

# Diabetes in children and young people

Quality standard

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This standard is based on NG18.

This standard should be read in conjunction with QS6, QS94, QS109, QS120, QS127, QS131 and QS134.

## Introduction

This quality standard covers the diagnosis and management of type 1 and type 2 diabetes in children and young people aged under 18. This quality standard will not cover care for children and young people with other forms of diabetes mellitus (such as monogenic diabetes or cystic fibrosis-related diabetes). Management of diabetes in women aged under 18 who are planning pregnancy or already pregnant is covered by the [NICE guideline](#) and [quality standard](#) on diabetes in pregnancy.

For more information see the [diabetes in children and young people topic overview](#).

### *Why this quality standard is needed*

Diabetes is a long-term condition that can have a major impact on the life of a child or young person, as well as their family or carers. In addition to insulin therapy, diabetes management should include education, support and access to psychological services. Preparations should also be made for the transition from paediatric to adult services, which have a different model of care and evidence base.

Type 1 diabetes is becoming more common in the UK, and since 2004 type 2 diabetes is also being diagnosed with increasing frequency. The [2013–14 National Paediatric Diabetes Audit](#) identified 26,364 children and young people with type 1 diabetes and 533 with type 2 diabetes. Much of the general care for type 2 diabetes is the same as for type 1 diabetes, although the initial management is different.

Since 2004 there have been major changes to the routine management of type 1 diabetes in an attempt to achieve much stricter targets for blood glucose control, to further reduce the long-term risks associated with the condition. NICE's guideline on [diabetes in children and young people](#) is the first national guidance for children and young people to recommend attempting to reach a glycated haemoglobin (HbA1c) level near the normal range and near normoglycaemia. This tight control may be achieved by intensive insulin management (multiple daily injections or insulin pump therapy) from diagnosis, accompanied by carbohydrate counting. Newer technology such as

continuous subcutaneous glucose monitoring may also help children and young people to achieve better blood glucose control, although this is not currently advised for all children and young people with type 1 diabetes.

The quality standard is expected to contribute to improvements in the following outcomes:

- prompt diagnosis of type 1 diabetes
- control of blood glucose and HbA1c levels
- diabetes complications (for example, prevention of diabetic ketoacidosis [DKA])
- quality of life
- patient, parent and carer satisfaction
- life expectancy.

### *How this quality standard supports delivery of outcome frameworks*

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – safety, experience and effectiveness of care – for a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 2 outcome frameworks published by the Department of Health:

- [NHS Outcomes Framework 2016–17](#)
- [Public health outcomes framework for England, 2016–19.](#)

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

**Table 1 [NHS Outcomes Framework 2016–17](#)**

Domain	Overarching indicators and improvement areas
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<p>1 Preventing people from dying prematurely</p>	<p><b>Overarching indicators</b></p> <p>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare</p> <p>ii Children and young people</p>
<p>2 Enhancing quality of life for people with long-term conditions</p>	<p><b>Improvement area</b></p> <p>Reducing time spent in hospital by people with long-term conditions</p> <p>2.3 ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s</p>
<p>4 Ensuring that people have a positive experience of care</p>	<p><b>Overarching indicators</b></p> <p>Improving children and young people's experience of healthcare</p> <p><i>4.8 Children and young people's experience of inpatient services</i></p>
<p><b>Alignment with Public Health Outcomes Framework</b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

**Table 2** Public health outcomes framework for England, 2016–19

Domain	Objectives and indicators
<p>2 Health improvement</p>	<p><b>Objective</b></p> <p>People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities</p> <p><b>Indicator</b></p> <p>2.11 Diet</p>

<p>4 Healthcare public health and preventing premature mortality</p>	<p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities</p> <p><b>Indicator</b></p> <p>4.12 Preventable sight loss</p>
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## *Safety and people's experience of care*

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to diabetes in children and young people.

## *Coordinated services*

The quality standard for diabetes in children and young people specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole diabetes care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to children and young people with diabetes.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality service for children and young people with diabetes are listed in [related quality standards](#).

