

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

SCOPE

1 Guideline title

Diabetes in children and young people: diagnosis and management of type 1 and type 2 diabetes in children and young people

1.1 *Short title*

Diabetes in children and young people

2 The remit

This is a partial update of 'Type 1 diabetes' (NICE clinical guideline 15). See section 4.3.1 for details of which sections will be updated for children and young people. We will also carry out an editorial review of all recommendations to ensure that they comply with NICE's duties under equalities legislation.

This update is being undertaken as part of the guideline review cycle.

This guideline is being extended to cover type 2 diabetes in children and young people

3 Clinical need for the guideline

3.1 *Epidemiology*

3.1.1 Type 1 diabetes

- a) Type 1 diabetes is an autoimmune disorder resulting in the destruction of insulin-producing cells in the pancreas. It predominantly affects children and young people and inevitably requires insulin replacement treatment.

- b) Around 26,500 children and young people in the UK are estimated to have type 1 diabetes requiring insulin replacement therapy.
- c) Although having an affected relative increases a child's risk of developing type 1 diabetes most children are new cases in the family (though there may be related disorders such as thyroid disease or rheumatoid diseases in the family). Children and young people with a family history of type 1 diabetes have an increased risk of developing type 1 diabetes. (For children with an identical twin with type 1 diabetes the risk of developing the disorder is 1 in 3, for children with a father with type 1 diabetes the risk is 1 in 16, and for children with a mother with type 1 diabetes the risk is 1 in 40. By comparison, the population risk is roughly 1 in 500 although this varies with geographical location.
- d) Children and young people with type 1 diabetes have the worst rates of very high risk glucose control and of the acute metabolic complication diabetic ketoacidosis (DKA). Nine per cent of children and young people with diabetes experienced at least one episode of DKA in 2009–2010.
- e) Systems of surveillance for the early detection of complications in children and young people with type 1 diabetes are important, as is effective management of late complications when they occur.
- f) Good blood glucose control is known to prevent or delay the long-term complications of both type 1 and type 2 diabetes.

3.1.2 Type 2 diabetes

- g) Around 300 children and young people in the UK are estimated to have type 2 diabetes.
- h) Type 2 diabetes is initially an insulin resistant state whose primary treatment is weight loss and exercise. Pharmacological measures to increase insulin sensitivity or increase insulin release may be added to lifestyle interventions and insulin may be required if there

is subsequent beta cell failure. Both types of diabetes have a significant impact on lifestyle in the short term, and are associated with major long-term complications and reduced life expectancy.

- i) Obesity is the most common risk factor for type 2 diabetes. Type 2 diabetes is up to 6 times more common in people of South Asian family origin and up to 3 times more common among people of African and African-Caribbean origin. In Europeans, type 2 diabetes in children is associated with the most severe degrees of obesity.
- j) People from the most deprived socioeconomic backgrounds are two-and-a-half times more likely than average to have type 2 diabetes at any given age.

3.2 Current practice

- a) Fewer than 20% of children and young people with diabetes receive the basic care recommended by NICE guidelines.
- b) Current standard care for children and young people with diabetes includes patient education, dietary advice, psychological support and management of complications. Standard care for children and young people with type 1 diabetes also includes insulin therapy.
- c) For children and young people with type 2 diabetes, first-line routine care includes lifestyle and dietary therapy with metformin to increase insulin sensitivity. If good glycaemic control is not achieved then additional insulin or other agents may be needed.
- d) The aim of patient education is to enable children and young people and/or their parents or carers to live a normal life and minimise the risk of complications. It includes advice on diet, improving glycaemic control and how complications are managed.
- e) Management of hypoglycaemia depends on its severity. Hospital care may be needed if the child or young person is unresponsive or

unconscious but some children and young people can be cared for at home.

