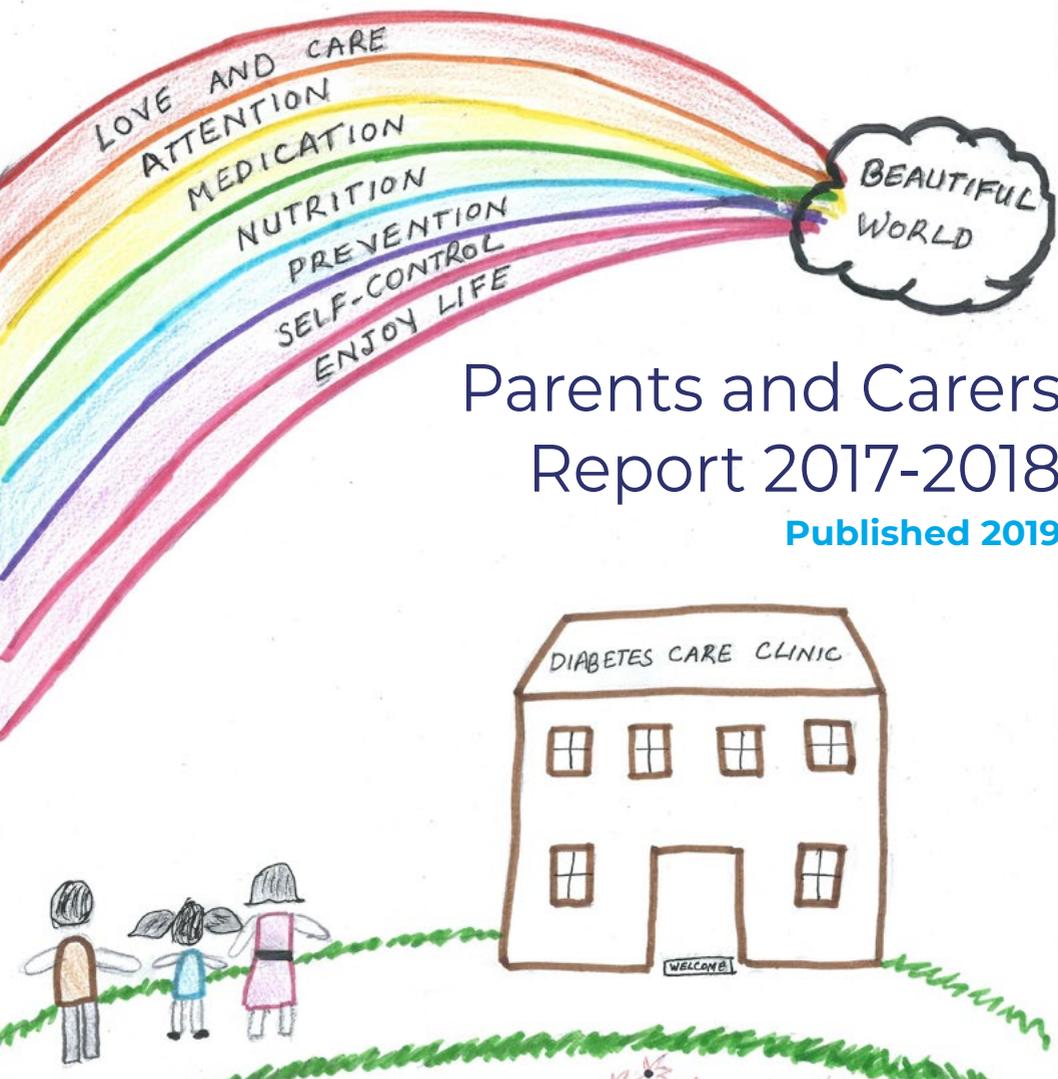


NPDA

National Paediatric
Diabetes Audit

RCPCH Audits



Parents and Carers Report 2017-2018

Published 2019



HQIP

Healthcare Quality
Improvement Partnership

RCPCH

Royal College of
Paediatrics and Child Health

Leading the way in Children's Health

Diabetes

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

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

In the 2017-18 audit year, there were just over 2800 new diagnoses of Type 1 diabetes in children and young people in England and Wales. There were just under 150 newly diagnosed children and young people with Type 2 diabetes receiving care within a paediatric diabetes clinic.

On [page 32](#), you will find a glossary of key words and terms used in this report relating to diabetes care, so you may find it helpful to browse through the glossary if you come across anything in the report that you are unfamiliar with.

Overview

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

The clinic you attend is participating in the NPDA. This means sending the NPDA team information about all the health checks for diabetes that they have carried out in the last year, and their results. The NPDA team uses this information to create reports. These reports show how clinics compare to each other on different aspects of care. They also show where national improvements in care can be made. This means that diabetes teams can work together to make any improvements needed.

In 2017-18, all 173 paediatric diabetes clinics in England and Wales took part in the NPDA, with information provided for over 29,700 children and young people attending for paediatric care.

