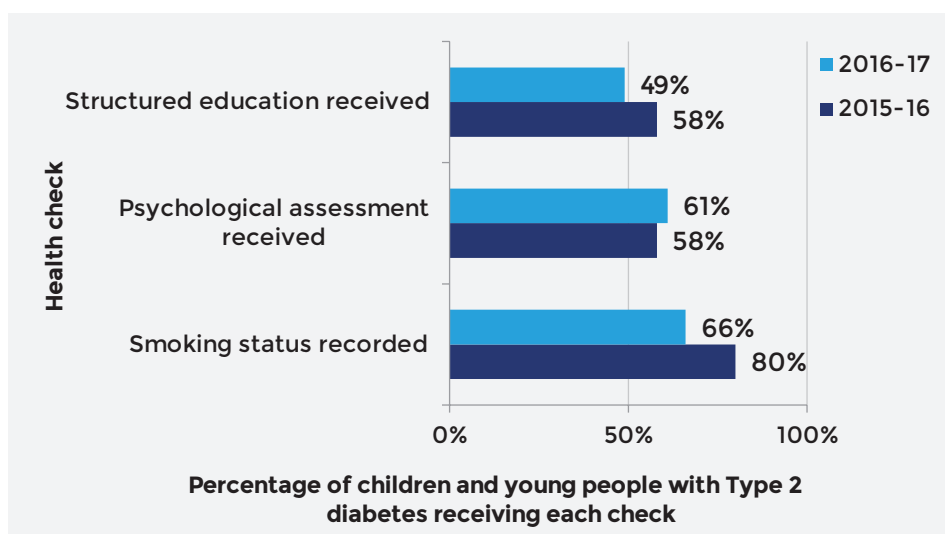


More children and young people with Type 2 diabetes are receiving the checks since 2015-16. However, completion rates are not as good as those for children and young people with Type 1 diabetes.

## Other checks

### Smoking, psychological screening and structured education

Percentages of children and young people with Type 2 diabetes receiving structured education, psychological and smoking checks in 2016-17 compared to 2015-16 are shown below:



# Completion of health checks

## Understanding the results

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Although there have been significant improvements, not all children and young people with diabetes are being checked every year for the warning signs associated with the risk of developing diabetes-related complications (see pages 18-20).

### What can I do to help?

- Ask your diabetes team about your 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.
- Ask your clinic for age-appropriate, structured education to support your child's management of their diabetes if they have not already been offered this.

### Why is it that some checks aren't completed?

There are various reasons why health checks aren't always completed. These can include:

- Parents being unable to bring their child to all their clinic appointments
- Missing annual review appointments
- Being unable to attend eye screening appointments
- Fear of blood tests
- Lack of resource and staffing within diabetes teams

These possibilities are not exhaustive and do not provide an excuse for why the tests are not done. The screening programme is part of nationally agreed guidance and essential to keep children and young people with diabetes in good health.

## How can clinics make sure everyone gets the recommended checks?

In 2014/15, only 24% of children and young people with Type 1 diabetes at West Middlesex University Hospital received all seven key health checks, but by 2016/17 nearly 100% received them. We asked Dr Jayanti Rangasami at West Middlesex University Hospital how they did it!

“

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### NPDA:

How did you improve the numbers of children and young people with Type 1 diabetes who received all seven key health checks?

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“

.....

### Dr Rangasami:

We improved our numbers by:

- Employing more staff – including administrative support, a paediatric diabetes nurse specialist, and a consultant
- Running extra clinics for patients who were at risk of not completing their health checks
- Working together as a team and regularly reviewing the status of completed health checks
- Increasing dietetic and psychology sessions

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# Outcomes - HbA1c

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HbA1c is an indicator of blood glucose levels over the six to eight weeks before the test. The HbA1c result is considered to be one of the best indicators of blood glucose levels and can predict future risk of complications from diabetes.

An HbA1c level above 80 mmol/mol (9.5%) is considered to show very high blood glucose levels and is associated with an increased risk of developing diabetes-related complications (see pages 18-20).

