NICE National Institute for Health and Care Excellence



Diabetes in children and young people

Quality standard Published: 14 July 2016 Last updated: 31 March 2022

www.nice.org.uk/guidance/qs125

Contents

Quality statements	4
Quality statement 1: Same-day referral and appointments	5
Quality statement	5
Rationale	5
Quality measures	5
What the quality statement means for different audiences	6
Source guidance	7
Definition of terms used in this quality statement	7
Equality and diversity considerations	7
Quality statement 2: Education and information	8
Quality statement	8
Rationale	8
Quality measures	8
What the quality statement means for different audiences	0
Source guidance 1	1
Definitions of terms used in this quality statement 1	1
Equality and diversity considerations 1	2
Quality statement 3: Intensive insulin therapy and level 3 carbohydrate-counting education for type 1 diabetes	3
Quality statement	3
Rationale	3
Quality measures	3
What the quality statement means for different audiences 14	4
Source guidance	5
Definitions of terms used in this quality statement	5
Equality and diversity considerations 10	6
Quality statement 4: Continuous glucose monitoring in type 1 diabetes	7

Quality statement	17
Rationale	17
Quality measures	17
What the quality statement means for different audiences	18
Source guidance	19
Definitions of terms used in this quality statement	19
Equality and diversity considerations	19
Quality statement 5: Blood ketone monitoring in type 1 diabetes	21
Quality statement	21
Rationale	21
Quality measures	21
What the quality statement means for different audiences	23
Source guidance	23
Equality and diversity considerations	23
Quality statement 6: Access to mental health professionals with an understanding of type 1 or type 2 diabetes	25
Quality statement	25
Rationale	25
Quality measures	25
What the quality statement means for different audiences	27
Source guidance	28
Definitions of terms used in this quality statement	28
Equality and diversity considerations	28
Update information	30
About this quality standard	31
Resource impact	31
Diversity, equality and language	32

This standard is based on NG18.

This standard should be read in conjunction with QS6, QS94, QS109, QS120, QS127, QS131, QS134, QS175 and QS196.

Quality statements

<u>Statement 1</u> 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.

<u>Statement 2</u> 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.

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

<u>Statement 4</u> Children and young people with type 1 diabetes are offered real-time continuous glucose monitoring (rtCGM).

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

<u>Statement 6</u> 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by provider organisations, for example from local referral pathways and service agreements.

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: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

Outcome

Presentations of DKA.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records and audits of admission records.

What the quality statement means for different audiences

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 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.

Children and young peoplewho 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. NICE guideline NG18 (2015, updated 2023), 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 <u>Diabetes UK</u>]

Equality and diversity considerations

Children and young people with suspected diabetes and their family members or carers (as appropriate) should be provided with information that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in <u>NHS England's Accessible Information</u> <u>Standard</u> or the equivalent standards for the devolved nations.

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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

Outcome

a) Quality of life of children and young people with type 1 or type 2 diabetes.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by provider organisations, for

example from patient satisfaction surveys.

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

What the quality statement means for different audiences

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 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.

Children and young peoplewith 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. NICE guideline NG18 (2015, updated 2023), recommendations 1.2.1, 1.2.2, 1.2.82, 1.3.2 and 1.3.3

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, how to take it and how to adjust the dosage
- blood glucose monitoring, including continuous glucose monitoring, blood glucose and HbA1c targets, and time-in-range targets
- how diet, physical activity and intercurrent illness affect blood glucose levels
- managing intercurrent illness ('sick-day rules', including monitoring of blood ketones [beta-hydroxybutyrate])
- detecting and managing hypoglycaemia, hyperglycaemia and ketosis
- the importance of good oral hygiene and regular oral health reviews for preventing periodontitis.

[Adapted from <u>NICE's guideline on diabetes (type 1 and type 2) in children and young</u> people, recommendations 1.2.1, 1.2.2 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:

- the importance of managing glucose levels, including achieving and maintaining glucose and HbA1c targets
- how and when to take capillary blood glucose measurements (self-monitoring)
- how diet, increasing physical activity and reducing body weight can reduce the symptoms of type 2 diabetes and lead to remission
- how diet, physical activity, body weight and intercurrent illness affect blood glucose levels
- how metformin can help, and its possible adverse effects
- the complications of type 2 diabetes and how to prevent them.