This booklet provides a summary for parents and carers of the core annual national report, and two additional 'spotlight reports' published by the NPDA this year, based on data collected within the 2017-18 audit year:

- **The NPDA annual care processes and outcomes report (core report)**

This report looked at whether children and young people were receiving the recommended diabetes-related health checks and how many were reaching blood glucose targets. It also showed how many were at risk of developing diabetes-related complications – health problems that can occur when blood glucose levels are high for a long period of time.

- **The NPDA spotlight audit report on diabetes-related technologies**

This report looked at the use of diabetes-related technologies (insulin pumps and continuous glucose monitoring (CGM)) amongst children and young people with Type 1 diabetes across England and Wales, and highlighted differences in use, access to, and funding of such technologies.

- **The NPDA spotlight audit report on the workforce in paediatric diabetes clinics**

This report looked at staffing levels within paediatric diabetes clinics in England and Wales, how they are offering access to diabetes advice and support, and how young people are moving into adult diabetes care services.



Image by Chloe Martinelo

Health checks 2017-18

The care your child should receive

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The NPDA annual care processes and outcomes report 2017-18 provides information about the key health checks that your child should receive.

The National Institute for Health and Care Excellence (NICE) recommends several health checks which should be performed at least once annually for children and young people with diabetes. The NPDA describes seven of these to be 'key' annual checks for children and young people with Type 1 and Type 2 diabetes in the report.

The tables on the next pages describe these seven key checks for Type 1 and Type 2 diabetes, and tell you when your child should receive them.

Key health checks your child should receive

.....

My child has Type 1 diabetes

Health Check	When?
HbA1c A measure of blood glucose levels	At diagnosis, then every three months*
Height and weight, allowing for calculation of Body Mass Index (BMI) A check for healthy growth	At diagnosis, then every three months*
Blood pressure A check for high blood pressure	At 12 years-old, then annually*
Urinary albumin A check for kidney damage	At 12 years-old, then annually*
Thyroid A check for thyroid disease	At diagnosis, then annually*
Eye (retinopathy) screening A check for eye disease	At 12 years-old, then annually*
Foot examination A check for healthy feet	At 12 years-old, then annually*

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

Key health checks your child should receive

.....

My child has Type 2 diabetes

Health Check	When?
HbA1c A measure of blood glucose levels	At diagnosis, then every three months*
Height and weight, allowing for calculation of Body Mass Index (BMI) A check for healthy growth	At diagnosis, then every three months*
Blood pressure A check for high blood pressure	At diagnosis, then annually*
Urinary albumin A check for kidney damage	At diagnosis, then annually*
Cholesterol A check for cholesterol levels in the blood	At diagnosis, then annually*
Eye (retinopathy) screening A check for eye disease	At 12 years-old, then annually*
Foot examination A check for healthy feet	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:

At diagnosis:

- **Screen for thyroid and coeliac disease** within 90 days of diagnosis, as children and young people with Type 1 diabetes have a higher risk of these autoimmune conditions.
Type 1
- **Provide Level 3 carbohydrate counting education** - education in calculating the carbohydrates in meals, snacks and drinks so that the right amount of insulin can be taken - within 14 days of diagnosis, to help children, young people and their parents and carers manage diabetes effectively and confidently.
Type 1

Within the audit year:

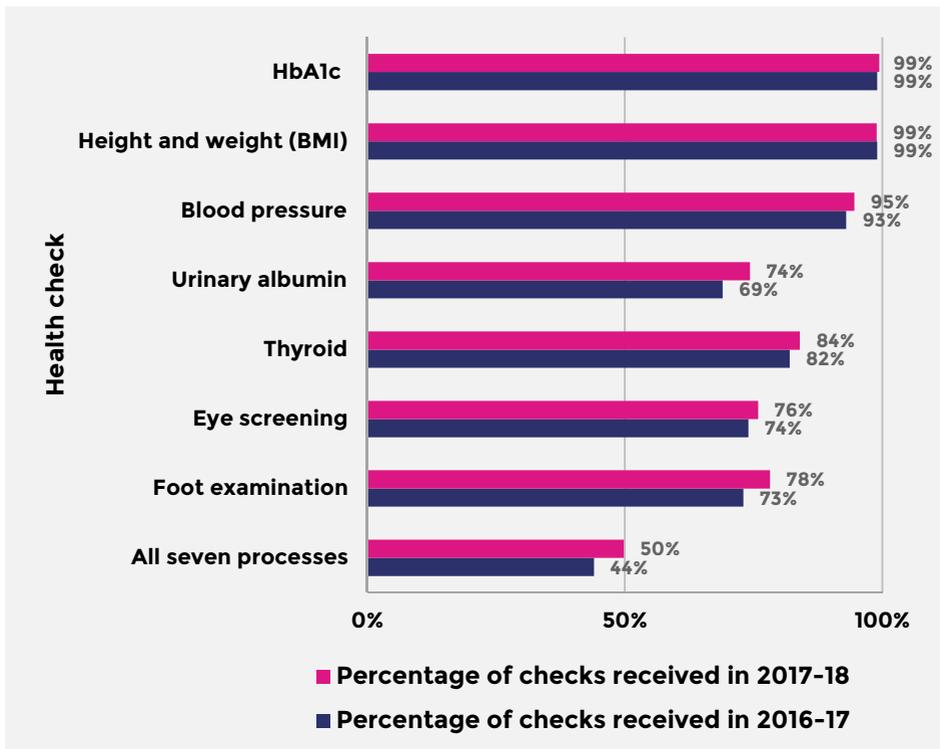
- **Complete a psychological screening assessment** since problems such as anxiety, depression and disordered eating can be more common in children and young people with diabetes.
Type 1 & Type 2
- **Ask about smoking**, so that support for reducing or quitting smoking can be offered if necessary.
Type 1 & Type 2
- **Recommend a flu vaccine** as the risk of serious illness from flu is higher among those with diabetes.
Type 1 & Type 2
- **Provide 'sick-day rules' advice** to allow families to manage diabetes during other illness such as coughs and colds.
Type 1 & Type 2
- **Offer at least one additional dietetic appointment** with a registered dietitian.
Type 1 & Type 2
- **Offer training in the use of blood ketone testing strips.** Lack of insulin leads to the production of ketones. A build-up of ketones in the blood can lead to a serious condition called diabetic ketoacidosis (DKA). Children and young people with Type 1 diabetes are particularly at risk of DKA at times of other illness when they may need to use 'sick day rules'. 'Sick day rules' will include information on ketone testing.
Type 1