It is recommended that people with diabetes should aim for as low an HbA1c level as possible, with a target of 48 mmol/mol (6.5%) or lower to reduce this risk.

Low numbers of children and young people are meeting this target in England and Wales, although the numbers are increasing every year.

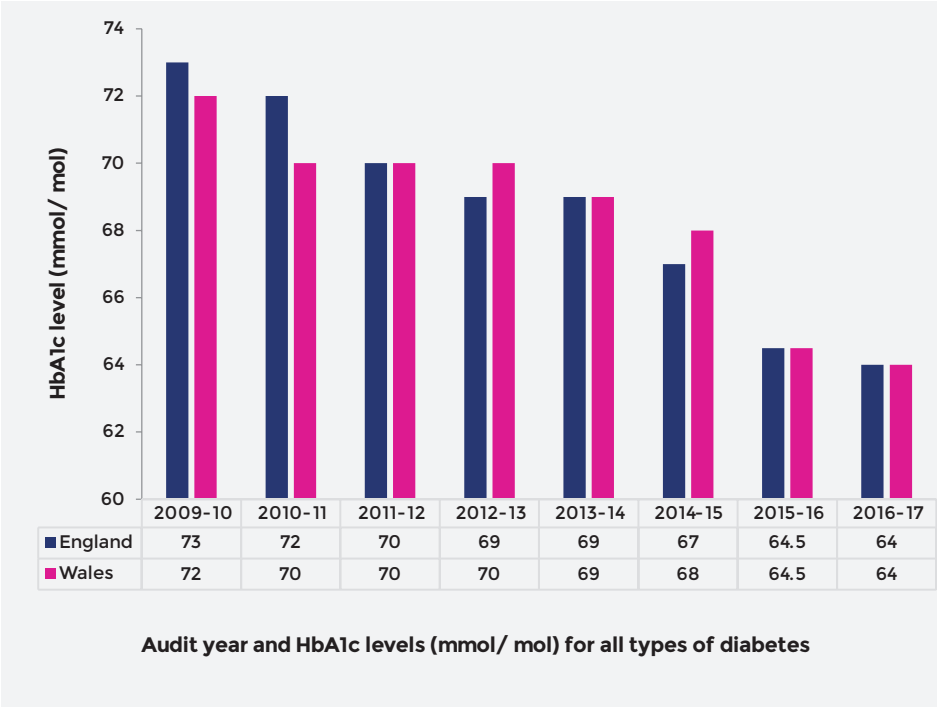
This section looks at the HbA1c results of children and young people with diabetes in 2016-17.

# HbA1c results

The average (median) HbA1c level in children and young people with Type 1 diabetes in England and Wales was 64 mmol/mol (8.0%) in 2016-17.

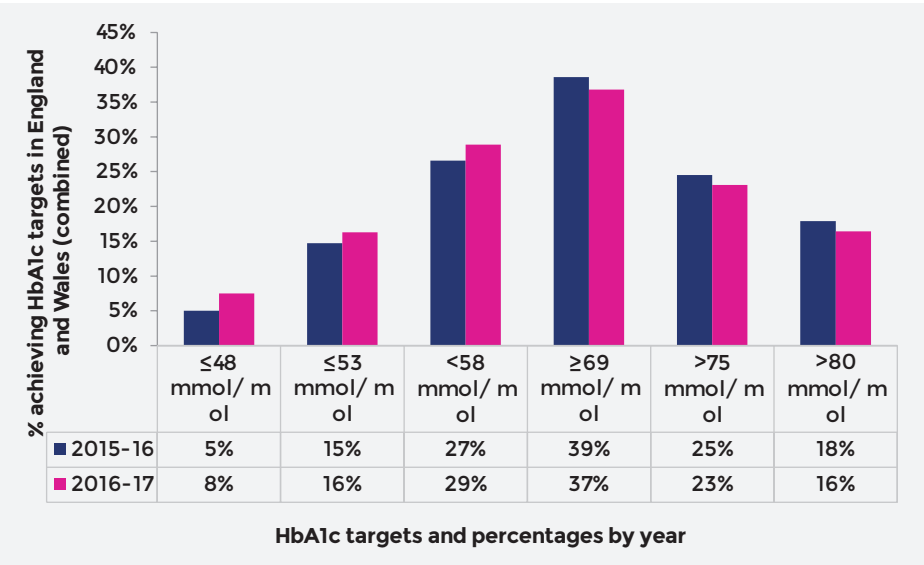
The average (median) HbA1c level in children and young people with Type 2 diabetes in England and Wales was 52 mmol/mol (6.9%) in 2016-17.

