Diabetes in children and young people

NICE quality standard

Draft for consultation

February 2016

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). Also, 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[1] identified 26,500 children and young people with type 1diabetes and 500 with type 2. 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

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[1] National Paediatric Diabetes Audit report 2013–14. Royal College of Paediatrics and Child Health

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
- blood glucose control
- diabetes complications (for example, prevention of diabetic ketoacidosis)
- 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 – patient safety, patient experience and clinical effectiveness – 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 2015–16
- Public Health Outcomes Framework 2013–16.

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

Table 1 [NHS Outcomes Framework 2015–16]

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	***Overarching indicators*** 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare ii Children and young people
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Reducing time spent in hospital by people with long-term conditions** 2.3 ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care *4c Friends and family test* *4d Patient experience characterised as poor or worse* *i Primary care* *ii Hospital care* ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving people's experience of accident and emergency services** 4.3 Patient experience of A&E services **Improving access to primary care services** 4.4 Access to GP services **Improving children and young people's experience of healthcare** *4.8 Children and young people's experience of inpatient services* **Improving people's experience of integrated care** *4.9 People's experience of integrated care***
Alignment with Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 3 [Public health outcomes framework for England, 2013–16]

Domain	Objectives and indicators
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators***

	2.11 Diet
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.12 Preventable sight loss

Patient experience and safety issues

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 care pathway for diabetes in children and young people. 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 source 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 type 1 diabetes are referred on the same day to a multidisciplinary paediatric diabetes team.

Statement 2. Children and young people with type 1 or type 2 diabetes and their family members or carers are offered a continuing, structured diabetes education programme at diagnosis.

Statement 3. Children and young people with type 1 diabetes are offered multiple daily injection basal–bolus insulin regimens at diagnosis.

Statement 4. Children and young people with type 1 diabetes who are using a multiple daily insulin injection regimen and their family members or carers are offered level 3 carbohydrate-counting education at diagnosis, and at least annual repeated intervals thereafter.

Statement 5. Children and young people with type 1 diabetes are supported to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

Statement 6. Children and young people with type 1 diabetes who have frequent severe hypoglycaemia or an impaired awareness of their hypoglycaemic symptoms are offered ongoing real-time continuous glucose monitoring with alarms.

Statement 7. Children and young people with type 1 diabetes are offered blood ketone testing strips and a blood ketone meter.

Statement 8. Mental health professionals with an understanding of diabetes are core members of the multidisciplinary paediatric diabetes team.

Questions for consultation

Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these systems and structures to be put in place?

Question 3 Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

Question 4: Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources required to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Question 5 The final quality standards should highlight a small number of priorities for improvement. Can you tell us what the 5 most important statements within this standard are?

Questions about the individual quality statements

Question 6 For draft quality **s**tatement 2: To aid measurability how many times per year would children and young people receive this education programme?

Question 7 For draft quality statements 3 and 4: As quality statements 3 and 4 aim to be delivered at diagnosis could these be merged into a single statement. Please detail your answer.

Quality statement 1: Same-day referral

Quality statement

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

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, 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 type 1 diabetes are referred on the same day to a multidisciplinary paediatric diabetes team.

Data source: Local data collection.

Process

Proportion of children and young people presenting in primary care with suspected type 1 diabetes who are referred on the same day to a multidisciplinary paediatric diabetes team.

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

Denominator – the number of children and young people presenting in primary care with suspected type 1 diabetes.

Data source: Local data collection.

Outcome

a) Presentations of diabetic ketoacidosis.

Data source: Local data collection.

b) Prompt diagnosis of type 1 diabetes.

Data source: Local data collection.

c) Immediate care.

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 to refer children and young people presenting in primary care with suspected type 1 diabetes on the same day to a multidisciplinary paediatric diabetes team.

Healthcare professionals (such as GPs) ensure to refer children and young people presenting in primary care with suspected type 1 diabetes on the same day to a multidisciplinary paediatric diabetes team.

Commissioners (NHS England area teams and clinical commissioning groups) commission services that make sure children and young people presenting in primary care with suspected type 1 diabetes are referred on the same day to a multidisciplinary paediatric diabetes team.

What the quality statement means for patients, service users and carers

Children and young people who see their GP with symptoms of suspected type 1 diabetes are referred on the same day to a team that specialises in caring for children and young people with diabetes. The symptoms of suspected type 1 diabetes include feeling thirstier and more tired than normal, needing to pass urine more often, 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

Multidisciplinary paediatric diabetes team

A team that consists, as a minimum, of:

- a paediatric consultant
- a paediatric diabetes nurse specialist
- a paediatric dietitian
- a clinical psychologist involved in the care of children and young people with diabetes.