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 6](#)).

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 (2017-18) are shown below, with the results from 2016-17 for comparison:



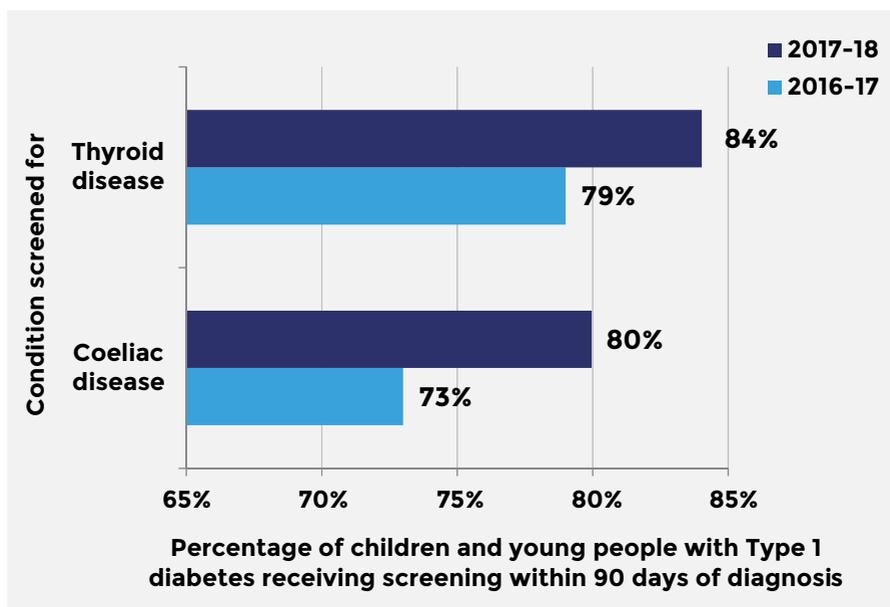
There is clear improvement in completion rates of most key health checks between 2016-17 to 2017-18. These checks are important to detect any problems linked to diabetes so that advice can be provided if anything is detected.

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 diabetes team and submitted to the NPDA so that your clinic is shown to have provided the recommended care.