For the seventh consecutive year, there has been a fall in the average HbA1c levels for children and young people with all types of diabetes in England and Wales:





Percentages of children and young people with Type 1 diabetes achieving HbA1c targets in England and Wales in 2016-17, compared to 2015-16 are shown below.



Compared to the previous audit year, higher percentages of children and young people are achieving the lower targets, and lower percentages of children and young people are exceeding the upper values.

These graphs are examples of good news, and a credit to all the hard work that has been carried out by families and healthcare professionals to drive improvements in diabetes care in children and young people.

However, there are differences between clinics and regions, with some achieving better HbA1c than others.



# Complications of diabetes



Children and young people with diabetes are at higher risk of complications affecting their small and large blood vessels. The NPDA looks at the percentage of children and young people who have started to develop these.

In order to reduce the risk of developing diabetes-related complications it is important to aim for the lowest possible HbA1c level, eat a healthy diet, and exercise regularly. Do discuss strategies for improving HbA1c with your clinic.

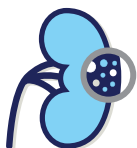
# Type 1 diabetes

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## Eye disease

Early signs of increased risk of blindness were found in 13.6% of young people (12 years and over).



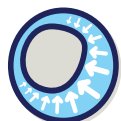
## Albuminuria (warning sign for kidney disease)

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



## Smoking

3.2% of children and young people who were asked said they were a smoker.



## High cholesterol

Found in 23% of young people (12 years and over).



## High blood pressure

Found in 25.8% of young people (12 years and over).



## Overweight

16.8% of 0-11-year olds and 18.1% of those aged 12 and above were found to be overweight.

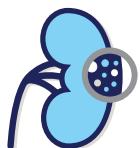
# Type 2 diabetes

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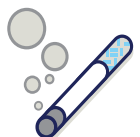
## Eye disease

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



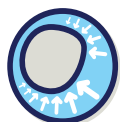
## Albuminuria (warning sign for kidney disease)

Found in 20.1% of young people (12 years and over).



## Smoking

4.5% of children and young people who were asked said they were a smoker.



## High cholesterol

Found in 36.2% of young people (12 years and over).



## High blood pressure

Found in 45.6% of young people (12 years and over).



## Overweight

78.6% of children and young people were found to be overweight.

# Insulin regimen

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In Type 1 diabetes, the pancreas has stopped making enough insulin, so insulin therapy using injections or a pump is necessary. In other types of diabetes, the body might not be making enough insulin, or the body might not be able to use the insulin properly that is produced. This can sometimes be managed by dietary changes, or tablets.

The NPDA recommends that children and young people with diabetes should be offered therapy tailored to their needs to provide the best possible management. The NPDA collects information on the insulin regimen and other diabetes treatments used in England and Wales.