The importance of regular oral health reviews should also be included. [Adapted from NICE's guideline on diabetes (type 1 and type 2) in children and young people, recommendation 1.3.2, 1.3.3, 1.3.91 and expert opinion]

Equality and diversity considerations

Children and young people with diabetes and their family members or carers (as appropriate) should be provided with information that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in <u>NHS England's Accessible Information</u> <u>Standard</u> or the equivalent standards for the devolved nations.

Quality statement 3: Intensive insulin therapy and level 3 carbohydratecounting 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by provider organisations, for

example from clinical protocols.

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: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

Outcome

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

b) Quality of life of children and young people with type 1 diabetes.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient satisfaction surveys.

What the quality statement means for different audiences

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 commission services that offer intensive insulin therapy and level 3 carbohydrate-counting education at diagnosis to children and young people with type 1 diabetes.

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. NICE guideline NG18 (2015, updated 2023), recommendations 1.2.18, 1.2.19 and 1.2.38

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 <u>NICE's 2015 full guideline on diabetes (type 1 and type 2) in children and</u> young people 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 <u>NICE's 2015</u> <u>full guideline on diabetes (type 1 and type 2) in children and young people</u> 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 <u>NICE's 2015 full guideline on diabetes (type 1 and type 2) in children and young people</u> and expert opinion]

Equality and diversity considerations

Children and young people with type 1 diabetes and their family members or carers (as appropriate) should be provided with information on intensive insulin therapy and level 3 carbohydrate counting that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in <u>NHS England's Accessible Information</u> <u>Standard</u> or the equivalent standards for the devolved nations.

Quality statement 4: Continuous glucose monitoring in type 1 diabetes

Quality statement

Children and young people with type 1 diabetes are offered real-time continuous glucose monitoring (rtCGM).

Rationale

rtCGM helps children and young people with type 1 diabetes and their family members or carers (as appropriate) respond more quickly to changes in blood glucose levels throughout the day. It also leads to a decrease in HbA1c and an increase in time spent within the target range. The monitor can be connected to a phone or device belonging to the child or young person, or their parent or carer, so they can easily track the data and share it with their healthcare professionals when needed. For children and young people with frequent severe hypoglycaemia (particularly those who have difficulty recognising or reporting it), continuous glucose monitoring can help improve their control of blood glucose and HbA1c levels.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

Evidence of local arrangements to ensure that rtCGM is available to all children and young people with type 1 diabetes.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from procurement records.

Process

Proportion of children and young people with type 1 diabetes who receive rtCGM.

Numerator – the number in the denominator who receive rtCGM.

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

Outcome

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

b) Time in range.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

c) Quality of life of children and young people with type 1 diabetes.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient satisfaction surveys. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

What the quality statement means for different audiences

Service providers (secondary care providers) ensure that systems are in place to offer rtCGM to children and young people with type 1 diabetes. They should ensure education is

provided alongside rtCGM to support children and young people and their families and carers to use it.

Healthcare professionals (such as consultants and diabetes specialist nurses) offer rtCGM to children and young people with type 1 diabetes and provide education alongside it to support them and their families and carers to use rtCGM.

Commissioners commission services that offer rtCGM to children and young people with type 1 diabetes. They also ensure that the services provide education and support to use rtCGM to children, young people and their families.

Children and young people with type 1 diabetes are offered real-time continuous glucose monitoring. This is special equipment that checks the person's blood glucose in real time, without them having to do finger-prick tests.

Source guidance

Diabetes (type 1 and type 2) in children and young people: diagnosis and management. NICE guideline NG18 (2015, updated 2023), recommendation 1.2.60

Definitions of terms used in this quality statement

Real-time continuous glucose monitoring

Continuous glucose monitoring gives information about glucose levels every few minutes. The person using it has a sensor that measures the glucose level in the tissue just below the skin. 'Real-time continuous' means the device takes real-time measurements for as long as it is worn. [Expert opinion and <u>Juvenile Diabetes Research Foundation (JDRF)</u>]

Equality and diversity considerations

Children and young people with type 1 diabetes living in deprived areas are less likely to use rtCGM. This is also the case for Black and Asian children and young people. It is therefore important for the services to work closely with these groups to ensure that they are aware of the benefits of rtCGM and that they can access it and any additional equipment if they want to use it. Children and young people with type 1 diabetes and their family members or carers (as appropriate) should be provided with information about rtCGM that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in <u>NHS England's Accessible Information</u> <u>Standard</u> or the equivalent standards for the devolved nations.