Other checks and specialist appointments

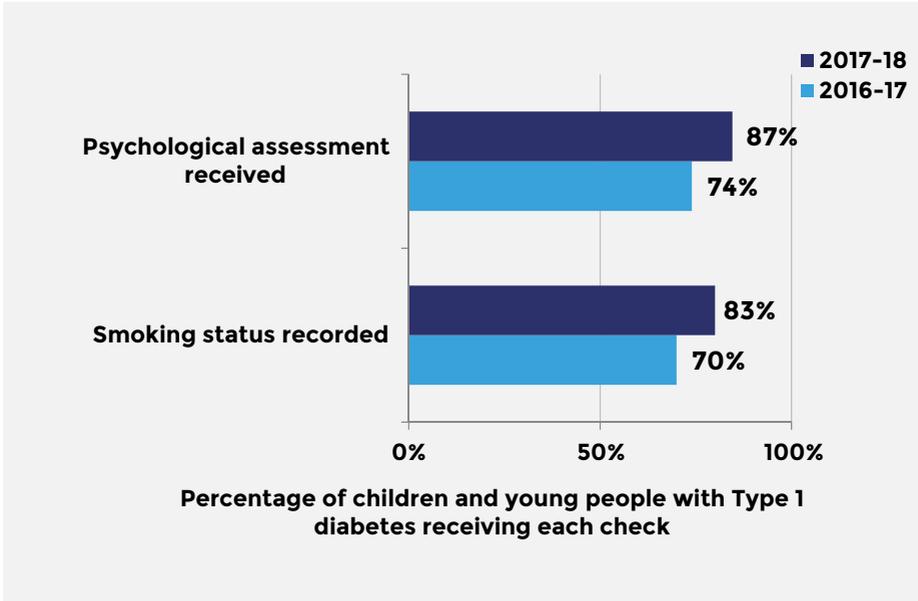
Thyroid and coeliac disease

Four out of five children and young people newly diagnosed with Type 1 diabetes received screening for thyroid and coeliac disease in 2017-18 within 90 days of diagnosis. Completion rates for both improved between 2016-17 and 2017-18.



Psychological assessment and smoking status

Percentages of children and young people with Type 1 diabetes receiving psychological and smoking checks in 2017-18 compared to 2016-17 are shown below. There were improvements in the completion rates of both checks.



For the 2017-18 audit year, the NPDA collected information on additional checks and specialist appointments ([see page 8](#)) for the first time. Percentages of children and young people with Type 1 diabetes who received these are shown in the table below:

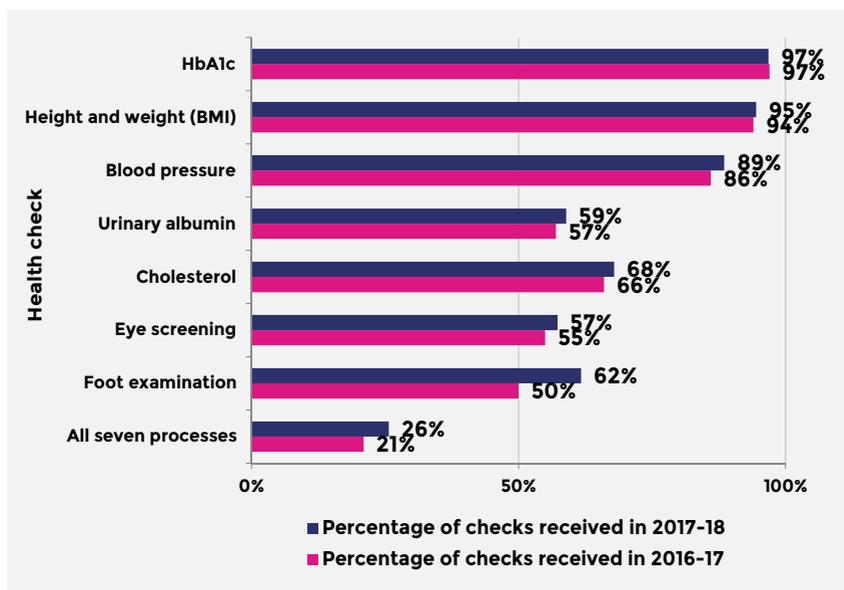
Level 3 carb counting education	Flu vaccine	'Sick-day rules' advice given	Additional dietetic appointment offered	Blood ketone testing training
68%	76%	77%	85%	83%

Completion of health checks

Type 2 diabetes

The NPDA investigated how many children and young people with Type 2 diabetes received their seven key health checks (as described on [page 7](#)).

The percentages of children and young people with Type 2 diabetes in England and Wales who received each key health check in the 2017-18 audit year are shown below, with the results from 2016-17 for comparison. There was improvement in completion rates of almost all between 2016-17 and 2017-18.



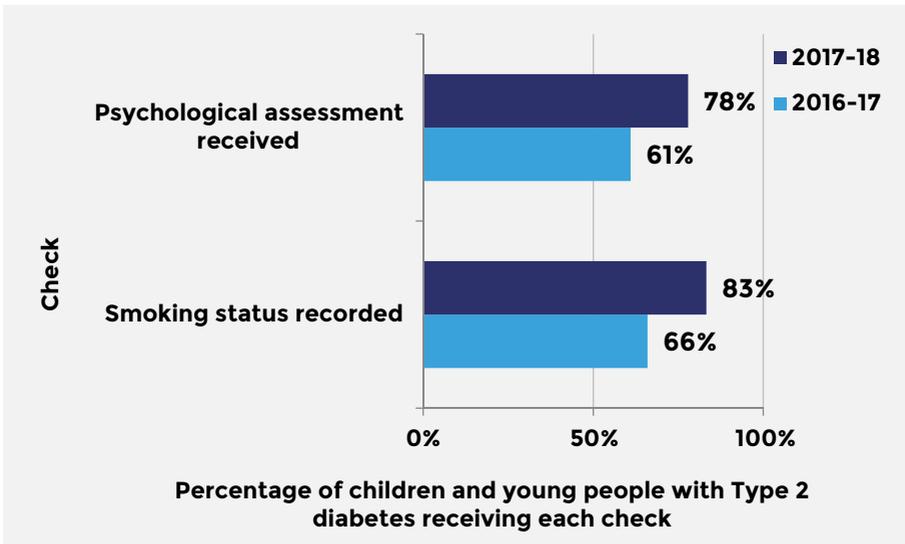
More children and young people with Type 2 diabetes are receiving the recommended checks since 2016-17. However, completion rates are not as good as those for children and young people with Type 1 diabetes. It is really important that children and young people with Type 2 diabetes

receive all recommended checks every year, because this condition can be very aggressive in the young. Regular health checks can help ensure that any health problems linked to Type 2 diabetes are caught early and managed before they get worse.