- f) Children and young people with diabetes receive an integrated package of care delivered by a multidisciplinary care team specialising in paediatric diabetes, with expertise in clinical, educational, dietetic, lifestyle and psychological management.
- g) Children and young people with type 1 diabetes are monitored for growth and pubertal development, blood pressure, injection site complications, thyroid disease and coeliac disease. From the age of 12 they are also monitored for retinopathy, nephropathy and microalbuminuria. Rare associated conditions (juvenile cataracts, necrobiosis lipoidica, rheumatoid disease and Addison's disease amongst others) may also be considered.
- h) Children and young people with type 1 or type 2 diabetes receive annual foot care reviews. Minor problems (ingrown toenails or verrucas) are common and may be treated by a chiropodist. Serious foot problems are very rare in children and young people.
- i) Psychological and social issues are also important to consider at each clinic visit, and treatment or advice is given where necessary.
- j) There is a process of transition so that from the age of 13, young people are prepared for eventual transfer to adult care. This includes agreed protocols and joint clinics if possible. Young people are given time to familiarise themselves with this process and it is only completed when they are ready to move to adult services. The timing of transition depends on the young person's physical development, emotional maturity, stability of health, other life changes and local circumstances.

4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, 'Further information').

The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

- a) Children and young people (younger than 18 years) with type 1 diabetes.
- b) Children and young people (younger than 18 years) with type 2 diabetes (new 2012).
- c) Where available, evidence will be reported for children and young people by:
 - ethnic group
 - socioeconomic group.

4.1.2 Groups that will not be covered

- a) Young women with diabetes who wish to conceive or who are pregnant.
- b) Children and young people with other forms of diabetes mellitus (for example monogenic diabetes and cystic fibrosis-related diabetes) (new 2012).
- c) Adults (aged 18 years and older) with type 1 diabetes.
- d) Adults (aged 18 years and older) with type 2 diabetes.

4.2 Healthcare setting

All settings in which NHS care is received or commissioned.

The guideline will address the support and advice that the NHS should offer to crèches, nurseries, schools and other institutions.

The guideline will also be relevant to the work but will not cover the practice of:

- social services and the voluntary sector
- services supplied by secondary and tertiary specialties for late complications of diabetes (for example, renal, cardiology, urology and ophthalmology services) to whom patients have been referred
- the education sector.

4.3 *Clinical management*

4.3.1 Key clinical issues that will be covered

Note that guideline recommendations will normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will assume that prescribers will use a drug's summary of product characteristics to inform decisions made with individual patients.

Areas from the original guideline that will be updated

- a) Diagnosis of type 1 diabetes (including distinguishing type 1 and type 2 diabetes).
- b) Structured education programmes and behavioural interventions to improve adherence in children and young people with type 1 diabetes.
- c) Multiple daily injections versus mixed insulin injections in children and young people with type 1 diabetes.
- d) Glucose monitoring strategies in children and young people with type 1 diabetes, including blood glucose targets and methods of monitoring (continuous, frequent or infrequent).

- e) Dietetic advice, including glycaemic index and carbohydrate counting, for children and young people with type 1 diabetes.
- f) Recognition of complications and comorbidities in children and young people with type 1 diabetes (retinopathy and nephropathy).

Areas not in the original guideline that will be included in the update

- g) Structured education programmes and behavioural interventions to improve adherence in children and young people with type 2 diabetes.
- h) Metformin monotherapy for children and young people with type 2 diabetes.
- i) Haemoglobin A_{1c} (HbA_{1c}) targets for children and young people with type 2 diabetes.
- j) Recognition of complications and comorbidities in children and young people with type 2 diabetes (dyslipidaemia, retinopathy, nephropathy).

4.3.2 Clinical issues that will not be covered

Areas from the original guideline that will not be updated

- a) Location of initial management following diagnosis.
- b) Advice on the natural history of type 1 diabetes.
- c) Insulin preparations including new short- and long-acting insulins.
- d) Methods of delivering insulin.
- e) Metformin in addition to insulin for type 1 diabetes.
- f) Monitoring of blood ketones.
- g) Management of diabetic ketoacidosis.