## **Training and competencies**

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating children and young people with diabetes should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development sources on specific types of training for the topic that exceed standard professional training are considered during quality statement development.



## **Role of families and carers**

Quality standards recognise the important role families and carers have in supporting children and young people with diabetes. If appropriate, healthcare professionals should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

## List of quality statements

Statement 1. Children and young people presenting in primary care with suspected diabetes are referred to and seen by a multidisciplinary paediatric diabetes team on the same day.

Statement 2. Children and young people with type 1 or type 2 diabetes are offered a programme of diabetes education from diagnosis that is updated at least annually.

Statement 3. Children and young people with type 1 diabetes are offered intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis.

Statement 4. Children and young people with type 1 diabetes who have frequent severe hypoglycaemia are offered ongoing real-time continuous glucose monitoring with alarms.

Statement 5. Children and young people with type 1 diabetes are offered blood ketone testing strips and a blood ketone meter.

Statement 6. Children and young people with type 1 or type 2 diabetes are offered access to mental health professionals with an understanding of diabetes.

## Quality statement 1: Same-day referral and appointments

### *Quality statement*

Children and young people presenting in primary care with suspected diabetes are referred to and seen by a multidisciplinary paediatric diabetes team on the same day.

### *Rationale*

Multidisciplinary paediatric diabetes teams can confirm a diagnosis of diabetes and provide immediate care. Children and young people whose diagnosis and care are delayed are at higher risk of diabetic ketoacidosis (DKA), which is life-threatening but preventable.

### *Quality measures*

#### **Structure**

Evidence of local arrangements and written clinical protocols to ensure that children and young people presenting in primary care with suspected diabetes are referred to and seen by a multidisciplinary paediatric diabetes team on the same day.

*Data source:* Local data collection.

#### **Process**

Proportion of children and young people presenting in primary care with suspected diabetes who are referred to and seen by a multidisciplinary paediatric diabetes team on the same day.

Numerator – the number in the denominator who are referred to and seen by a multidisciplinary paediatric diabetes team on the same day.

Denominator – the number of children and young people presenting in primary care with suspected diabetes.

*Data source:* Local data collection.

#### **Outcome**

Presentations of DKA.

*Data source:* Local data collection.

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (primary care services) ensure that systems are in place for children and young people presenting in primary care with suspected diabetes to be referred to and seen by a multidisciplinary paediatric diabetes team on the same day.

**Healthcare professionals** (such as GPs) immediately refer children and young people presenting in primary care with suspected diabetes to a multidisciplinary paediatric diabetes team, to be seen on the same day.

**Commissioners** (NHS England regional teams and clinical commissioning groups) commission services that make sure children and young people presenting in primary care with suspected diabetes are immediately referred to and seen by a multidisciplinary paediatric diabetes team.

### *What the quality statement means for children and young people and their parents and carers*

Children and young people who see their GP with suspected diabetes are immediately referred to and seen by a team that specialises in caring for children and young people with diabetes. The symptoms of diabetes include feeling very thirsty or tired, needing to urinate more often than usual, or recently losing weight without trying to.

### *Source guidance*

- [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18, recommendation 1.1.2

### *Definition of terms used in this quality statement*

#### **Suspected diabetes**

Recognised symptoms of diabetes in children and young people include one or more of the following: increased thirst, increased urination, excessive tiredness and recent unexplained weight loss. A plasma glucose level above 11 mmol/litre indicates the presence of diabetes.

[Expert consensus and [Diabetes UK](#)]

### *Equality and diversity considerations*

Particular care should be taken when communicating with children and young people with diabetes and their family members or carers (as appropriate) if they have, for example:

- physical, cognitive or sensory disabilities
- difficulties speaking or reading English.

## Quality statement 2: Education and information

### *Quality statement*

Children and young people with type 1 or type 2 diabetes are offered a programme of diabetes education from diagnosis that is updated at least annually.

### *Rationale*

Education is essential in enabling self-management of diabetes and reducing the chance of complications. It should start at diagnosis and continue throughout a person's life. It is important to focus education on core topics and tailor it to the individual needs and learning styles of the child or young person and their family members or carers (as appropriate).