Other checks and specialist appointments

Psychological assessment and smoking status

Percentages of children and young people with Type 2 diabetes receiving psychological and smoking checks in 2017-18 compared to 2016-17 are shown below.



For the 2017-18 audit year, the NPDA collected information on the additional checks and specialist appointments ([see page 8](#)). Percentages of children and young people with Type 2 diabetes who received these are shown in the table below:

Flu vaccine recommended	'Sick-day rules' advice given	Additional dietetic appointment offered
49%	42%	70%

Completion of health checks

Understanding the results

Although there have been many improvements, not all children and young people with diabetes are being checked every year for the warning signs of diabetes related complications (see [pages 19-21](#)).

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 diabetes-related complications later. If your child misses any key checks at annual review, discuss this with your diabetes team at their next appointment.

Why is it that some checks aren't completed?

There are various reasons why health checks aren't always completed. For example:

- 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 do not provide an excuse for not completing the recommended health checks. Health checks are part of nationally agreed guidance and are essential to keep children and young people with diabetes in good health.

How can clinics make sure everyone gets the recommended checks?

In 2016-17, just over half (58%) of children and young people with diabetes attending Barts Health NHS Trust - Newham University Hospital completed all seven key health checks. By 2017-18, this percentage improved dramatically, as nearly all (90%) of children and young people received all seven checks. We asked Dr Evelien Gevers, Dr Mala Kurre and Dr Ruben Willemsen, at Barts Health NHS Trust how they did it...



.....

NPDA:

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



.....

Dr Gevers, Dr Kurre & Dr Willemsen:

We improved our numbers by:

- Creating an outreach clinic with a consultant from Newham's sister hospital, The Royal London, to increase communication and align practice
- Regularly monitoring our health check completion rates in monthly team meetings
- Creating an age-banded teenage/transition clinic with a consistent team of healthcare practitioners
- Getting extra time for our data administrator



Outcomes - HbA1c

HbA1c is related to your average blood glucose levels over the previous two to three months before measurement. It provides a useful measure of diabetes management in the two to three months before the HbA1c test.

An HbA1c level above 80 mmol/mol (9.5%) is considered to show very high blood glucose levels, which increases the risk of developing diabetes-related complications ([see pages 19-21](#)).

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.

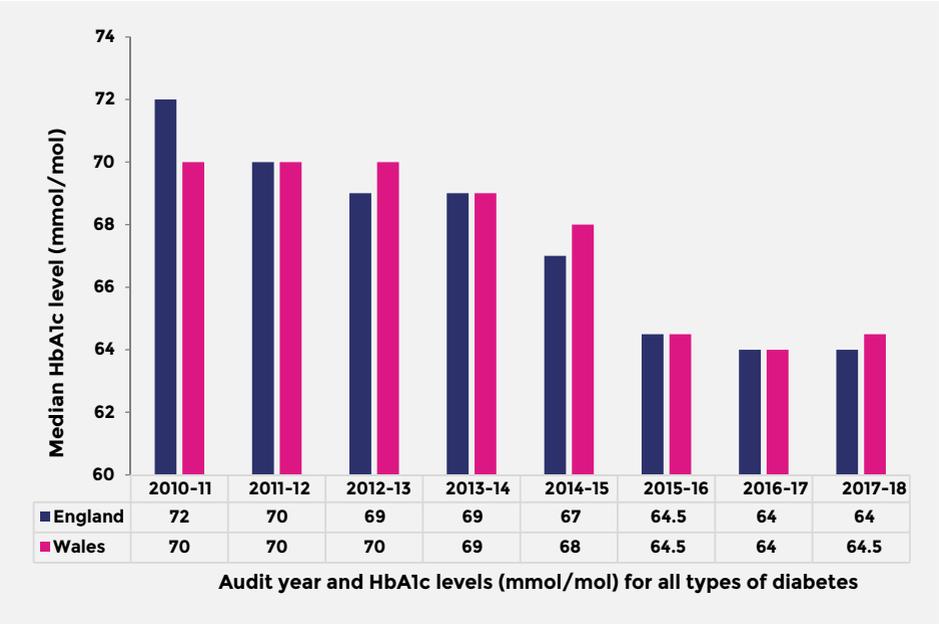
Low numbers of children and young people are meeting this target in England and Wales, although the numbers are increasing every year.

