# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

# Guideline

# Diabetes (type 1 and type 2) in children and young people: diagnosis and management

## Draft for consultation, November 2021

This is an update to NICE guideline NG18 (published August 2015). We have:

- reviewed the evidence on continuous glucose monitoring (CGM) for children and young people with type 1 diabetes
- replaced existing recommendations on CGM (previously numbered 1.2.63 to 1.2.65) with new recommendations
- moved or updated other recommendations to reflect these changes.

### Who is it for?

- Healthcare professionals who care for children and young people with diabetes
- Commissioners and providers of diabetes services
- Children and young people with type 1 diabetes, and their families and carers

### What does it include?

- the recommendations that have been updated
- related recommendations that have not been updated but are included here for context (shaded in grey and marked **[2004], [2015]** or **[2015, amended 2022]**)
- recommendations for research
- rationale and impact sections that explain why the committee made the 2022 recommendations and how they might affect practice

- the guideline context.

Information about how the guideline was developed is on the guideline's webpage. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

### Commenting on this update

We have reviewed the evidence on continuous glucose monitoring in children and young people with type 1 diabetes. You are invited to comment on the new and updated recommendations. These are marked as **[2022].**

We have not reviewed the evidence for the recommendations marked **[2004, amended 2015], [2015]** or **[2015, amended 2022]** (shaded in grey) and cannot accept comments on them. In some cases, we have made minor wording changes for clarification (shaded in yellow).

Sections of the guideline that have had no changes at all have been temporarily removed for this consultation and will be re-instated when the final guideline is published. See the existing short version of the guideline.

See update information for a full explanation of what is being updated.

Full details of the evidence and the committee's discussion on the 2022 recommendations are in the evidence reviews. Evidence for the 2015 recommendations is in the full version of the 2015 guideline.

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# Contents

# Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

## 1.2 Type 1 diabetes

### Blood glucose monitoring

1.2.62 Explain to children and young people with type 1 diabetes and their families or carers that blood glucose levels should be interpreted in the 'whole child' context, which includes the social, emotional and physical environment. **[2004]**

### Continuous glucose monitoring

1.2.63 Offer real-time continuous glucose monitoring to all children and young people with type 1 diabetes, as long as it is provided alongside education to support children and young people and their families and carers to use it (see recommendation 1.2.68). **[2022]**

1.2.64 Offer intermittently scanned CGM (isCGM, commonly referred to as 'flash') to children and young people (aged 4 years and over) with type 1 diabetes who are unable to use real-time CGM or who express a clear preference for isCGM. **[2022]**

1.2.65 Offer children and young people with type 1 diabetes a choice of real-time CGM device based on their individual preferences, needs, characteristics, and the functionality of the devices available. See

box 1 for examples of factors to consider as part of this discussion. **[2022]**

**Box 1 factors to consider when choosing a continuous glucose monitoring device**

- Whether the device provides predictive alerts or alarms and whether these need to be shared with anyone else, for example a parent or carer.
- Whether using the device requires access to particular technologies (such as a smartphone and up-to-date phone software).
- How easy the device is to use and take readings from, including for people with limited dexterity (taking into account the age and abilities of the child or young person and also whether the device needs to be used by others).
- The child or young person's insulin regimen or type of insulin pump, if relevant (taking into account whether a particular device integrates with their pump as part of a hybrid closed loop or insulin suspend function).
- Whether, how often and how the device needs to be calibrated.
- Whether data can be extracted and shared with the child or young person's healthcare provider.
- How unpredictable the child or young person's activity and blood glucose levels are and whether erratic blood glucose is affecting their quality of life.
- Whether the child or young person takes part in sports or exercise when glucose levels will need additional management.
- Whether the child or young person has situations when symptoms of hypoglycaemia cannot be communicated or can be confused, for example during exercise.
- Frequency of sensor replacement.
- Sensitivities to the device, for example local skin reactions.
- Cosmetic factors.

1.2.66 Continuous glucose monitoring should be provided by a team with expertise in its use, as part of supporting children and young people to self-manage their diabetes. **[2022]**

1.2.67 If a child or young person is unable or does not wish to use any real-time CGM or isCGM device, offer capillary blood glucose monitoring. **[2022]**

1.2.68 Include continuous glucose monitoring in the continuing programme of education provided to children and young people with type 1 diabetes and their families or carers (see the section on education and information in the existing version of the guideline), and ensure that children and young people using it are empowered to do so. **[2022]**

1.2.69 Monitor and review the child or young person's use of continuous glucose monitoring as part of reviewing their diabetes care plan, and explain to them the importance of continuously wearing the device. **[2022]**

1.2.70 If the child or young person is not using their device at least 70% of the time, discuss with them any possible barriers or problems in using the device and offer further education and support to overcome these. **[2022]**

For a short explanation of why the committee made these recommendations see the rationale and impact section on continuous glucose monitoring.