### *Quality measures*

#### **Structure**

a) Evidence of local arrangements and written protocols to ensure that children and young people with type 1 diabetes are offered a programme of diabetes education from diagnosis that is updated at least annually.

**Data source:** Local data collection and [2013–14 National Paediatric Diabetes Audit](#).

b) Evidence of local arrangements and written protocols to ensure that children and young people with type 2 diabetes are offered a programme of diabetes education from diagnosis that is updated at least annually.

**Data source:** Local data collection and [2013–14 National Paediatric Diabetes Audit](#).

#### **Process**

a) Proportion of children and young people with type 1 diabetes who are offered a programme of diabetes education from diagnosis that is updated at least annually.

**Numerator** – the number in the denominator who receive a programme of diabetes education from diagnosis that is updated at least annually.

**Denominator** – the number of children and young people with type 1 diabetes.

**Data source:** Local data collection and 2013–14 National Paediatric Diabetes Audit.

b) Proportion of children and young people with type 2 diabetes who are offered a programme of diabetes education from diagnosis that is updated at least annually.

Numerator – the number in the denominator who receive a programme of diabetes education from diagnosis that is updated at least annually.

Denominator – the number of children and young people with type 2 diabetes.

**Data source:** Local data collection and 2013–14 National Paediatric Diabetes Audit.

## Outcome

a) Quality of life.

**Data source:** Local data collection.

b) HbA1c level of 48 mmol/mol or lower.

**Data source:** Local data collection and 2013–14 National Paediatric Diabetes Audit.

c) Satisfaction of children, young people and their family members or carers (as appropriate) with the education intervention.

**Data source:** Local data collection and 2013–14 National Paediatric Diabetes Audit.

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (secondary care diabetes services for children and young people) ensure that systems are in place to offer children and young people with type 1 or type 2 diabetes and their family members or carers (as appropriate) a programme of diabetes education from diagnosis that is tailored to their individual needs and learning styles and updated at least annually.

**Healthcare professionals** (such as those providing diabetes services for children and young people) offer children and young people with type 1 or type 2 diabetes and their family members or carers

(as appropriate) a programme of diabetes education from diagnosis that is tailored to their individual needs and learning styles and updated at least annually.

Commissioners (NHS England regional teams and clinical commissioning groups) commission services that offer children and young people with type 1 or type 2 diabetes and their family members or carers (as appropriate) a programme of diabetes education from diagnosis that is updated at least annually.

### *What the quality statement means for children and young people and their parents and carers*

Children and young people with type 1 or type 2 diabetes and their family members or carers are offered a programme of diabetes education when they are diagnosed with diabetes. This education should continue throughout their life, and be updated every year.

The programme should teach them what they need to know about their condition and what changes they might need to make now that they have diabetes. This includes clear advice (designed specifically for each child or young person) on what to do when they are ill or have high blood glucose levels.

### *Source guidance*

- [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18, recommendations 1.2.1, 1.2.73 and 1.3.1.

### *Definitions of terms used in this quality statement*

#### **Programme of diabetes education (type 1 diabetes)**

A continuing programme of education that is age appropriate, tailored to need and revisited at least annually. The following core topics should be included from diagnosis:

- insulin therapy, including its aims, how it works, its mode of delivery and dosage adjustment
- blood glucose monitoring, including targets for blood glucose control (blood glucose and HbA1c levels)
- the effects of diet, physical activity and intercurrent illness on blood glucose control



- managing intercurrent illness ('sick-day rules', including monitoring of blood ketones [beta-hydroxybutyrate])
- detecting and managing hypoglycaemia, hyperglycaemia and ketosis.

[Adapted from [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management](#) (2015) NICE guideline NG18, recommendation 1.2.1 and expert opinion]

### **Programme of diabetes education (type 2 diabetes)**

A continuing programme of education that is age appropriate, tailored to need and revisited at least annually. The following core topics should be included from diagnosis:

- HbA1c monitoring and targets
- the effects of diet, physical activity, body weight and intercurrent illness on blood glucose control
- the aims of metformin therapy and possible adverse effects
- the complications of type 2 diabetes and how to prevent them.

