

Type 1 Technology

A guide for young people and families



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Introduction

This guide has been co-produced by Diabetes UK, INPUT Patient Advocacy and JDRF with input from NICE. It highlights new recommendations from NICE on treatments and technology for children and young people with type 1 diabetes. It also gives an update on some technologies that NICE hasn't made recommendations on.

We hope this will be a useful tool when talking to your healthcare professionals about the technology you use to manage your diabetes.

NICE stands for the National Institute for Health and Care Excellence. NICE is an independent organisation, set up by the Government in 1999. They make recommendations about how to best treat different health conditions, including diabetes. Their recommendations on diabetes are written by doctors, nurses and other healthcare professionals, and by people who have diabetes or care for someone with diabetes.

You can read the information NICE has written about type 1 diabetes for children, young people and their parents or carers [here](#). You can read the information NICE has written about access to insulin pumps [here](#).

NICE guidance is developed for the NHS in England, and not all of it applies to other parts of the UK. You can see what NICE guidance applies in different parts of the UK [here](#).

Different types of NICE guidance

NICE issues lots of different types of guidance. For type 1 diabetes, it has produced Clinical Guidelines, Technology Appraisals and Diagnostic Assessments. To see what different kinds of guidance NICE produces, see [this page](#) on the NICE website.

This guide is written to coincide with the publication of the new NICE Guideline called 'Diabetes (type 1 and type 2) in children and young people: diagnosis and management' (published August 2015). NICE Guidelines advice on the care and support that should be offered to people who use health and care services, and healthcare professionals in the NHS should follow these guidelines whenever possible. Technology Appraisals, such as 'TA151' covering insulin pumps, are different from NICE Guidelines. Once a NICE Technology Appraisal recommends a

treatment 'as an option', the NHS must make sure it is available within 3 months (unless otherwise specified) of the publication date.

For the purpose of this document, 'children and young people' refers to anyone with diabetes being treated in paediatric or transition clinics.

Different strengths of recommendation

NICE's guideline recommendations vary in strength, based on how good the evidence there is for how well a treatment works and how much it costs. The benefits and risks (for example side effects) of a treatment are also important. A NICE recommendation does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

The different strengths of NICE recommendations are set out below:

NICE wording	Definition
Must (must not)	NICE usually use ‘must’ or ‘must not’ only if there is a legal duty to apply the recommendation. Occasionally NICE use ‘must’ (or ‘must not’) if the consequences of not following the recommendation could be extremely serious or potentially life threatening.
Should (offer / refer / advise)	NICE use ‘offer’ (and similar words such as ‘refer’ or ‘advise’) when they are confident that, for the vast majority of patients, an intervention will do more good than harm, and be cost effective. NICE use similar forms of words (for example, ‘do not offer...’) when they are confident that an intervention will not be of benefit for most patients.
Could (Consider)	NICE use ‘consider’ when they are confident that an intervention will do more good than harm for most patients, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the patient’s values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the patient.

1. Injections and pumps

Everyone with type 1 diabetes needs to take insulin. There are two main ways of taking insulin – through injections or through an insulin pump. The new guideline makes four recommendations on insulin pumps: 1.2.19, 1.2.22, 1.2.25 and 1.2.30. It also refers to a Technology Appraisal that has further recommendations.

Under the guidelines all children and young people should be **offered** a basal-bolus insulin regimen (also called a multiple daily injection or MDI regimen) from the time they are diagnosed. This involves taking a slow-acting ‘basal’ insulin

once or twice a day; and a rapid-acting ‘bolus’ insulin with meals.

The guideline also recommends that your diabetes team should **consider** giving you an insulin pump if injections are ‘not appropriate’:

It can be hard to define what is ‘not appropriate’ and the interpretation varies between clinics.

For example, some clinics think it is not appropriate:

- to expect a child under the age of 5 to have 4 or more injections per day
- if a child needs such small doses of insulin that it’s difficult to get the dose right using an injection pen.

What does NICE say?

1.2.19

Offer children and young people with type 1 diabetes multiple daily injection basal–bolus insulin regimens from diagnosis. If a multiple daily injection regimen is not appropriate for a child or young person with type 1 diabetes, consider continuous subcutaneous insulin infusion (CSII or insulin pump) therapy as recommended in [Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus](#) (NICE technology appraisal guidance 151).