# Insulin regimen

Insulin regimens include:

- **Insulin injections**  
Using a syringe or pen to inject insulin under the skin
- **Insulin pump therapy**  
Attaching a small device to the body, which continuously delivers insulin beneath the skin

Regimens for non-Type 1 diabetes include:

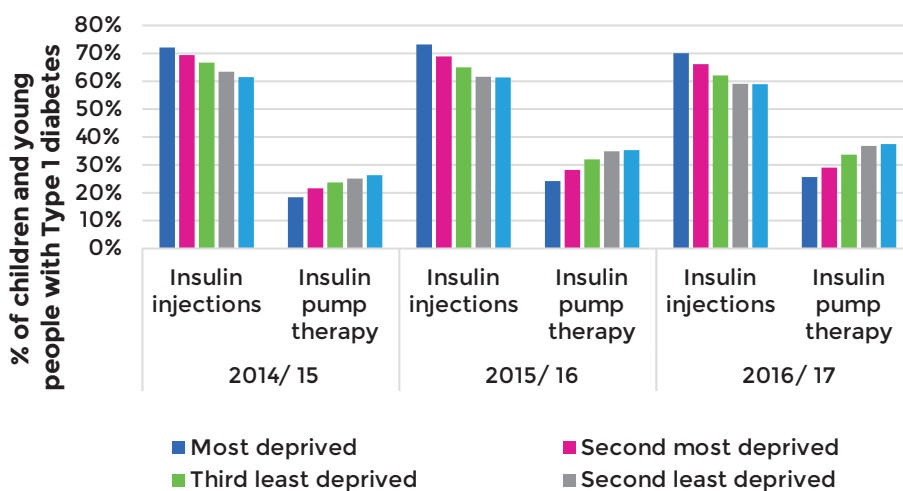
- **Oral hypoglycaemic agents, with or without insulin**  
Taking tablets to regulate insulin sensitivity, with or without insulin therapy
- **Dietary management**  
Controlling the amount of glucose in the body by eating a healthy diet

The percentages of children and young people with Type 1 and Type 2 diabetes using each regimen in 2016-17 are shown below:

	Type 1	Type 2
No insulin/dietary management	n/a	16.9%
1-3 insulin injections per day	3.4%	2.6%
4 or more insulin injections per day	60.1%	9.8%
Insulin pump therapy	32.2%	0.8%
Oral hypoglycaemic agents +/- insulin	0.5%	61%
Missing data	3.8%	8.8%

### The NPDA also found that:

- Usage of insulin pumps has increased for Type 1 diabetes across all ages since 2014-15
- Insulin pumps are more commonly used by younger children with Type 1 diabetes, females, and those living in the least deprived areas
- As shown in the graph below, inequality in pump usage is widening, with children and young people living in the least deprived areas being more likely to use a pump compared to those in the most deprived areas



# Key conclusions

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There have been significant improvements in the care of children and young people with diabetes.

This has been demonstrated by:

- A continuing decrease in national HbA1c levels
- Increases in the percentages of children and young people with diabetes receiving their recommended health checks

Parents and carers of children and young people with diabetes should:

- Talk to their diabetes clinics about receiving and discussing the results of health checks, suitable for their age
- 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 psychological assessment and ongoing support, structured educational packages, and blood glucose target setting to reduce the risk of long term complications.

**NPDA**  
**National Paediatric**  
**Diabetes Audit**



# How does the audit support improvements in diabetes care for children and young people?

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## **In the last year, the NPDA has:**

- Launched a new data submission website allowing clinic staff to enter data throughout the year. It shows them which children and young people using their service have not yet received all the recommended health checks so that they can be followed up.
- Hosted the annual NPDA conference, bringing together clinical staff from diabetes clinics all around England and Wales who shared their ideas and experiences of improving care for the children and young people using their services.
- Written to clinical leads, medical directors and chief executives from NHS trusts with a clinic where the results are not as good as others, so that support can be provided and action taken.
- Published national, regional, clinic, Clinical Commissioning Group (CCG, England only) and Local Health Board (LHB, Wales only) reports to allow comparison of diabetes care and encourage improvements.
- Started to collect examples of how diabetes clinics have made improvements in their services to share within our national report.