[Adapted from [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management](#) (2015) NICE guideline NG18, recommendation 1.3.1 and expert opinion]

### ***Equality and diversity considerations***

Particular care should be taken when communicating with children and young people with type 1 or type 2 diabetes and their family members or carers (as appropriate) if they have, for example:

- physical, cognitive or sensory disabilities
- difficulties speaking or reading English.

## Quality statement 3: Intensive insulin therapy and level 3 carbohydrate-counting education for type 1 diabetes

### *Quality statement*

Children and young people with type 1 diabetes are offered intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis.

### *Rationale*

The aim of intensive insulin therapy is to reach near-normal blood glucose levels, to reduce the risk of long-term complications and improve quality of life. Dietary management can also improve control of blood glucose and HbA1c levels. When using intensive insulin therapy it is important to match the insulin dose to carbohydrate intake, in line with individualised insulin-to-carbohydrate ratios (level 3 carbohydrate-counting). Children and young people and their family members or carers (as appropriate) should be taught how to do this at diagnosis.

### *Quality measures*

#### **Structure**

Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 1 diabetes are offered intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis.

**Data source:** Local data collection.

#### **Process**

Proportion of children and young people with type 1 diabetes who are offered intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis.

Numerator – the number in the denominator who receive intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis.

Denominator – the number of children and young people with type 1 diabetes.

**Data source:** Local data collection.

## Outcome

a) HbA1c level of 48 mmol/mol or lower.

*Data source:* Local data collection and [2013–14 National Paediatric Diabetes Audit](#).

b) Quality of life.

*Data source:* Local data collection and [2013–14 National Paediatric Diabetes Audit](#).

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (secondary care diabetes services for children and young people) ensure that systems are in place to offer intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis to children and young people with type 1 diabetes.

**Healthcare professionals** (those providing diabetes services for children and young people) offer intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis to children and young people with type 1 diabetes.

**Commissioners** (NHS England regional teams and clinical commissioning groups) commission services that offer intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis to children and young people with type 1 diabetes.

### *What the quality statement means for children and young people and their parents and carers*

**Children and young people with type 1 diabetes** are offered intensive insulin therapy (either multiple daily injections or an insulin pump) and level 3 carbohydrate-counting education at diagnosis.

'Multiple daily injections' means injecting a long-acting (slow) insulin once or twice a day, and a rapid-acting (fast) insulin before eating. An insulin pump is a small machine connected to your body that gives you insulin throughout the day, so you don't need to inject yourself.

'Level 3 carbohydrate counting' means counting the carbohydrates in your food and drink, so you can make sure you are injecting the right amount of insulin.

## Source guidance

- [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18, recommendations 1.2.19 and 1.2.37 (key priorities for implementation).

## Definitions of terms used in this quality statement

### Intensive insulin therapy

Insulin therapy is aimed at reaching near-normal blood glucose levels. There are 2 types of intensive insulin therapy:

#### *Multiple daily injection basal-bolus insulin regimens*

An intermediate or long-acting insulin that is usually injected once or twice a day (basal), and a rapid-acting insulin that is injected as needed before each meal and snack.

[Adapted from [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18 (full guideline) and expert opinion]

#### *Continuous subcutaneous insulin infusion (insulin pump therapy)*

A programmable pump and insulin storage device that delivers a background or basal supply of insulin (either a rapid-acting analogue or a short-acting insulin) and boluses of insulin as needed, through a subcutaneous needle or cannula.

[Adapted from [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18 (full guideline) and expert opinion]

### Level 3 carbohydrate counting

Carbohydrate counting for people with type 1 diabetes who are using intensive insulin regimens (multiple daily injections or insulin pump) involves calculating insulin-to-carbohydrate ratios that are individualised according to age, sex, pubertal status, duration of diabetes, time of day and activity. Pre-meal insulin is adjusted according to the estimated carbohydrate content of meals and snacks using the specified insulin-to-carbohydrate ratios.