NICE Technology Appraisal 151 was published in 2008. The Technology Appraisal gives the specific reasons people should be given an insulin pump. If these reasons apply to you and your doctor believes an insulin pump is right for you, the NHS is legally required to provide you with one:

What does NICE say?

NICE technology appraisal guidance 151

Insulin pump therapy is recommended as a treatment option for adults and children 12 years and older with type 1 diabetes mellitus provided that:

- attempts to achieve target haemoglobin A1c (HbA1c) levels with multiple daily injections (MDIs) result in the person experiencing disabling hypoglycaemia. For the purpose of this guidance, disabling hypoglycaemia is defined as the repeated and unpredictable occurrence of hypoglycaemia that results in persistent anxiety about recurrence and is associated with a significant adverse effect on quality of life
- or
- HbA1c levels have remained high (that is, at 8.5% [69 mmol/mol] or above) on MDI therapy (including, if appropriate, the use of long-acting insulin analogues) despite a high level of care.
- Insulin pump therapy is recommended as a treatment option for children younger than 12 years with type 1 diabetes mellitus provided that:
- MDI therapy is considered to be impractical or inappropriate, and
- children on insulin pumps would be expected to undergo a trial of MDI therapy between the ages of 12 and 18 years.

As well as setting out these criteria, the guideline also states you should be **offered** a choice of injections or pumps that take into account your personal preferences:

What does NICE say?

1.2.25

Offer children and young people with type 1 diabetes a choice of insulin delivery systems that takes account of their insulin requirements and personal preferences.

It also states that if a child or young person with type 1 diabetes does not have optimal blood glucose control, additional support or an alternative insulin regimen should be **offered**. NICE defines optimal control as:

- fasting glucose level of 4–7 mmol/L on waking;
 - 4–7 mmol/L before meals at other times of the day;
 - 5–9 mmol/L after meals;
 - at least 5 mmol/L when driving
- and**
- an HbA1c of 48 mmol/mol (6.5%) or lower

What does NICE say?

1.2.30

If a child or young person with type 1 diabetes does not have optimal blood glucose control (see recommendations 1.2.54 and 1.2.67): offer appropriate additional support such as increased contact frequency with their diabetes team, and if necessary, offer an alternative insulin regimen (multiple daily injections, continuous subcutaneous insulin infusion [CSII or insulin pump] therapy or once-, twice- or three-times daily mixed insulin injections).

Your healthcare professional should take all of these factors into account when discussing whether you would like to use injections or a pump.

If you do use an insulin pump, the guideline also recommends that you should be trained to use it, and provided with ongoing support:

What does NICE say?

1.2.22

Provide all children and young people with type 1 diabetes who are starting continuous subcutaneous insulin infusion (CSII or insulin pump) therapy and their family members or carers (as appropriate) with specific training in its use. Provide ongoing support from a specialist team, particularly in the period immediately after starting continuous subcutaneous insulin infusion. Specialist teams should agree a common core of advice for continuous subcutaneous insulin infusion users.

If you think the reasons in the technology appraisal apply to you but your clinic will not consider an insulin pump, has a waiting list longer than 6 months for a pump, or recommends a pump but cannot tell you how long it will take to provide it, you can contact [INPUT](#) for advice and support.

2. Appropriate length of injection needles

For people who take their insulin by injection, using the right length of injection needle can help to make injections less uncomfortable and ensure the insulin goes into the fat under the skin rather than into muscle.

Injecting insulin into muscle can make it difficult for your body to absorb the insulin properly, and can cause hypoglycaemia and visible bruising.

The NICE guideline recommends that young people with type 1 diabetes are given insulin injection needles that are the right length for their amount of body fat.

The [Forum for Injection Technique](#) (a group of UK experienced diabetes specialist nurses) recommends that children and adolescents should use a 4, 5 or 6mm needle.

If you or your child has been prescribed needles that could be too long, speak with the specialist nurse and ask them to write to your GP if they think the prescription should be changed.

What does NICE say?

1.2.26

Provide children and young people with type 1 diabetes with insulin injection needles that are of an appropriate length for their body fat.

