National Paediatric Diabetes Audit

Parent and Carers Report 2014-15

Commissioned by the Healthcare Quality Improvement Partnership
Managed by the Royal College of Paediatrics and Child Health
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 2014-15 there were just over 1000 new cases diagnosed in England and Wales).

The vast majority of children and young people (around 95.5%), have Type 1 diabetes, whereas only a small number (around 4.5%), have Type 2 diabetes or other rare forms of diabetes.

(www.diabetes.co.uk)
Common differences between Type 1 and Type 2 diabetes:

<table>
<thead>
<tr>
<th>Type 1 diabetes</th>
<th>Type 2 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Often diagnosed in childhood</td>
<td>• Usually diagnosed in people aged over 30</td>
</tr>
<tr>
<td>• Not associated with excess body weight</td>
<td>• Often associated with excess body weight</td>
</tr>
<tr>
<td>• Usually associated with higher than normal ketone levels at diagnosis</td>
<td>• Often associated with high blood pressure and/or cholesterol levels at diagnosis</td>
</tr>
<tr>
<td>• Treated with insulin injections or insulin via a pump</td>
<td>• Is usually treated initially with special diet, lifestyle changes and oral medication</td>
</tr>
<tr>
<td>• Cannot be controlled without taking insulin</td>
<td>• Sometimes possible to come off diabetes medication</td>
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</tbody>
</table>
Overview

The National Paediatric Diabetes Audit (NPDA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England and the Welsh Government. It has been running for 12 years.

The NPDA analyses and reports data provided by your clinic about the quality of care your child receives. The audit produces yearly National and clinic reports to describe the quality of care received by children and young people with diabetes. This summary for parents and carers includes the main findings reported in the National Report for 2014-15.

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 2015, 176 diabetes clinics in England and Wales were audited, with information provided for over 27,600 children and young people under 25 years-old.

What did we find?

- This year’s findings revealed a marked improvement in diabetes control across England and Wales, which has improved consistently since 2010. However, there are differences between clinics and regions in completing and recording ALL key healthcare checks.

- The number of children with high HbA1c remains too high, putting them at increased risk of complications. The findings also revealed there are a number of young people presenting with early signs of diabetes complications such as kidney and eye disease.
Completion rates of key checks

The NPDA investigated how many children and young people with diabetes were receiving the key healthcare checks in this audit year (2014-15).

The key healthcare checks listed below are performed to monitor a child with diabetes. They enable clinicians to look for early warning signs that the child might be developing complications so that appropriate advice can be given and action taken. Some of the checks are for all ages and some are for young people aged 12 and above. These should be continued annually into adulthood.

List of key healthcare checks:

1. **HbA1c** (for all ages – a measure of blood glucose control)
2. **Height and weight** (for all ages – a check for healthy growth)
3. **Blood pressure** – a check for hypertension (high blood pressure)
4. **Urinary albumin** – a check for kidney damage
5. **Cholesterol** – a check for high cholesterol
6. **Eye screening** – a check for eye disease (retinopathy)
7. **Foot examination** – a check for damage to nerves (neuropathy)
The percentages of children and young people with diabetes in England and Wales who received each key health check are shown below:
Overall, the **number of children and young people with diabetes completing the individual key checks has improved** since the last audit (2013-14).

This is encouraging because early detection of complications by these checks will enable treatment to start earlier. It is possible that more **checks are being performed in some services but not recorded**. This needs to improve if we are to better understand where to focus efforts to improve the care of children and young people with diabetes.

If you are the parent or carer of a child or young person with diabetes you should **ask your diabetes clinic about receiving these key checks**, discussing the results and having them recorded so that they can be included in the audit.
There are five further important key healthcare checks which the NPDA have reported this year.

1. **Thyroid** and **coeliac disease** screening for children and young people with Type 1 diabetes is important because the risk of developing these diseases is increased.

2. **Smoking** is bad for anyone’s health and it increases the risk of developing diabetes complications. Recording whether or not the patient smokes is important so that education packages aimed at reducing smoking can be offered if necessary.

3. **Psychological assessment** is important for children and young people with diabetes since problems such as depression and eating disorders are more common.

4. **Structured self-management education** enables children, young people and their parents to understand how to keep blood glucose under control and how to avoid diabetes complications. It is important to check whether this has been received.
The percentage of children and young people with diabetes that are receiving each of these five key healthcare checks or care processes:

<table>
<thead>
<tr>
<th>Healthcare Check</th>
<th>2014-15</th>
<th>2013-14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thyroid function screen</td>
<td>71%</td>
<td>52%</td>
</tr>
<tr>
<td>Screening for coeliac disease</td>
<td>58%</td>
<td>45%</td>
</tr>
<tr>
<td>Structured education</td>
<td>57%</td>
<td>45%</td>
</tr>
<tr>
<td>Smoking status recorded</td>
<td>56%</td>
<td>67%</td>
</tr>
<tr>
<td>Psychological assessment</td>
<td>57%</td>
<td>48%</td>
</tr>
</tbody>
</table>

What does this mean?

- Not all children and young people with diabetes are being checked every year for warning signs associated with risk of developing diabetes complications.
- Parents and carers should ask their diabetes team about their child’s completion of the key healthcare checks as part of an annual assessment. Finding problems early can reduce the risk of further complications later.
Collecting information on outcome measures is an important part of monitoring diabetes control and care.