Full details of the evidence and the committee's discussion are in evidence review A: continuous glucose monitoring in children and young people with type 1 diabetes.

**Monitoring capillary blood glucose for children and young people not using continuous glucose monitoring**

1.2.71 Advise children and young people with type 1 diabetes who are using capillary blood glucose monitoring (and their families or

carers) to routinely perform at least 5 capillary blood glucose tests per day. **[2015, amended 2022]**

1.2.72 Advise children and young people with type 1 diabetes who are using capillary blood glucose monitoring (and their families or carers) that more frequent testing is often needed (for example with physical activity and during intercurrent illness). Ensure they have enough test strips for this. **[2015, amended 2022]**

1.2.73 Offer children and young people with type 1 diabetes who are using capillary blood glucose monitoring (and their families or carers) a choice of equipment for monitoring so that they can optimise their blood glucose management in response to changes in their insulin, diet and exercise. **[2004, amended 2022]**

## Terms used in this guideline

### Insulin pump

Continuous subcutaneous insulin infusion. A programmable pump and insulin storage device that gives a regular or continuous amount of insulin (usually a rapid-acting insulin analogue or short-acting insulin) through a subcutaneous needle or cannula.

# Recommendations for research

The guideline committee has made the following recommendations for research.

## Key recommendations for research

### 1 Peer-led education programmes for young people with type 1 diabetes

What is the effectiveness of education programmes in which young people with type 1 diabetes provide training for their peers? **[2015]**

## 2 Optimal upper limit and timing for blood glucose measurements after meals for children and young people with type 1 diabetes

What is the optimal upper limit and timing for blood glucose measurements after meals for children and young people with type 1 diabetes to reach an HbA1c level of 48 mmol/mol (6.5%) without unacceptable hypoglycaemia? **[2015]**

## 3 Metformin preparations for children and young people with type 2 diabetes

What is the long-term comparative clinical and cost effectiveness of different metformin preparations for treating type 2 diabetes in children and young people? **[2015]**

## 4 Dietary advice based on glycaemic index for children and young people with type 1 diabetes from diagnosis

What is the impact of educating children and young people with type 1 diabetes and their family members or carers (as appropriate) about their glycaemic index from diagnosis? **[2015]**

## 5 Optimal dosage of intravenous insulin for managing diabetic ketoacidosis in children and young people

What is the optimal dosage of intravenous insulin for managing diabetic ketoacidosis (DKA) in children and young people? **[2015]**

## 6 Effective resuscitation fluid for managing DKA

In children and young people with diabetic ketoacidosis, what is the most effective resuscitation fluid (0.9% sodium chloride vs PlasmaLyte 148) for managing DKA? **[2020]**

## 7 Continuous glucose monitoring in children and young people with type 2 diabetes

What is the effectiveness and cost effectiveness of continuous glucose monitoring devices in children and young people with type 2 diabetes? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on continuous glucose monitoring.

Full details of the evidence and the committee's discussion are in evidence review A: continuous glucose monitoring in children and young people with type 1 diabetes.

## 8 Use of routinely collected real-world data to examine the effectiveness and cost effectiveness of continuous glucose monitoring

What is the effectiveness and cost effectiveness of CGM devices (both real-time CGM and isCGM) to improve glycaemic control in children and young people using routinely collected real-world data? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on continuous glucose monitoring.

Full details of the evidence and the committee's discussion are in evidence review A: continuous glucose monitoring in children and young people with type 1 diabetes.

## 9 Continuous glucose monitor sensor adhesive to prevent sensitivities

What is the best CGM sensor adhesive to prevent sensitivities to the device, for example local skin reactions? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on continuous glucose monitoring.

Full details of the evidence and the committee's discussion are in evidence review A: continuous glucose monitoring in children and young people with type 1 diabetes.

# Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice.

## Continuous glucose monitoring

Recommendations 1.2.63 to 1.2.70

### Why the committee made the recommendations

The evidence on real-time continuous glucose monitoring (real-time CGM) showed a decrease in the key outcome of HbA1c and an increase in the key outcome of time in range, which reflected the committee's experience in clinical practice. They highlighted that the continuous nature of real-time CGM, and the fact that it can be connected to the phone or device of a parent or carer so they can track the data, were particularly important components for children and young people.