This section looks at the HbA1c results of children and young people with diabetes in 2017-18.

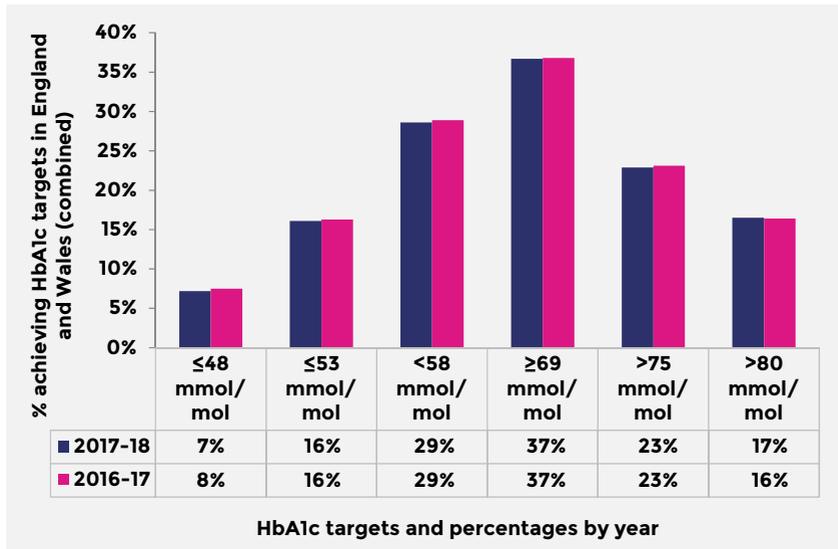
HbA1c results

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 2017-18. This remains unchanged from 2016-17.

The average (median) HbA1c level in children and young people with Type 2 diabetes in England and Wales was 53 mmol/mol (7.0%) in 2017-18, a 1 mmol/mol increase since 2016-17.



As the graph below shows, percentages of children and young people with Type 1 diabetes achieving HbA1c targets in England and Wales in 2017-18 have remained similar to the previous audit year. However, the audit found differences in average HbA1c between clinics and regions.



Paediatric diabetes clinics across England and Wales are increasingly working together on quality improvement activities. By taking part in the National Children and Young People's Diabetes Network and the new National Children and Young People's Diabetes Quality Programme, clinics are showing strong commitment to improving care and outcomes.

Ask your diabetes clinic about their involvement in these activities.



Complications of diabetes

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

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.

Type 1 diabetes



Eye disease

Early signs of increased risk of future sight problems caused by damage to blood vessels in the eye were found in 13% of young people (12 years and over).



Albuminuria (warning sign for kidney disease)

Found in 10% of young people (12 years and over).



Smoking

A small number (3%) of children and young people who were asked said they were a smoker, putting them at higher risk of complications.



High cholesterol

Was found in 22% of young people (12 years and over).



High blood pressure

Was found in 27% of young people (12 years and over).



Overweight

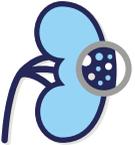
17% of children aged 0 to 11 years were overweight, and 17% were obese; of those aged 12 years and above, 18% were overweight and 23% obese.

Type 2 diabetes



Eye disease

Early signs of increased risk of future sight problems caused by damage to blood vessels in the eye were found in 6% of young people (12 years and over).



Albuminuria (warning sign for kidney disease)

Was found in 22% of young people (12 years and over).



Smoking

A small number (3%) of children and young people who were asked said they were a smoker.



High cholesterol

Was found in 34% of young people (12 years and over).



High blood pressure

Was found in 45% of young people (12 years and over).



Overweight

10% of children and young people were overweight, while 85% were obese.

Spotlight audit: Diabetes-related technologies

.....

Depending on the type, diabetes-related technologies can monitor current blood glucose levels, and alert you to highs/ lows, show blood glucose trends over time, and/or help deliver insulin automatically. This spotlight audit looked into the diabetes-related technologies used in England and Wales, including:

- *Insulin pump therapy*
Attaching a small electronic device to the body, which continuously delivers insulin beneath the skin.
- *Continuous glucose monitors (CGM)*
Small devices that you wear just under your skin. They measure your glucose levels continuously throughout the day and night, let you see trends in your levels and can alert you to highs and lows.

Diabetes-related technologies

Our findings

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The NPDA found that:

- Children and young people using insulin pumps and continuous glucose monitors (CGM) had lower HbA1c, on average, than those using injections or not using a CGM.
- Children and young people of non-White ethnicity, and those living in the most deprived areas were less likely to be using an insulin pump or CGM.
- There were big differences in waiting times for starting on an insulin pump between clinics, country and regions. In England, the most common wait time was 1-3 months, while half of clinics in Wales said their patients typically waited six months or more after approval to start.
- Almost all (99%) children and young people with Type 1 diabetes using insulin pump therapy had their pumps paid for by the NHS.
- Most CGM users had their device paid for by the NHS, although 11% bought their own.
- Small numbers (29) children and young people in England and Wales were reported to be using a 'D-I-Y' closed loop artificial pancreas' system to manage their diabetes. There may be more families using these systems as many clinics reported that they didn't know if any of their families were using this technology. This is an unapproved system used outside of a clinical trial which links CGM, an insulin pump and open source software.