[Expert opinion]

Symptoms of suspected type 1 diabetes

Children and young peoples' symptoms include increased thirst, increased urination, increased tiredness and recent unexplained weight loss.

[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 and 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 and their family members or carers are offered a continuing, structured diabetes education programme at diagnosis.

Rationale

Education should be a planned life-long process, starting from the point of diagnosis and is an essential ongoing component of diabetes care to enable self-management and reduce the likelihood of complications. 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. The education should contain clear, individualised, annually updated advice on managing diabetes during intercurrent illness or hyperglycaemic episodes helps children and young people to avoid dehydration and diabetic ketoacidosis.

Quality measures

Structure

a) Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 1 diabetes are offered a continuing, structured diabetes education programme at diagnosis.

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

b) Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 2 diabetes are offered a continuing, structured diabetes education programme at diagnosis.

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

c) Evidence of local arrangements and written clinical protocols to ensure that children and young people with diabetes and their family members or carers are given clear, individualised, annually updated advice on what to do during intercurrent illness or hyperglycaemic episodes.

Data source: Local data collection.

Process

a) Proportion of children and young people newly diagnosed with type 1 diabetes who are offered a continuing, structured diabetes education programme at diagnosis.

Numerator – the number in the denominator who receive a continuing, structured diabetes education programme at diagnosis.

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

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

b) Proportion of children and young people newly diagnosed with type 2 diabetes who are offered a continuing, structured diabetes education programme at diagnosis.

Numerator – the number in the denominator who receive a continuing, structured diabetes education programme at diagnosis.

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

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

c) Proportion of children and young people with diabetes who receive individualised advice on what to do during intercurrent illness or hyperglycaemic episodes.

Numerator – the number in the denominator who receive individualised advice on what to do during intercurrent illness or hyperglycaemic episodes.

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

Data source: Local data collection.

Outcome

a) Quality of life.

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

b) Blood glucose control.

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

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

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

d) Hospital admissions for diabetic ketoacidosis in children and young people with known type 1 diabetes.

Data source: Local data collection.

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

Service providers (children and young people's diabetes secondary care services) 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 a continuing, structured diabetes education programme at diagnosis. This information will also contain individualised, annually updated management advice on what to do during intercurrent illness or hyperglycaemic episodes to children and young people with diabetes.

Healthcare professionals (such as those involved in children and young people's diabetes services) offer children and young people with type 1 or type 2 diabetes and their family members or carers a continuing, structured diabetes education programme at diagnosis. This includes individualised, annually updated management advice on what to do during intercurrent illness or hyperglycaemic episodes to children and young people with diabetes

Commissioners (NHS England area 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 a continuing, structured diabetes education programme at diagnosis. This includes individualised, annually updated management advice on what to do during intercurrent illness or hyperglycaemic episodes to children and young people with diabetes.

What the quality statement means for patients, service users and carers

Children and young people with type 1 or type 2 diabetes and their family members or carers are offered an education programme when they are diagnosed with diabetes. This 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 management advice, designed specifically for them, on what to do when they are ill or have high blood glucose levels. This advice should be updated every year.

Source guidance

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

Definitions of terms used in this quality statement

Type 1 diabetes education programme for children and young people and their family members or carers

A structured, age-appropriate continuing programme of education that should include the following core topics from diagnosis of type 1 diabetes:

- 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.

[Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18, recommendation 1.2.1]

Type 2 diabetes education programme for children and young people and their family members or carers

A structured, age-appropriate continuing programme of education that should include the following core topics from diagnosis of type 2 diabetes:

- 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.

[Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18, recommendation 1.3.1]

Individualised, annually updated advice

Oral and written management advice about type 1 diabetes during intercurrent illness or hyperglycaemic episodes. It should cover:

- monitoring blood glucose
- monitoring and interpreting blood ketones (beta-hydroxybutyrate)
- adjusting insulin regimen
- food and fluid intake
- when and where to seek further advice or help.

The advice provided to the child or young person and their family members or carers (as appropriate) should be repeated at least annually.

[Adapted from Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18 recommendation 1.2.73 and 1.3.1]

Intercurrent illness

Illness associated with fever tends to raise blood glucose due to higher levels of stress hormones, gluconeogenesis and insulin resistance. Illness associated with vomiting and diarrhoea (for example, gastroenteritis) may lower blood glucose and possibility cause hypoglycaemia.

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

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 and sensory disabilities
- difficulties speaking or reading English

Question for consultation

To aid measurability how many times per year would children and young people receive this education programme?