For intermittently scanned CGM (isCGM, or 'flash'), no clinically meaningful effect was seen for any of the outcomes that were looked at in the evidence. The committee acknowledged that flash is not licensed for children aged under 4. They also discussed how, in their experience, the intermittent nature of flash can affect adherence in children and young people.

Because the evidence showed similar benefits of real-time CGM for children and young people as for adults, the committee extrapolated the cost-effectiveness results from adults, concluding that real-time CGM was cost effective in this population. However, because the same clinical benefits were not found for flash in children and young people as in adults, the committee agreed those cost-effectiveness findings could not be extrapolated, so they could not conclude that flash is a cost-effective technology for the full population. They therefore agreed that flash should be restricted to those children and young people who are unable or do not want to use real-time CGM and would prefer flash.

The committee agreed that children and young people needed support to understand how CGM works and the benefits it can provide, so they emphasised that real-time CGM should only be provided along with education on how to use it.

The committee wanted to highlight the importance of providing choice between the different CGM devices because the best device for each person would vary, so they produced a list of what to consider when discussing this with children and young people.

They also agreed that CGM should be included in the continuing programme of education that children and young people with type 1 diabetes are offered, and they should also be supported by a team with expertise in using CGM. This will help them to use the technology effectively to manage their diabetes.

The committee made the recommendation about discussing possible problems with children and young people who are not using their device 70% of the time because it is important that the CGM device is used for a significant proportion of time for it to have a positive effect. They wanted to avoid a child or young person feeling 'punished' for using it less than that, but agreed that less than 70% use should trigger a discussion to find out if extra support is needed. The committee acknowledged that CGM is not offered as a permanent solution, and can be stopped if it is not being used effectively or not perceived to be providing enough benefit.

One of the known factors determining the use of CGM devices among children and young people with type 1 diabetes is sensitivities to the device, for example local skin reactions to the adhesive used in the sensor. The committee agreed that research is needed to investigate strategies to reduce local skin reactions to promote ease of use and adherence of these devices, so they made a recommendation for research on continuous glucose monitor sensor adhesive to prevent sensitivities.

The committee also made a recommendation for research using routinely collected real-world data to examine the effectiveness and cost effectiveness of CGM. They agreed that this has the potential to show the direct effects of

implemented technology in children and young people instead of interpreting it through the results of clinical trials. Increased monitoring of routine healthcare data including registries and audits would ensure the findings from a broader population is captured.

### Continuous glucose monitoring in children and young people with type 2 diabetes

An increasing number of children and young people with type 2 diabetes need to be catered for with specific guidance. There is currently a lack of evidence on the effectiveness of CGM in children and young people with type 2 diabetes. An adequately powered randomised controlled trial is needed to explore the effectiveness and cost effectiveness of real-time CGM and flash compared with intermittent capillary blood glucose monitoring, so the committee made a recommendation for research on continuous glucose monitoring in children and young people with type 2 diabetes.

### How the recommendations might affect practice

These recommendations are likely to result in broader access to real-time CGM and flash devices for children and young people. This will increase costs but should reduce inequalities and enable more people to access the technology. Currently, children and young people and their parents or carers who have more time and knowledge to advocate or self-advocate are often more likely to gain access to these devices.

## Context

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, as detailed in this guideline. Preparations should also be made for the transition from paediatric to adult services, which have a somewhat 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. In 2019,

there were an estimated 36,000 children and young people in the UK with diabetes under the age of 19, up from 31,500 in 2015. Type 1 diabetes constitutes the vast majority (90%) of diabetes in children and young people. There were 866 children and young people with Type 2 diabetes reported to the National Paediatric Diabetes Audit, of whom 201 (23.2%) were newly diagnosed within the audit year (2019-2020). Much of the general care for type 2 diabetes is the same as for type 1 diabetes, although the initial management is different. In addition, the overweight and obesity associated with type 2 diabetes also bring an increased risk of renal complications in particular, and of problems such as hypertension and dyslipidaemia. A variety of genetic conditions (such as maturity-onset diabetes in the young) and other conditions (such as cystic fibrosis-related diabetes) may also lead to diabetes in children and young people, but the care of these diverse conditions is beyond the scope of this guideline.

This guideline recommends attempting to reach a glycated haemoglobin (HbA1c) level near the normal range and near normoglycaemia. This is to further reduce the long-term risks associated with diabetes. Tight management may be achieved by intensive insulin management (multiple daily injections or insulin pump therapy) from diagnosis, accompanied by carbohydrate counting.

By implementing the strict blood glucose management recommended in this guideline, improvements can be made to diabetes care that reduce the impact of the condition on the future health of children and young people.

## Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE webpage on diabetes.

For details of the guideline committee see the committee member list.