- h) Exercise.
- i) Advice on alcohol, smoking and recreational drugs.
- j) Long-distance travel.
- k) Immunisation.
- l) Care during surgery.
- m) Emotional and behavioural problems, anxiety, depression and eating disorders.
- n) Cognitive disorders.
- o) Behavioural and conduct disorders.
- p) Psychosocial support.
- q) Adolescence.
- r) Communication between organisations.
- s) Transition from paediatric to adult care.
- t) Monitoring for complications and comorbidities of type 1 diabetes other than those specified in section 4.3.1.

Areas not covered by the original guideline or the update

- u) Glycaemic monitoring strategies for type 2 diabetes.
- v) Contraceptive, pre-pregnancy and conception advice .Treatment for children and young people with type 2 diabetes in whom glycaemic control is not maintained with metformin.
- w) Other medical treatments, for example, stains.
- x) Management of hypoglycaemia unawareness in children and young people with type 1 diabetes.

- y) Specific diet, exercise and lifestyle advice for children and young people with type 2 diabetes.
- z) Foot care.
- aa) Bariatric surgery for children and young people with type 2 diabetes.
- bb) Monitoring for complications and comorbidities of type 1 or type 2 diabetes other than those specified in section 4.3.1.
- cc) Management of complications and comorbidities of type 1 or type 2 diabetes.

4.4 *Main outcomes*

- a) Glycaemic control.
- b) Any adverse effects of interventions used to treat type 1 or type 2 diabetes.
- c) Diabetes-specific health related quality of life.
- d) Complications of diabetes.
- e) Mortality.
- f) Psychological outcomes.
- g) Patient satisfaction.

4.5 *Review questions*

4.5.1 Type 1 diabetes

Differential diagnosis

- What are the indications for the use of an antibody test to confirm the clinical diagnosis in children and young people of either type 1 diabetes or type 2 diabetes?

- For children and young people who have failed to respond to treatment, which of the following tests is the most accurate in correctly identifying or confirming type 1 diabetes and type 2 diabetes:
 - glutamic Acid Decarboxylase Autoantibodies (GADA)
 - insulinoma-Associated-2 Autoantibodies (IA-2A)
 - insulin Autoantibodies (IAA)
- when compared with Islet Cell Cytoplasmic Autoantibodies (ICA)?

Structured education programmes and behavioural interventions

- What is the effectiveness of structured education programmes in improving clinical and patient outcomes in children and young people with type 1 diabetes?
- What is the effectiveness of behavioural interventions to improve adherence in children and young people with type 1 diabetes?

Multiple daily injections versus mixed insulin injections

- What is the effectiveness of multiple daily injections of insulin when compared with mixed insulin injections in improving glycaemic control in children and young people with type 1 diabetes?

Glucose monitoring strategies

- What is the effectiveness of continuous glucose monitoring in children and young people with type 1 diabetes when compared with:
 - intermittent continuous glucose monitoring
 - frequent glucose monitoring
 - infrequent glucose monitoring?
- What are the optimal blood glucose targets for children and young people with type 1 diabetes?

Dietetic advice

- What is the effectiveness of dietetic advice using carbohydrate counting in maintaining glycaemic control in children and young people with type 1 diabetes?
- What is the effectiveness of dietetic advice using glycaemic index in maintaining glycaemic control in children and young people with type 1 diabetes?

Recognition of complications and comorbidities

- How soon after diagnosis should monitoring for retinopathy start in children and young people with type 1 diabetes?
- At what prevalence rate is monitoring for retinopathy indicated?
- How soon after diagnosis should monitoring for nephropathy start in children and young people with type 1 diabetes?
- At what prevalence rate is monitoring for nephropathy indicated?