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. <u>NICE's guideline on diabetes (type 1 and type 2) in children and young people</u> 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from local protocols.

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: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

Outcome

a) DKA.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

b) Hospital admission rates of children and young people with type 1 diabetes.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Included in the Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit.

c) 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: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient satisfaction surveys.

What the quality statement means for different audiences

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 commission services that offer children and young people with type 1 diabetes blood ketone testing strips and a blood ketone meter.

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. NICE guideline NG18 (2015, updated 2023), recommendation 1.2.83

Equality and diversity considerations

Children and young people with type 1 diabetes and their family members or carers (as appropriate) should be provided with information about blood ketone monitoring that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss,

information should be provided as set out in <u>NHS England's Accessible Information</u> <u>Standard</u> or the equivalent standards for the devolved nations.

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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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: Data can be collected from information recorded locally by provider organisations, for example from local referral pathways and service agreements.

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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

Outcome

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

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

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

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

c) Quality of life of children and young people with type 1 or type 2 diabetes.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records and satisfaction surveys.

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

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient satisfaction surveys.

e) Anxiety or depression in children and young people with type 1 or type 2 diabetes.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

f) School performance or attendance of children and young people with type 1 or type 2 diabetes.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records and school attendance records.

What the quality statement means for different audiences

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 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.

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. NICE guideline NG18 (2015, updated 2023), recommendations 1.2.107 and 1.3.68

Definitions 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 <u>NICE's 2015 full</u> guideline on diabetes (type 1 and type 2) in children and young people and expert opinion]

Equality and diversity considerations

Children and young people with diabetes and their family members or carers (as appropriate) should be provided with information from mental health professionals that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed. For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in <u>NHS England's Accessible Information</u> <u>Standard</u> or the equivalent standards for the devolved nations.

Update information

March 2022: Changes have been made to align this quality standard with the updated <u>NICE guideline on diabetes (type 1 and type 2) in children and young people</u>. Statement 4 has been updated to reflect changes to the guidance on continuous glucose monitoring for type 1 diabetes. Links, definitions, data sources and source guidance sections have also been updated throughout.

Minor changes since publication

May 2023: Changes have been made to align this quality standard with the updated <u>NICE</u> <u>guideline on diabetes (type 1 and type 2) in children and young people</u>. Definitions in statement 2 have been updated to reflect revised recommendation wording, and source guidance references have been updated throughout.

June 2022: Changes have been made to align this quality standard with the updated NICE guideline on diabetes (type 1 and type 2) in children and young people. Definitions in statement 2 have been updated to include the prevention of periodontitis.

December 2020: This quality standard has been updated to ensure alignment with the NICE guideline on diabetes (type 1 and type 2) in children and young people. Source guidance references have been amended for statements 2, 3, 4, 5 and 6. The definition of a programme of diabetes education for both type 1 and type 2 diabetes used in statement 2 on education and information has been updated to ensure alignment with this guideline.

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.

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, this may not always be appropriate in practice. Taking account of safety, shared decision making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See our <u>webpage on quality standards advisory committees</u> for details about our standing committees. Information about the topic experts invited to join the standing members is available from the <u>webpage for this quality standard</u>.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource

impact work for the source guidance. Organisations are encouraged to use the <u>resource</u> <u>impact products for NICE's guideline on diabetes (type 1 and type 2) in children and young</u> <u>people: diagnosis and management</u> to help estimate local costs.

Diversity, equality and language

Equality issues were considered during development and <u>equality assessments for this</u> <u>quality standard</u> are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

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.

ISBN: 978-1-4731-1962-8

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 evidencebased 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
- College of General Dentistry