[Adapted from [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18 (full guideline) and expert opinion]

## *Equality and diversity considerations*

Particular care should be taken when communicating with children and young people with type 1 diabetes and their family members or carers (as appropriate) if they have, for example:

- physical, cognitive or sensory disabilities
- different cultural, ethnic or family traditions to the healthcare professional
- difficulties speaking or reading English.

## Quality statement 4: Continuous glucose monitoring in type 1 diabetes

### *Quality statement*

Children and young people with type 1 diabetes who have frequent severe hypoglycaemia are offered ongoing real-time continuous glucose monitoring with alarms.

### *Rationale*

Continuous glucose monitoring helps children and young people with type 1 diabetes and their family members or carers (as appropriate) to respond more quickly to changes in blood glucose levels throughout the day. For children and young people with frequent severe hypoglycaemia (particularly those who have difficulty recognising or reporting it), continuous glucose monitoring can help to improve their control of blood glucose and HbA1c levels.

### *Quality measures*

#### **Structure**

Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 1 diabetes who have frequent severe hypoglycaemia are offered ongoing real-time continuous glucose monitoring with alarms.

**Data source:** Local data collection.

#### **Process**

Proportion of children and young people with type 1 diabetes with frequent severe hypoglycaemia who are offered ongoing real-time continuous glucose monitoring with alarms.

Numerator – the number in the denominator who receive ongoing real-time continuous glucose monitoring with alarms.

Denominator – the number of children and young people with type 1 diabetes who have frequent severe hypoglycaemia.

**Data source:** Local data collection.

## Outcome

a) HbA1c level of 48 mmol/mol or lower.

*Data source:* Local data collection and [2013–14 National Paediatric Diabetes Audit](#).

b) Quality of life.

*Data source:* Local data collection and [2013–14 National Paediatric Diabetes Audit](#).

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (secondary care providers) ensure that systems are in place to offer ongoing real-time continuous glucose monitoring with alarms to children and young people with type 1 diabetes who have frequent severe hypoglycaemia.

**Healthcare professionals** (such as consultants) offer ongoing real-time continuous glucose monitoring with alarms to children and young people with type 1 diabetes who have frequent severe hypoglycaemia.

**Commissioners** (NHS England regional teams) commission services that offer ongoing real-time continuous glucose monitoring with alarms to children and young people with type 1 diabetes who have frequent severe hypoglycaemia.

### *What the quality statement means for children and young people and their parents and carers*

**Children and young people with type 1 diabetes who have frequent severe hypoglycaemia (a hypo that they need help from someone else to treat)** are offered ongoing real-time continuous glucose monitoring with alarms. This is special equipment that checks the person's blood glucose all the time, without them having to do finger-prick tests. It sounds an alarm if blood glucose levels fall too low.

## Source guidance

- [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18, recommendation 1.2.62 (key priority for implementation)

## *Definitions of terms used in this quality statement*

### **Frequent severe hypoglycaemia**

Having low blood glucose levels that require assistance from another person to treat. 'Frequent' is when this is happening often enough to have a significant impact on school, work or quality of life.

[Expert opinion and [Diabetes.co.uk](http://Diabetes.co.uk)]

### **Ongoing real-time continuous glucose monitoring with alarms**

A type of system for continually monitoring glucose. 'Ongoing' means the device is used for weeks, months or longer. 'Real-time continuous' means the device takes real-time measurements for as long as it is worn.

[Expert opinion and [Juvenile Diabetes Research Foundation](http://Juvenile Diabetes Research Foundation)]



## Quality statement 5: Blood ketone monitoring in type 1 diabetes

### *Quality statement*

Children and young people with type 1 diabetes are offered blood ketone testing strips and a blood ketone meter.

### *Rationale*

Insufficient insulin can lead to increased ketone levels which, if untreated, can lead to progressive dehydration and diabetic ketoacidosis (DKA). The risk of DKA is increased if a child or young person with type 1 diabetes has an illness such as flu or a urinary tract infection, or has missed some insulin doses. NICE's guideline on [diabetes in children and young people](#) suggests that blood ketone testing is more cost effective than urine ketone testing for preventing hospital admission during intercurrent illness. It is important not to use out-of-date testing strips because the result might not be accurate. Education on how to prevent, detect and manage increased ketone levels is also vital.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that children and young people with type 1 diabetes are offered blood ketone testing strips and a blood ketone meter.