4.5.2 Type 2 diabetes

Structured education programmes and behavioural interventions

- What is the effectiveness of structured education programmes in improving clinical and patient outcomes in children and young people with type 2 diabetes?
- What is the effectiveness of behavioural interventions to promote engagement with clinical services and adherence in children and young people with type 2 diabetes?

Metformin monotherapy

- What is the effectiveness of metformin in improving glycaemic control in children and young people with type 2 diabetes when compared with usual care or placebo?

Optimal HbA1c target

- What is the optimal HbA1c target for children and young people with type 2 diabetes?

Recognition of complications and comorbidities

- How soon after diagnosis should monitoring for dyslipidaemia start in children and young people with type 2 diabetes?
- At what prevalence rate is monitoring for dyslipidaemia indicated?
- How soon after diagnosis should monitoring for retinopathy start in children and young people with type 2 diabetes?
- At what prevalence rate is monitoring for retinopathy indicated?
- How soon after diagnosis should monitoring for nephropathy start in children and young people with type 2 diabetes?
- At what prevalence rate is monitoring for nephropathy indicated?

4.6 *Economic aspects*

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the quality-adjusted life year (QALY), and the costs considered will usually be only from an NHS and personal social services (PSS) perspective. Further detail on the methods can be found in 'The guidelines manual' (see 'Further information').

4.7 *Status*

4.7.1 *Scope*

This is the consultation draft of the scope. The consultation dates are 4 July to 29 August 2012.

4.7.2 *Timing*

The development of the guideline recommendations will begin in October 2012.

5 Related NICE guidance

5.1 *Published guidance*

5.1.1 NICE guidance to be updated

Depending on the evidence, this guideline might update and replace parts of the following NICE guidance:

- [Type 1 diabetes](#). NICE clinical guideline 15 (2004).

5.1.2 Related NICE guidance

- . NICE technology appraisal guidance 248 (2012).
- [Preventing type 2 diabetes: population and community-level interventions in high-risk groups and the general population](#). NICE public health guidance 35 (2011).
- . NICE technology appraisal guidance 203 (2010).
- [Type 2 diabetes - newer agents](#). NICE clinical guideline 87 (2009).
- [Promoting physical activity for children and young people](#). NICE public health guidance 17 (2009).
- [Allogeneic pancreatic islet cell transplantation for type 1 diabetes mellitus](#). NICE interventional procedure guidance 257 (2008).
- [Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus](#). NICE technology appraisal guidance 151 (2008).
- [Four commonly used methods to increase physical activity](#). NICE public health guidance 2 (2006).
- [Type 2 diabetes: prevention and management of foot problems](#). NICE clinical guideline 10 (2004).
- [Guidance on the use of patient-education models for diabetes](#). NICE technology appraisal guidance 60 (2003).
- [Guidance on the use of long-acting insulin analogues for the treatment of diabetes – insulin glargine](#). NICE technology appraisal guidance 53 (2002).

5.2 *Guidance under development*

NICE is currently developing the following related guidance (details available from the NICE website):

- Preventing type 2 diabetes – risk identification and interventions for individuals at high risk. NICE public health guidance. Publication expected 2012.
- Obesity – working with local communities. NICE public health guidance. Publication expected 2013.
- Overweight and obese children and young people – lifestyle weight management services. NICE public health guidance. Publication expected 2013.
- Type 1 diabetes (update). NICE clinical guideline. Publication expected 2014.
- Type 2 diabetes (update). NICE clinical guideline. Publication expected 2014.
- Diabetes in pregnancy. NICE clinical guideline. Publication expected 2014.
- Buccal insulin for the management of type 1 diabetes. NICE technology appraisal guidance. Publication date to be confirmed.

6 Further information

Information on the guideline development process is provided in the following documents, available from the NICE website:

- [‘How NICE clinical guidelines are developed: an overview for stakeholders the public and the NHS’](#)
- [‘The guidelines manual’](#).

Information on the progress of the guideline will also be available from the [NICE website](#).