3. Blood glucose monitoring (choice of system and sufficient strips)

Blood glucose meters come in all shapes and sizes. A recent 'Meds & Kit' guide from Diabetes UK found 38 different blood glucose meters currently on the market. The NICE guideline recommends that you should be offered a choice of equipment for monitoring your blood glucose levels.

What does NICE say?

1.2.60

Offer children and young people with type 1 diabetes and their family members or carers (as appropriate) a choice of equipment for monitoring capillary blood glucose, so they can optimise their blood glucose control in response to adjustment of insulin, diet and exercise.

However, in some areas, people with type 1 diabetes have reported being pushed into using a specific meter. If this happens, mention to your GP that NICE says people should have a choice of blood glucose meters and discuss the reasons why you prefer a different system. If your GP will not provide test strips for a system you prefer and it is recommended by your diabetes team, ask the team to write to your GP.

The NICE guideline also recommends that children and young people with type 1 diabetes should perform at least 5 blood glucose tests per day:

What does NICE say?

1.2.58

Advise children and young people with type 1 diabetes and their family members or carers (as appropriate) to routinely perform at least 5 capillary blood glucose tests per day.

This is a minimum, and should not be used by healthcare professionals or commissioners to limit test strips. In fact, the guidelines state that more frequent testing is often needed and that healthcare providers should ensure that patients have enough test strips:

What does NICE say?

1.2.59

Advise children and young people with type 1 diabetes and their family members or carers (as appropriate) that more frequent testing is often needed (for example with physical activity and during intercurrent illness), and ensure they have enough test strips for this.

If your GP will not provide enough test strips for you, ask your diabetes team to write to them and tell them how many strips should be prescribed.

4. Continuous Glucose Monitoring (CGM)

CGM systems measure your glucose levels every few minutes, so that you get a graph of glucose levels over time rather than just a single measurement. There are two main types of CGM: 'Real-time' CGM is a system that allows you to check your glucose levels at any time. The other kind of CGM is 'retrospective', which let you look back at results by downloading results to a computer. CGM alarms can be set to let you know when your glucose levels go too high or too low.

Helping people to reach their personal blood glucose and HbA1c targets is a key priority of the guideline.

The NICE guideline recommends that children and young people are **offered** ongoing use of real-time CGM with alarms to young people with type 1 diabetes in certain circumstances:

What does NICE say?

1.2.62

Offer ongoing real-time continuous glucose monitoring with alarms to children and young people with type 1 diabetes who have:

- frequent severe hypoglycaemia or
- impaired awareness of hypoglycaemia associated with adverse consequences (for example, seizures or anxiety) or
- inability to recognise, or communicate about, symptoms of hypoglycaemia (for example, because of cognitive or neurological disabilities).

Typically, a 'severe' hypo is one that the person needs help from another person to treat or is one that needs treatment in a hospital. 'Frequent' is not defined in the guideline, so is open to interpretation by your clinic.

'Impaired awareness of hypoglycaemia' means the person cannot recognise that they are having a hypo until it becomes severe.

In addition, the guideline recommends that ongoing use of real-time CGM should also be **considered** for other groups:

What does NICE say?

1.2.63

Consider ongoing real-time continuous glucose monitoring for:

- neonates, infants and pre-school children
- children and young people who undertake high levels of physical activity (for example, sport at a regional, national or international level)
- children and young people who have comorbidities (for example anorexia nervosa) or who are receiving treatments (for example corticosteroids) that can make blood glucose control difficult.

The guideline also recommends **considering** occasional use of CGM to help children and young people to improve their glucose control:

What does NICE say?

1.2.64

Consider intermittent (real-time or retrospective) continuous glucose monitoring to help improve blood glucose control in children and young people who continue to have hyperglycaemia despite insulin adjustment and additional support.

Note that the NHS is not legally obliged to provide funding for CGM. However, the guideline makes a strong recommendation for CGM to be used with children who are unable to recognise or communicate about hypo symptoms. This includes very young children who cannot tell you they are having a hypo even if they recognise it.

More background on CGM funding can be found [here](#).