Quality statement 3: Intensive insulin therapy for type 1 diabetes

Quality statement

Children and young people with type 1 diabetes are offered multiple daily injection basal–bolus insulin regimens at diagnosis.

Rationale

A multiple daily injection basal–bolus insulin regimen is designed to replicate the pattern of insulin release in people without diabetes. It should cover basal insulin requirements throughout the day, and match meal-time insulin doses to food intake. The aim is to reach near-normal blood glucose levels, to reduce the risk of long-term complications and improve quality of life.

Quality measures

Structure

Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 1 diabetes are offered multiple daily injection basal–bolus insulin regimens at diagnosis.

Data source: Local data collection.

Process

Proportion of children and young people with type 1 diabetes who receive multiple daily injection basal–bolus insulin regimens at diagnosis.

Numerator – the number in the denominator who receive multiple daily injection basal–bolus insulin regimens at diagnosis.

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

Data source: Local data collection.

Outcome

a) Blood glucose control.

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 (children and young people's diabetes secondary care services) ensure that systems are in place to offer children and young people with type 1 diabetes multiple daily injection basal–bolus insulin regimens at diagnosis.

Healthcare professionals (those involved in children and young people's diabetes services) offer children and young people with type 1 diabetes multiple daily injection basal–bolus insulin regimens at diagnosis.

Commissioners (Clinical commissioning groups) commission services that offer children and young people with type 1 diabetes multiple daily injection basal–bolus insulin regimens at diagnosis.

What the quality statement means for patients, service users and carers

Children and young people with type 1 diabetes are offered multiple daily injection basal–bolus insulin regimens when they are diagnosed with diabetes. 'Multiple daily injections' means injecting a long-acting (slow) insulin once or twice a day, and a rapid-acting (fast) insulin before eating.

Source guidance

- Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18, recommendation 1.2.19 (key priority for implementation)

Definition of terms used in this quality statement

Multiple daily injection basal–bolus insulin regimens

A long-acting insulin that is injected once or twice a day and a rapid-acting insulin that is injected before each meal and snack. The aim is to reach near-normal blood glucose levels.

[Adapted from Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18 (full version) 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 if they have, for example:

- Physical, cognitive and sensory disabilities
- difficulties speaking or reading English

Question for consultation

As draft quality statements 3 and 4 aim to be delivered at diagnosis could these be merged into a single statement. Please detail your answer.

Quality statement 4: Level 3 carbohydrate-counting education with type 1 diabetes

Quality statement

Children and young people with type 1 diabetes who are using a multiple daily insulin injection regimen and their family members or carers are offered level 3 carbohydrate-counting education at diagnosis, and at least annual repeated intervals thereafter.

Rationale

When using multiple daily insulin injection regimens it is important to match insulin dose to carbohydrate intake, in line with insulin-to-carbohydrate ratios. To do this, children and young people and their family members or carers need to be taught how to count the carbohydrate content of foods (level 3 carbohydrate counting). Dietary management can also improve glycaemic control.

Quality measures

Structure

Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 1 diabetes who are using a multiple daily insulin injection regimen and their family members or carers are offered level 3 carbohydrate-counting education at diagnosis, and at least annual repeated intervals thereafter.

Data source: Local data collection.

Process

a) Proportion of children and young people with type 1 diabetes using multiple daily injection basal–bolus insulin regimens who receive level 3 carbohydrate-counting education at diagnosis.

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

Denominator – the number of children and young people with type 1 diabetes who are newly diagnosed and are using multiple daily injection basal–bolus insulin regimens.

Data source: Local data collection.

a) Proportion of children and young people with type 1 diabetes using multiple daily injection basal–bolus insulin regimens who are offered level 3 carbohydrate-counting education at least annual repeated intervals after diagnosis.

Numerator – the number in the denominator who are receive level 3 carbohydrate-counting education at diagnosis, and at least annual repeated intervals after diagnosis.

Denominator – the number of children and young people with type 1 diabetes who are using multiple daily injection basal–bolus insulin regimens.

Data source: Local data collection.

Outcome

a) Blood glucose control.

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 for level 3 carbohydrate counting education to be offered at diagnosis to children and young people with type 1 diabetes who are using multiple daily insulin injection regimens and their family members or carers, and at least annual repeated intervals thereafter.

Healthcare professionals (such as consultants) offer level 3 carbohydrate counting education at diagnosis to children and young people with type 1 diabetes who are using multiple daily insulin injection regimens and their family members or carers, and at least annual repeated intervals thereafter.

Commissioners (Clinical commissioning groups) commission services that offer level 3 carbohydrate counting education at diagnosis to children and young people with type 1 diabetes who are using multiple daily insulin injection regimens and their family members or carers, and at least annual repeated intervals thereafter.