Treatment regimen and CGM use

In 2017-18, the core audit found around a third (35%) of children and young people with Type 1 diabetes in England and Wales were using insulin pump therapy. Just over 60% were using multiple daily insulin injections (MDI) - using a syringe or pen to inject insulin under the skin.

The spotlight audit performed a statistical analysis looking at the impact on HbA1c of using technology, taking into account the child's age, sex, ethnicity, duration of diabetes and level of deprivation. It found that compared to those using MDI without CGM, the lowest average HbA1c was achieved by children and young people with Type 1 diabetes who were using insulin pump therapy combined with CGM. On average, those using MDI and CGM, and those using an insulin pump alone also had lower average HbA1c than those using MDI alone.

However, the analysis showed that use of technology only explained a small amount of the differences in HbA1c between children and young people with diabetes, and that some children and young people are able to have a low HbA1c using injections or without CGM.

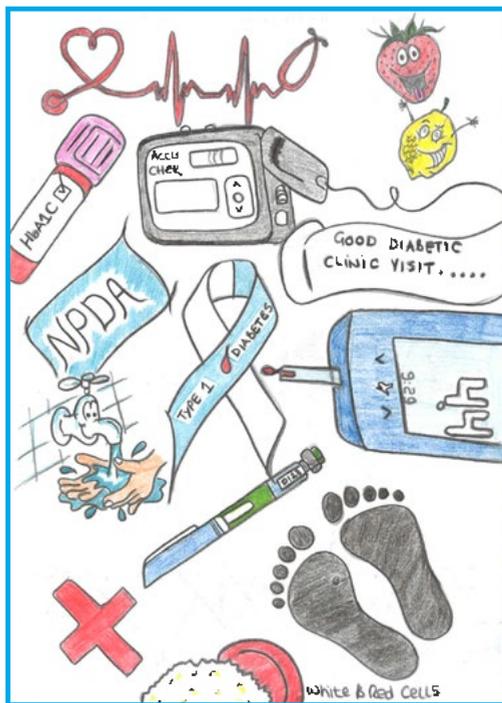


Image by Sienna Leigh Ferguson

Additional findings

- Almost all clinics (over 90%) provide a competency/training programme before starting insulin pump therapy.
- Most families had access to 24-hour technical (non-clinical) support, for using insulin pump therapy (for example from a representative from a pump company).
- Two thirds of clinics had a written policy and/or guideline for managing children and young people with diabetes on insulin pump therapy who are admitted to hospital, and 96% had a written policy/guideline for those having surgery in hospital.
- Almost all (99%) clinics allowed children and young people with diabetes on insulin pumps or their parents to continue to self-manage after admission to hospital where possible.

To read the full report, please visit www.rcpch.ac.uk/resources/npda-spotlight-audit-reports



Image by Katie Prescott

Spotlight audit: The workforce in diabetes clinics

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The NPDA spotlight audit report on the workforce in diabetes teams looked at staffing levels within clinics in England and Wales.

It also explored how young people move (transition) from children's to adult diabetes services in different areas, funding for paediatric diabetes services, and access to support and services for children and young people with diabetes and their families.

Diabetes-related technologies

Our findings

.....

The NPDA found that:

- Total staffing levels have increased in clinics in England and Wales since 2014. However, numbers of doctors and psychologists are below those recommended by the International Society for Pediatric and Adolescent Diabetes (ISPAD), while numbers of nurses and dietitians are the same as or higher than ISPAD recommendations.
- Overall, staffing levels were not associated with average HbA1c in paediatric diabetes clinics.
- Despite the staffing increases, over a third of clinics had at least one vacancy, with most of these being unfilled for three months or longer, putting additional strain on the already busy workforce.
- Most clinics in England were achieving Best Practice Tariff payments – an amount of money per child/young person that is paid by NHS commissioners to cover the costs of diabetes care. However only 28% of clinics knew the percentage of these payments that they were receiving directly into their service.

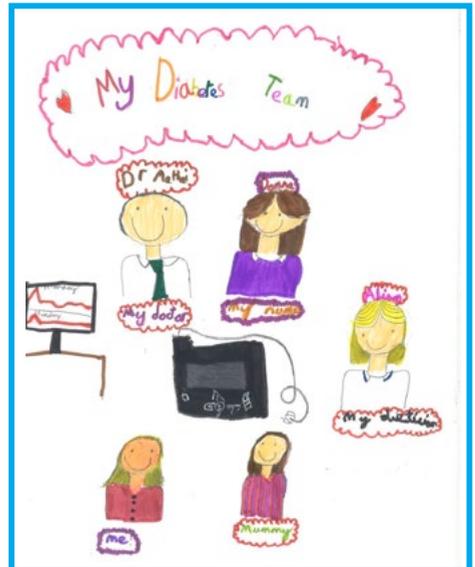


Image by Beth Cameron Crossman

Transition to young adult services

Our spotlight audit looked at how young people with diabetes move (transition) from paediatric diabetes services into young adult services.