5. Flash Glucose Monitoring

Flash glucose monitoring is a new kind of glucose monitoring that is not covered by the NICE guideline. It was initially launched in the UK in September 2014, and at the time of writing (August 2015) Abbott's Freestyle Libre is the only device of this kind. The Freestyle Libre has been very popular since launch and the manufacturer has struggled to meet demand for sensors.

To use the system, a Freestyle Libre sensor is inserted in the arm and worn for 14 days before being replaced. The user or their carer holds a handheld 'reader' very close to the sensor to 'scan' or 'flash' the sensor. The reader then shows a real-time glucose value with an arrow showing if blood glucose levels are going up or down, and a graph of glucose levels over the past 8 hours. The Freestyle Libre reader includes a smart blood glucose meter that uses FreeStyle Optium test strips and a blood ketone meter.

Unlike CGM, flash glucose monitoring sensors do not continually send glucose measurements to the reader, so it will not alert the user or their carer to changes in glucose levels until the sensor is scanned with the reader.

At the time of writing, Freestyle Libre is only approved for use by people over the age of 18. It

is not currently funded by the NHS. NICE has not looked at how effective flash glucose monitoring is, and has made no recommendations on it.

6. Sensor-augmented pumps

Sensor-augmented pumps are insulin pumps that can receive readings from a CGM sensor. Some sensor-augmented pumps use CGM readings to adjust the user's insulin dose automatically, for example by reducing or stopping insulin delivery when the system predicts or detects a low glucose level. As of August 2015, the only sensor-augmented pumps available that automatically alter insulin dose based on CGM readings are the Veo and 640G, both made by Medtronic.

Sensor-augmented pumps are not covered by the NICE guideline, but NICE is expected to publish Diagnostics Guidance on MiniMed Paradigm Veo and Animas Vibe in October 2015. The draft guidance (July 2015) recommends the Veo system 'as an option for people who experience frequent episodes of severe hypoglycaemia, despite optimal management' with an insulin pump, or who 'feel ongoing anxiety about these episodes happening again'. The Animas Vibe is not recommended due to a lack of evidence on how well it works.

The Diagnostic Guidance is a draft, and may change before publication. NICE's Diagnostics Guidance is different to its Technology Appraisals, and the NHS is not legally required to follow them.

If you think that you or your child fit the criteria and could benefit from using the Veo or 640G, print out the relevant page from the [Diagnostics Assessment](#) for discussion with the diabetes care team.

7. Blood ketone monitoring

It is important for people with type 1 diabetes to check their ketone levels when their glucose levels are very high or they are unwell. Like a blood glucose meter, a blood ketone meter gives a real-time result, compared to urine testing, which can only show the glucose levels that were in the blood a few hours ago. Checking blood rather than urine ketones and acting quickly to reduce them can help prevent hospital admission for diabetic ketoacidosis (DKA), a potentially life-threatening complication of diabetes.

The NICE guideline recommends that young people with type 1 diabetes should be offered a blood ketone meter and blood ketone test strips, and be advised how and when to use them.

What does NICE say?

1.2.74

Offer children and young people with type 1 diabetes blood ketone testing strips and a meter, and advise them and their family members or carers (as appropriate) to test for ketonaemia if they are ill or have hyperglycaemia.

Your diabetes clinic is unlikely to object to the need for a blood ketone meter. If the GP will not provide blood ketone test strips because of their cost, ask your diabetes team to write to your GP and request the prescription.

Further information and support

If you experience difficulty accessing any technologies described in this guide in accordance with the NICE Clinical Guideline or Technology Appraisal, you can contact INPUT, the charity supporting patients' access to diabetes education and technology, for more information and assistance.

www.inputdiabetes.org.uk [or 0800 228 9977 (answerphone) if you do not have Internet access]

JDRF is the type 1 diabetes charity, improving lives until we find the cure. We fund research to cure, treat and prevent type 1 diabetes including a major initiative to speed up the artificial pancreas, a technology that could revolutionise treatment of type 1 diabetes.

www.jdrf.org.uk

Diabetes UK is the leading charity that cares for, connects with and campaigns on behalf of every person affected by or at risk of diabetes.

www.diabetes.org.uk

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NICE has checked the accuracy of the recommendations from the clinical guideline and technology appraisal. See the NICE website for full information about NICE and NICE guidance on diabetes.