What the quality statement means for patients, service users and carers

Children and young people who are using multiple daily injection basal–bolus insulin regimens, and their family members or carers are offered level 3 carbohydrate-counting education when they are diagnosed with type 1 diabetes. ‘Multiple daily injections’ means injecting a long-acting (slow) insulin once or twice a day, and a rapid-acting (fast) insulin before eating. ‘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, recommendation 1.2.37 (key priority for implementation) and expert opinion]

Definitions of terms used in this quality statement

Level 3 carbohydrate-counting education

Carbohydrate counting for people with type 1 diabetes who are using multiple daily injection basal–bolus insulin regimens. It 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.

Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18 (full version)

Multiple daily injection basal–bolus insulin regimens

A long-acting insulin that is injected once or twice a day and a rapid-acting insulin that is injected before each meal and snack. The aim is to reach near-normal blood glucose levels.

[Adapted from Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18 (full version) 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 if they have, for example:

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

Question for consultation

As draft quality statements 3 and 4 aim to be delivered at diagnosis could these be merged into a single statement. Please detail your answer.

Quality statement 5: HbA1c targets for type 1 diabetes

Quality statement

Children and young people with type 1 diabetes are supported to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

Rationale

When agreeing a HbA1c target for glycaemic control in type 1 diabetes, the risks of long-term complications need to be balanced with the short-term risk of hypoglycaemia. An individualised lowest achievable HbA1c target should be discussed with each child or young person with type 1 diabetes and their family members or carers (as appropriate) with 48 mmol/mol (6.5%) or lower the ideal. This target will bring HbA1c levels near normal levels and reduce the risk of long-term complications.

Quality measures

Structure

Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 1 diabetes are supported to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

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

Process

Proportion of children and young people with type 1 diabetes who are supported to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

Numerator – the number in the denominator who are supported to maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

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

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

Outcome

a) Children and young people who achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

Data source: Local data collection

b) Blood glucose control.

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 (primary and secondary care providers) ensure that systems are in place to support children and young people with type 1 diabetes to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

Healthcare professionals (such as GPs and consultants) support children and young people with type 1 diabetes to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

Commissioners (Clinical commissioning groups) commission services that support children and young people with type 1 diabetes to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

What the quality statement means for patients, service users and carers

Children and young people with type 1 diabetes are helped to keep their HbA1c level at 48 mmol/mol (6.5%) or lower.

Source guidance

- Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18, recommendations 1.2.67, 1.2.68 (key priority for implementation), 1.2.69 and 1.2.70.

Definition of terms used in this quality statement

HbA1c level

The blood glucose measure in blood over the last 2 or 3 months.

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 and sensory disabilities
- difficulties speaking or reading English.

Quality statement 6: Continuous glucose monitoring

Quality statement

Children and young people with type 1 diabetes who have frequent severe hypoglycaemia or an impaired awareness of their hypoglycaemic symptoms 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 to respond more quickly to changes in blood glucose concentrations throughout the day. For children and young people in specific circumstances (such as those with frequent severe hypoglycaemia) this can improve their glycaemic control.

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 or an impaired awareness of their hypoglycaemic symptoms are offered ongoing real-time continuous glucose monitoring with alarms.

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

Process

Proportion of children and young people with type 1 diabetes who have frequent severe hypoglycaemia or an impaired awareness of their hypoglycaemic symptoms 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 or an impaired awareness of their hypoglycaemic symptoms.

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

Outcome

a) Blood glucose control.

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 or an impaired awareness of their hypoglycaemic symptoms.

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 or an impaired awareness of their hypoglycaemic symptoms.

Commissioners (Clinical commissioning groups) 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 or an impaired awareness of their hypoglycaemic symptoms.

What the quality statement means for patients, service users and carers

Children and young people with type 1 diabetes who have frequent severe hypoglycaemia or an impaired awareness of their hypoglycaemic symptoms are offered ongoing real-time continuous glucose monitoring with alarms.

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

Severe hypoglycaemia

A hypo makes it hard to stay awake or makes the person pass out.

Impaired awareness of hypoglycaemic symptoms

The person has trouble telling they are having a hypo until they get severe hypoglycaemia.

Ongoing real-time continuous glucose monitoring with alarms

Special equipment that a person with diabetes wears, and that measures their blood glucose all the time without them having to do finger-prick tests.

Quality statement 7: 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

A low insulin level leads to increased ketone levels. If untreated, increased ketone levels lead to progressive dehydration and diabetic ketoacidosis. The risk of diabetic ketoacidosis is increased in a child or young person with type 1 diabetes is ill with an infection such as flu or a urinary tract infection. It's important not to use out-of-date testing strips, or the test might not work properly. NICE's guideline (NG18) 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.