**Data source:** Local data collection.

#### **Process**

Proportion of children and young people with type 1 diabetes who receive blood ketone testing strips and a blood ketone meter.

Numerator – the number in the denominator who receive blood ketone testing strips and a blood ketone meter.

Denominator – the number of children and young people with type 1 diabetes.

**Data source:** Local data collection.

## Outcome

a) DKA.

*Data source:* Local data collection and 2013–14 National Paediatric Diabetes Audit.

b) Hospital admission rates.

*Data source:* Local data collection and 2013–14 National Paediatric Diabetes Audit.

c) Mortality.

*Data source:* Local data collection and 2013–14 National Paediatric Diabetes Audit.

d) Satisfaction of children and young people with type 1 diabetes and their family members or carers (as appropriate) with blood ketone testing strips and blood ketone meters.

*Data source:* Local data collection.

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (primary and secondary care providers) ensure that systems are in place to offer children and young people with type 1 diabetes blood ketone testing strips and a blood ketone meter.

**Healthcare professionals** (such as GPs and consultants) offer children and young people with type 1 diabetes blood ketone testing strips and a blood ketone meter, and advise them and their parents or carers on how to prevent, detect and manage increased ketone levels.

**Commissioners** (clinical commissioning groups) commission services that offer children and young people with type 1 diabetes blood ketone testing strips and a blood ketone meter.

### *What the quality statement means for children and young people and their parents and carers*

**Children and young people with type 1 diabetes** are offered blood ketone testing strips and a blood ketone meter to measure ketones in their blood. When people need more insulin (because they are

ill or have missed some insulin doses) their body makes ketones, and too many ketones can make people very ill – this is called diabetic ketoacidosis, or DKA for short.

### *Source guidance*

- [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18, recommendation 1.2.74 (key priority for implementation)

### *Equality and diversity considerations*

Particular care should be taken when communicating with children and young people with type 1 diabetes and their family members or carers (as appropriate) if they have, for example:

- physical, cognitive or sensory disabilities
- difficulties speaking or reading English.

## Quality statement 6: Access to mental health professionals with an understanding of type 1 or type 2 diabetes

### *Quality statement*

Children and young people with type 1 or type 2 diabetes are offered access to mental health professionals with an understanding of diabetes.

### *Rationale*

Psychological issues (such as anxiety, depression, behavioural problems, eating disorders, conduct disorders and family conflict) and psychosocial issues have a significant and adverse impact on the management of type 1 and type 2 diabetes, and on the general wellbeing of children and young people and their family members or carers.

Children and young people with diabetes are at high risk of anxiety and depression, and it is important that they have early access to mental health professionals when they need it. Mental health professionals who have an understanding of diabetes and the particular problems it causes are essential for delivering psychological interventions and engaging with children, young people and their families.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that children and young people with type 1 or type 2 diabetes are offered access to mental health professionals with an understanding of diabetes.

*Data source:* Local data collection and [2013–14 National Paediatric Diabetes Audit](#).

#### **Process**

a) Proportion of children and young people with type 1 diabetes who are offered access to mental health professionals with an understanding of diabetes.

Numerator – the number in the denominator who have access to mental health professionals with an understanding of diabetes.

Denominator – the number of children and young people with type 1 diabetes.

**Data source:** Local data collection and 2013–14 National Paediatric Diabetes Audit.

b) Proportion of children and young people with type 2 diabetes who are offered access to mental health professionals with an understanding of diabetes.

Numerator – the number in the denominator who have access to mental health professionals with an understanding of diabetes.

Denominator – the number of children and young people with type 2 diabetes.

**Data source:** Local data collection and 2013–14 National Paediatric Diabetes Audit.

## Outcome

a) Self-management of type 1 and type 2 diabetes.

**Data source:** Local data collection.

b) Adverse events (for example, severe hypoglycaemic episodes, diabetic ketoacidosis [DKA] or self-harm).