**HbA1c**

HbA1c refers to glycated haemoglobin. Measuring this gives an overall picture of diabetes control. It is an indicator of blood sugar levels over the six to eight weeks before the test. It is the best measure of long-term diabetes control.

New guidelines recommend that people with diabetes should aim for a target HbA1c below 48 mmol/mol (6.5%), however this is a general target and your child should be given a personal target to aim towards.

An HbA1c level above 75 mmol/mol (9%) is considered to show very poor control, 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 levels
- keeping a **routine, carbohydrate counting** and **insulin dose adjustment**
- exercise and **structured self-management education**
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 5 years.

However, there were considerable differences across England and Wales with some clinics and networks achieving better diabetes control than others. Higher average HbA1C levels were found amongst older children, which could reflect challenges associated with self-management and adolescence. There was also an association between social deprivation and poorer diabetes control, with children and young people living in the most deprived areas having an average HbA1C of 73.7 mmol/mol compared to an average of 67.2 mmol/mol amongst children and young people with diabetes in the least deprived areas.

More information about these differences can be found in the main NPDA 2014-15 report or in the individual paediatric diabetes clinic reports, available on the NPDA website: www.rcpch.ac.uk/npda.
Diabetes outcomes and complications in 2014-15

**Eye disease**
Early signs of increased risk of blindness were found in **12.8%** of young people (12 years and over).

**Albuminuria**
(warning sign for kidney disease)
Found in **11.6%** of young people (12 years and over) with diabetes.

**Smoking**
4% of children and young people who were asked said they were a smoker.

**High cholesterol**
Found in **21.8%** of young people with diabetes (12 years and over).
High blood pressure

Found in **27.1%** of young people with diabetes (12 years and over).

Obesity

**15.9%** of 0-11 year olds with diabetes were found to be obese, and **20.7%** of those were aged 12 and above.

HbA1C

**23.5%** of children and young people with diabetes had a good HbA1c level (<58 mmol/mol), showing good diabetes control. **21.3%** of children and young people had a very high HbA1c level (>80 mmol/mol), putting them in greater danger of developing complications.
Complications

Microvascular disease

High blood glucose levels over a longer period of time can damage the smallest blood vessels of the body. This is known as microvascular disease.

Parts of the body commonly affected by microvascular disease are the kidneys, eyes and feet. The early stages of microvascular disease in the kidneys can be found by checking for albuminuria - a higher level of albumin (a protein) in the urine.

In the eyes, microvascular disease can affect the blood vessels in the retina. This damage is called ‘retinopathy’ and it can cause blindness. Microvascular disease can also cause nerve damage (neuropathy) and reduce blood circulation in the feet, so foot examination is important to check for these complications.

- High albumin was found in 11.6% of young people with diabetes
- Abnormal eye screening was recorded in 12.8% of young people with diabetes
- Foot complications are not recorded by the NPDA but 55% of young people had their feet checked

What does this mean?

- Young people over 12 years-old should have eye, albuminuria, and foot checks at least once a year.
- Patients and families need to be aware of the seriousness of abnormal findings and possible consequences.
- Keeping good diabetes control reduces the risk of such complications.
Heart disease (cardiovascular) risk factors

People with diabetes are at risk of cardiovascular disease which can increase the risk of stroke and heart attack. The NPDA investigated factors which increase the risk of cardiovascular disease including high blood pressure, being overweight or obese, high cholesterol, and smoking in young people aged 12 and above:

- Just over a third of those (34.9%) with Type 1 diabetes had high blood pressure
- 15.9% of 0-11 year-olds and 20.7% of those 12 years and over were obese
- Over 1 in 5 (27.1%) young people over 12 with Type 1 diabetes had raised cholesterol
- 4% of young people with diabetes were smoking

What does this mean?

- A high proportion of children with Type 1 diabetes are at increased risk of developing cardiovascular disease.
- 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.
Structured education

Managing diet, blood glucose levels and insulin requirements on a day to day basis is a challenging balancing act for children, young people and parents.

**Structured Patient Education Programmes** teach you or your child how to manage their diabetes, and should be offered on an ongoing basis from the point of diagnosis. They should be aimed at the age and maturity level of your child, and should meet the needs of the individual child and family.

Do ask your clinic for age-appropriate, structured education to support your child’s management of their diabetes if you have not been offered it.

The NPDA found that **almost 60% of the children and young people in the audit received some form of structured education** in 2014-15, up from 55% in 2014.
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 who are over 12 years-old can talk to their diabetes clinics about receiving and discussing the results of the key healthcare checks on a yearly basis. These include: HbA1c, height and weight, blood pressure, urinary albumin, cholesterol, eye screening and foot examination.

Parents and carers should work with their diabetes team to achieve the best HbA1c level possible for their child. Together they should work on action plans to maintain good control of the diabetes for the child or young person.

Ongoing support for children and young people with diabetes is important. This should include structured educational packages, psychological assessment 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 2014-15
- 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
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 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 healthcare 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 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 GP, paediatrician or nurse.

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
• National Diabetes Audit (NDA): www.hscic.gov.uk/NDA
• Type 1 diabetes education: www.type1diabetestraining.co.uk
• Young people’s diabetic support service: www.upbete.co.uk

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

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