We found that:

- Most (94%) paediatric clinics were linked to a transition clinic or service, run jointly with an adult diabetes service.
- The most common way for young people to transition to adult services was a gradual process involving the adult team over 1-2 years, which is considered to be the best method. However, a few clinics reported that all patients were still moving directly from paediatric to adult care. **Ask your clinic how they manage transition.**
- Most clinics (72%) reported that their patients always had access to a dedicated young adult diabetes clinic following transfer from paediatric services.

Additional findings

- Almost all (95%) of the reported psychologist vacancy posts had been vacant for over three months.
- A range of structured education programmes designed to support families to manage diabetes well are being delivered in clinics, including 'Goals of Diabetes Education', 'SEREN' (in Wales), and locally developed programmes.
- Ninety percent of clinics reported that their service offered 24-hour telephone advice about diabetes management for children and young people, their parents or carers, seven days a week. However, only 42% of clinics (less than half), offered a 24/7 telephone service provided exclusively by members of the paediatric diabetes team, as recommended by NICE.

To read the full report, please visit
www.rcpch.ac.uk/resources/npda-spotlight-audit-reports

Key conclusions

- The 2017-18 NPDA report showed that more key health checks were completed for children and young people with diabetes since the previous audit year, but it also showed that national average HbA1c results have remained stable.
- Many clinics began participating in the Royal College of Paediatrics and Child Health's Diabetes Quality Programme, with an aim to improve the quality of care they provide.
- The diabetes-related technologies spotlight audit highlighted differences across clinics in England and Wales in both the use of technologies and in the average HbA1c of those using them. Overall, children and young people using an insulin pump and/or CGM had lower HbA1c levels.
- The workforce caring for children and young people with diabetes in England and Wales has grown since 2014. However, clinics need to think carefully about how they use their workforce as having more staff per patient was not shown to lead to better HbA1c outcomes overall.

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

- Talk to their diabetes clinics about receiving the health checks recommended for their child's age, and discuss their results.
- Work with their diabetes teams to achieve the best HbA1c level possible for their child, by aiming for blood glucose levels within targets set by their clinics.

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

.....

In the 2017-18 audit year, the NPDA has:

- Hosted the NPDA annual 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 and Local Health Boards with a clinic where the results are not as good as others, so that support (e.g extra resource) 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.
- Launched a national survey for children and young people with diabetes and their families, to capture views on their experiences of the services that paediatric diabetes units provide. Over 13,000 responses were collected. Once published, the results of these surveys will help to identify necessary improvements to paediatric diabetes care, both in local hospitals and more widely across England and Wales.

NPDA Results Online

www.npda-results.rcpch.ac.uk

NPDA Results Online is the NPDA's online reporting tool. This tool makes 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 you to:

- Read background information about the NPDA and access the Annual Report.
- View and download an annual summary report for your clinic. Reports are available from 2014-15 to 2017-18.
- 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

Albuminuria - *See Urinary albumin

Best Practice Tariff (BPT) - An amount of money per child/young person that is paid to providers by NHS commissioners to cover the costs of good diabetes care.

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 to 7](#).

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.

Continuous glucose monitoring (CGM) - A small device that you wear just under your skin. It measures your glucose levels continuously throughout the day and night, letting you see trends in your levels and alerts you to highs and lows.

Diabetic ketoacidosis (DKA) - A serious condition that can occur in

people with diabetes, indicating a severe lack of insulin. *See Ketones.

Glucose - A blood sugar which acts as a major source of energy for the body.

HbA1c (glycated haemoglobin) - Glucose in the blood can stick to haemoglobin (a protein) in red blood cells, making a substance called HbA1c.

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.

Insulin pump therapy - Attaching a small electronic device to the body, which continuously delivers insulin beneath the skin via a tiny tube called a cannula.

Ketones - A ketone is a chemical substance that the body makes when it does not have enough insulin in the blood.

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.

Multiple daily injections (MDI) - Using a syringe or pen to inject insulin under the skin as often as needed through the day and night.

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

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.

Fair processing

To learn more about the NPDA, compare clinic results, read the privacy notice and understand how your child's data is being used to drive national improvements in diabetes care, please visit www.rcpch.ac.uk/npda

Images

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.

Drawings and illustrations within this report have been designed by children and young people with diabetes, attending a clinic in England or Wales. Their designs are submissions to the December 2018 NPDA art competition asking children and young people to design an image based on the theme of 'a good diabetes clinic visit'.



Image by Arthur Wimpenny Ganjei

NPDA

**National Paediatric
Diabetes Audit**

www.rcpch.ac.uk/npda

Published by RCPCH December 2019



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