Quality measures

Structure

Evidence of local arrangements and written clinical protocols 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

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

Numerator – the number in the denominator who receive in-date blood ketone testing strips.

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

Data source: Local data collection.

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

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

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

Data source: Local data collection.

Outcome

a) Diabetic ketoacidosis.

Data source: Local data collection.

b) Hospital admission rates.

Data source: Local data collection.

c) Mortality.

Data source: Local data collection.

d) Satisfaction of children, young people and family members with in-date blood ketone testing strips and a blood ketone meter.

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 in-date 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 in-date blood ketone testing strips and a blood ketone meter.

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

What the quality statement means for patients, service users and carers

Children and young people with type 1 diabetes are offered in-date blood ketone testing strips and a blood ketone meter to measure ketones in their blood. When people have high blood glucose levels, their body makes ketones, and too many ketones can make people very ill.

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 and sensory disabilities
- difficulties speaking or reading English.

Quality statement 8: Access to mental health professionals with an understanding of type 1 or 2 diabetes

Quality statement

Mental health professionals with an understanding of diabetes are core members of the multidisciplinary paediatric diabetes team.

Rationale

Psychological (such as anxiety, depression, behavioural and conduct disorders and family conflict) and psychosocial issues can affect the management of type 1 and type 2 diabetes in children and young people. Children and young people with diabetes and their family members or carers are offered timely and ongoing access to mental health professionals via the multidisciplinary paediatric diabetes team.

Quality measures

Structure

Evidence of local arrangements and written clinical protocols to ensure that children and young people with type 1 or type 2 diabetes and their family members or carers have timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

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 receive timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

Numerator – the number in the denominator who receive timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

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 family members and carers of children and young people with type 1 diabetes who receive timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

Numerator – the number in the denominator who receive timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

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

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

c) Proportion of children and young people with type 2 diabetes who receive timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

Numerator – the number in the denominator who receive timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

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

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

d) Proportion of family members and carers of children and young people with type 2 diabetes who receive timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

Numerator – the number in the denominator who receive timely and ongoing access to mental healthcare professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

Denominator – the number of family members and carers 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 2 diabetes.

Data source: Local data collection.

b) Adverse events (for example severe hypoglycaemic episodes, diabetic ketoacidosis 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.

g) Risk-taking behaviours (such as smoking).

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 and their family members or carers timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

Healthcare professionals (such as consultants) offer children and young people with type 1 or type 2 diabetes and their family members or carers timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

Commissioners (NHS England area 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 timely and ongoing access to mental health professionals with an understanding of diabetes who is a core member of a multidisciplinary paediatric diabetes team.

What the quality statement means for patients, service users and carers

Children and young people with type 1 or type 2 diabetes and their family members or carers are able to see mental health professionals who understand the problems people with diabetes can have. The mental health professional should be a core member of a multidisciplinary paediatric 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

Timely and ongoing access

Multidisciplinary paediatric diabetes teams should include a psychologist, and provide timely and ongoing access to them. Ongoing access means that more than 1 appointment is available if needed. 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.

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 if they have, for example:

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

Status of this quality standard

This is the draft quality standard released for consultation from 15 February to 14 March 2016. It is not NICE's final quality standard on diabetes in children and young people. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 14 March 2016. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the NICE website from July 2016.

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. These include indicators developed by the Health and Social Care Information Centre through its Indicators for Quality Improvement Programme. 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.

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 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 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
- Welsh Government (2015) Food and physical activity
- 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
- Welsh Government (2014) Together for Health – a diabetes delivery plan
- NHS England (2014) Action for diabetes
- Scottish Government (2014) Diabetes improvement plan
- 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

- Welsh Government (2013) Together for health-a diabetes delivery plan. A Delivery Plan up to 2016 for NHS Wales and its partners
- 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

- Diabetes in pregnancy (2016) NICE quality standard 109
- Obesity: prevention and lifestyle weight management in children and young people (2015) NICE quality standard 94
- Diabetes in adults (2011) NICE quality standard 6

In development

- Medicines optimisation. Publication expected March 2016.
- Obesity: clinical assessment and management. Publication expected May 2016.
- Diabetes in adults (update). Publication expected June 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

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

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Mrs Jo Dalton

Diabetes Specialist Nurse – Transition

Dr Julie Edge

Consultant in Paediatric Diabetes

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Lay member

Dr Bill Lamb

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Stephanie Birtles

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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 pathway on diabetes 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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