**Data source:** Local data collection.

c) Quality of life.

**Data source:** Local data collection and 2013–14 National Paediatric Diabetes Audit.

d) Satisfaction of children, young people and their family members or carers (as appropriate) with the intervention.

**Data source:** Local data collection.

e) Anxiety or depression.

**Data source:** Local data collection.

f) School performance or attendance.

*Data source:* Local data collection.

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (secondary care providers) ensure that systems are in place to offer children and young people with type 1 or type 2 diabetes access to mental health professionals with an understanding of diabetes.

**Healthcare professionals** (such as consultants) offer children and young people with type 1 or type 2 diabetes access to mental health professionals who have an understanding of diabetes and the particular problems it causes and can deliver psychological interventions and engage with children, young people and their families.

**Commissioners** (NHS England regional teams and clinical commissioning groups) commission services that offer children and young people with type 1 or type 2 diabetes access to mental health professionals with an understanding of diabetes.

### *What the quality statement means for children and young people and their parents and carers*

**Children and young people with type 1 or type 2 diabetes** are able to see mental health professionals who understand the types of problems people with diabetes can have. The mental health professional should be one of the main members of the diabetes team.

### *Source guidance*

- [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\)](#) NICE guideline NG18, recommendations 1.2.98 and 1.3.37 (key priorities for implementation)

### *Definition of terms used in this quality statement*

#### **Access**

Multidisciplinary paediatric diabetes teams should include a psychologist, and provide access to them in an appropriate timeframe. Each child and young person with type 1 or type 2 diabetes

should have an annual assessment by their multidisciplinary team to decide whether they need support from the psychologist.

[Adapted from [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management](#) (2015) NICE guideline NG18 (full guideline) and expert opinion]

### *Equality and diversity considerations*

Particular care should be taken when communicating with children and young people with type 1 or type 2 diabetes and their family members or carers (as appropriate) if they have, for example:

- physical, cognitive or sensory disabilities
- difficulties speaking or reading English
- an increased risk of psychological difficulties.

## Using the quality standard

### *Quality measures*

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [what makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

### *Levels of achievement*

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

NICE's [quality standard service improvement template](#) helps providers to make an initial assessment of their service compared with a selection of quality statements. It includes assessing current practice, recording an action plan and monitoring quality improvement. This tool is updated monthly to include new quality standards.

### *Using other national guidance and policy documents*

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in [development sources](#).



## Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between healthcare professionals and children and young people with type 1 or type 2 diabetes, and their families or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Children and young people with type 1 or type 2 diabetes and their families or carers (if appropriate) should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

## Development sources

Further explanation of the methodology used can be found in the [quality standards process guide](#).

## Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management \(2015\) NICE guideline NG18](#)

## Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- NHS England (2015) [NHS Diabetes Prevention Programme \(NDPP\)](#)
- Department of Health (2015) [Government response to the House of Commons Health Select Committee report on the 'Impact of physical activity and diet on health', Sixth Report of Session 2014–15](#)
- Royal College of Paediatrics and Child Health (2015) [National Paediatric Diabetes Audit Report 2013–14 Part 1: Care processes and outcomes](#)
- Public Health England (2014) [Diabetic eye screening: guidance for commissioners](#)
- NHS England (2014) [Action for diabetes](#)
- Royal College of Nursing (2013) [Supporting children and young people with diabetes](#)
- Diabetes UK (2013) [State of the nation 2013](#)
- Department of Health (2013) [2010 to 2015 government policy: children's health](#)
- Department of Health (2013) [Chief Medical Officer's annual report 2012: Our children deserve better: prevention pays](#)
- Department of Health (2010) [Diabetes type 1 in childhood. National Service Framework for children, young people and maternity services](#)

- Royal College of Paediatrics and Child Health (2009) [Growing up with diabetes: children and young people with diabetes in England](#)

### *Definitions and data sources for the quality measures*

- Health & Social Care Information Centre (2015) [National Diabetes Audit 2012–2013, Report 2](#)
- Health & Social Care Information Centre (2014) [National Diabetes Audit 2012–2013, Report 1: Care processes and treatment targets](#)