# Update information

## November 2021

We have reviewed the evidence on continuous glucose monitoring for children and young people with type 1 diabetes.

Recommendations are marked **[2022]** if the evidence has been reviewed.

## Recommendations that have been deleted, or changed without an evidence review

We propose to delete some recommendations from the 2015 guideline. Table 1 sets out these recommendations and includes details of replacement recommendations. If there is no replacement recommendation, an explanation for the proposed deletion is given.

In recommendations shaded in grey and ending **[…amended 2022]**, we have made changes that could affect the intent without reviewing the evidence. Yellow shading is used to highlight these changes, and reasons for the changes are given in table 2.

**Table 1 Recommendations that have been deleted**

| Recommendation in 2015 guideline | Comment |
|---|---|
| Offer ongoing real-time continuous glucose monitoring with alarms to children and young people with type 1 diabetes who:<br>• have frequent severe hypoglycaemia or<br>• have impaired hypoglycaemia awareness that is associated with adverse consequences (for example, seizures or anxiety) or<br>• cannot recognise or communicate about symptoms of hypoglycaemia (for example, because of cognitive or neurological disabilities). (1.2.63). | Replaced by:<br>1.2.63 Offer real-time continuous glucose monitoring to all children and young people with type 1 diabetes, as long as it is provided alongside education to support children and young people and their families and carers to use it (see recommendation 1.2.68).<br><br>This recommendation has been deleted because we have reviewed the effectiveness and cost effectiveness of continuous glucose monitoring in children and young people with type 1 diabetes, and have found new evidence to make an updated recommendation. |
| Consider ongoing real-time continuous glucose monitoring for: | Replaced by: |

| | |
|---|---|
| • babies, infants and pre-school children<br>• children and young people with high levels of physical activity (for example national-level sport)<br>• children and young people who have comorbidities (for example anorexia nervosa), or who are having treatments (for example corticosteroids) that can make blood glucose management difficult. (1.2.64) | 1.2.63 Offer real-time continuous glucose monitoring to all children and young people with type 1 diabetes, as long as it is provided alongside education to support children and young people and their families and carers to use it (see recommendation 1.2.68).<br><br>This recommendation has been deleted because we have reviewed the effectiveness and cost effectiveness of continuous glucose monitoring in children and young people with type 1 diabetes, and have found new evidence to make an updated recommendation. |
| Consider intermittent (real-time or retrospective) continuous glucose monitoring to help improve blood glucose management for children and young people who continue to have hyperglycaemia despite insulin adjustment and additional support. (1.2.65) | Replaced by:<br>1.2.65 Offer children and young people with type 1 diabetes a choice of real-time CGM device based on their individual preferences, needs, characteristics, and the functionality of the devices available. See box 1 for examples of factors to consider as part of this discussion.<br><br>This recommendation has been deleted because we have reviewed the effectiveness and cost effectiveness of continuous glucose monitoring in children and young people with type 1 diabetes, and have found new evidence to make an updated recommendation. |

**Table 2 Amended recommendation wording (change to intent) without an evidence review**

| Recommendation in 2015 guideline | Recommendation in current guideline | Reason for change |
|---|---|---|
| 1.2.59 Advise children and young people with type 1 diabetes and their families or carers to routinely perform at least 5 capillary blood glucose tests per day. | 1.2.71 Advise children and young people with type 1 diabetes who are using capillary blood glucose monitoring (and their families or carers) to routinely perform at least 5 capillary blood glucose tests per day. | Recommendation clarified to clearly differentiate children and young people who are using capillary blood glucose monitoring from those using CGM. |

| | | |
|---|---|---|
| 1.2.60 Advise children and young people with type 1 diabetes and their families or carers that more frequent testing is often needed (for example with physical activity and during intercurrent illness). Ensure they have enough test strips for this. | 1.2.72 Advise children and young people with type 1 diabetes who are using capillary blood glucose monitoring (and their families or carers) that more frequent testing is often needed (for example with physical activity and during intercurrent illness). Ensure they have enough test strips for this. | Recommendation clarified to clearly differentiate children and young people who are using capillary blood glucose monitoring from those using CGM. |
| 1.2.61 Offer children and young people with type 1 diabetes and their families or carers a choice of equipment for monitoring capillary blood glucose so they can optimise their blood glucose management in response to changes in their insulin, diet and exercise. | 1.2.73 Offer children and young people with type 1 diabetes who are using capillary blood glucose monitoring (and their families or carers) a choice of equipment for monitoring so that they can optimise their blood glucose management in response to changes in their insulin, diet and exercise. | Recommendation clarified to clearly differentiate children and young people who are using capillary blood glucose monitoring from those using CGM. |

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