- Hosted a workshop with Diabetes UK to help us understand how we can support parents to use NPDA results to understand and support the care their child should be receiving.
- Shared data with researchers looking at how diabetes management can impact children's education, and with the National (adult) Diabetes Audit (NDA), to enable them to research care around transition to adult services.
- Funded the establishment of the National Children and Young People's Diabetes Quality Programme set up within the Royal College of Paediatrics and Child Health. This will involve diabetes teams around the country visiting each other to assess care quality being provided. They will share best practice, provide support, and discuss progress towards reducing HbA1c levels locally.



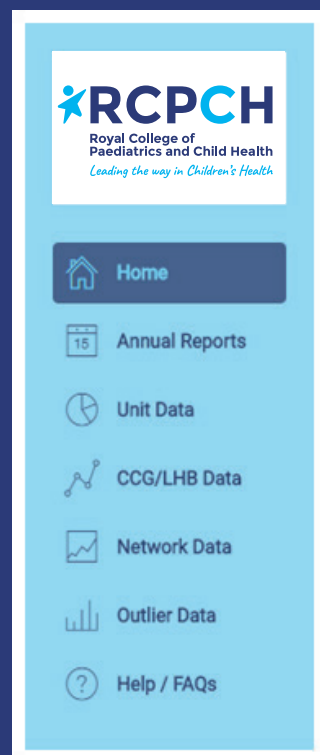
# NPDA Results Online

[www.npda-results.rcpch.ac.uk](http://www.npda-results.rcpch.ac.uk)

The NPDA has developed an online reporting tool (NPDA Results Online) to make it easier for parents and carers, 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:

- Read background information about the NPDA and access the Annual Report.
- View and download an annual summary report for their clinic. Reports are available from 2014-15 to 2016-17.
- View and compare the results for specific NPDA audit measures such as HbA1c outcomes, eye screening completion and structured education provision.
- View how your clinic or region performs against others.



# Glossary

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## **Albuminuria**

\*See Urinary albumin

## **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.

## **Care process**

A care process is an essential healthcare check that should be performed at least once per year e.g. HbA1c or height and weight check. There are some healthcare checks which only start once your child reaches 12 years such as eye screening. Please ask your clinic for further details or see pages 5 and 6.

## **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.

## **Clinical Commissioning Groups (CCGs)**

Clinical Commissioning Groups are clinically-led NHS bodies responsible for the planning and commissioning of health care services for their local area.

## **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 health checks**

These are the various measures that health care professionals should take as part of looking after those with diabetes.

## **Local Health Boards (LHBs)**

Local Health Boards are part of the National Health Service in Wales. They are responsible for planning, funding and delivering healthcare services within their local areas.

## **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 – this is known as albuminuria.

# Helpful resources

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

**Association of Children's Diabetes Clinicians:**

[www.a-c-d-c.org](http://www.a-c-d-c.org)

**Association of UK Dietitians:**

[www.bda.uk.com](http://www.bda.uk.com)

**Children with Diabetes:**

[www.childrenwithdiabetesuk.org](http://www.childrenwithdiabetesuk.org)

**Children and Young People's Diabetes Network:**

[www.cypdiabetesnetwork.nhs.uk](http://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](http://www.diabetes.org.uk)

**Health Quality Improvement Partnership:**

[www.hqip.org.uk](http://www.hqip.org.uk)

**Juvenile Diabetes Research Foundation:**

[www.jdrf.org.uk](http://www.jdrf.org.uk)

**NHS Digital:**

[www.digital.nhs.uk](http://www.digital.nhs.uk)

**Type 1 diabetes education:**

[www.type1diabetestraining.co.uk](http://www.type1diabetestraining.co.uk)

**Type 1 diabetes video platform and educational resource:**

[www.digibete.org](http://www.digibete.org)

Please visit **[www.rcpch.ac.uk/npda](http://www.rcpch.ac.uk/npda)** to view or download the full national NPDA report for 2016-17 and reports from the previous year



## 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. Find out more and view our privacy notice at:

**<https://www.rcpch.ac.uk/resources/national-paediatric-diabetes-audit-transparency-open-data>**

## 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.

# National Paediatric Diabetes Audit (NPDA) Parents and Carers Report 2016-17

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