## Related NICE quality standards

### *Published*

- [Medicines optimisation](#) (2016) NICE quality standard 120
- [Diabetes in pregnancy](#) (2016) NICE quality standard 109
- [Obesity in children and young people: prevention and lifestyle weight management programmes](#) (2015) NICE quality standard 94
- [Diabetes in adults](#) (2011) NICE quality standard 6

### *In development*

- [Obesity: clinical assessment and management](#). Publication expected August 2016
- [Diabetes in adults \(update\)](#). Publication expected August 2016
- [Early years: promoting health and wellbeing](#). Publication expected August 2016

### *Future quality standards*

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Long-term conditions, people with comorbidities, complex needs.
- Preventing sight loss.

The full list of quality standard topics referred to NICE is available from the [quality standards topic library](#) on the NICE website.

## Quality Standards Advisory Committee and NICE project team

### *Quality Standards Advisory Committee*

This quality standard has been developed by Quality Standards Advisory Committee 1. Membership of this committee is as follows:

**Dr Ivan Benett**

Clinical Director, Central Manchester Clinical Commissioning Group

**Dr Gita Bhutani**

Associate Director for Psychological Professions, Lancashire Care NHS Foundation Trust

**Mrs Jennifer Bostock**

Lay member

**Dr Helen Bromley**

Consultant in Public Health, Cheshire West and Chester Council

**Ms Amanda de la Motte**

Deputy Chief Nurse, South Lincolnshire Clinical Commissioning Group

**Mr Phillip Dick**

Psychiatric Liaison Team Manager, West London Mental Health Trust

**Ms Phyllis Dunn**

Clinical Lead Nurse, University Hospital of North Staffordshire

**Dr Steve Hajioff**

Director of Public Health, London Borough of Hillingdon

**Dr Ian Manifold**

Head of Measures Development, National Peer Review Programme, NHS England

**Mr Gavin Maxwell**

Lay member

**Ms Teresa Middleton**

Deputy Director of Quality, NHS Gloucestershire Clinical Commissioning Group

**Mrs Juliette Millard**

UK Nursing and Health Professions Adviser, Leonard Cheshire Disability

**Hazel Trender**

Senior Vascular Nurse Specialist, Sheffield Teaching Hospital Trust

**Dr Hugo van Woerden**

Director of Public Health, NHS Highland

**Dr Bee Wee (Chair)**

Consultant and Senior Clinical Lecturer in Palliative Medicine, Oxford University Hospitals NHS Trust and Oxford University

**Ms Karen Whitehead**

Strategic Lead Health, Families and Partnerships, Bury Council

**Ms Alyson Whitmarsh**

Programme Head for Clinical Audit, Health and Social Care Information Centre

**Ms Jane Worsley**

Chief Operating Officer, Options Group, Alcester Heath, Warwickshire

**Dr Arnold Zermansky**

GP, Leeds

The following specialist members joined the committee to develop this quality standard:

**Ms Laura Birch**

Paediatric Research Dietitian

**Mrs Jo Dalton**

Diabetes Specialist Nurse – Transition

**Dr Julie Edge**

Consultant in Paediatric Diabetes

**Mr Nikhil Gokani**

Lay member

**Dr Bill Lamb**

Consultant Paediatric Diabetologist

**Mrs Carol Metcalfe**

Lead Paediatric Diabetes Specialist Nurse

### *NICE project team*

**Nick Baillie**

Associate Director

**Karen Slade**

Consultant Clinical Adviser

**Stephanie Birtles**

Technical Adviser

**Sabina Keane**

Lead Technical Analyst

**Esther Clifford**

Programme Manager

**Jenny Mills**

Project Manager

**Jenny Mills and Julia Sus**

Coordinators

## About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).

This quality standard has been incorporated into the NICE pathways on [diabetes in children and young people](#) and [bedwetting \(nocturnal enuresis\) in children and young people](#).

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

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## *Endorsing organisation*

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

## *Supporting organisations*

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Royal College of Paediatrics and Child Health](#)



- Faculty of General Dental Practice