

National Institute for Health and Care Excellence

Diabetes in children and young people

Stakeholder Comments – Draft Guideline

NOTE:

NICE is unable to accept comments from non-registered organisations or individuals. If you wish your comments to be considered but are not a registered stakeholder, please register via the [NICE website](#) or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them.

Please fill in both the ‘stakeholder organisation’ and ‘name of commentator’ fields below in order for your comments to be considered.

Stakeholder Organisation:		DIABETES UK		
Name of commentator:				
Order number <i>(For internal use only)</i>	Document	Page Number	Line Number	Comments
	Indicate if you are referring to the Full version NICE version or the Appendices	Indicate number or ‘general’ if your comment relates to the whole document	Indicate number or ‘general’ if your comment relates to the whole document	<p>Please insert each new comment in a new row.</p> <p>Please do not paste other tables into this table, as your comments could get lost – type directly into this table.</p>
Example	Full	16	45	Our comments are as follows
Proformas that are not correctly submitted as detailed in the example above may be returned to you.				
				Diabetes UK’s responses are taken from the feedback we receive from parents and comments on the draft guidance from our Council of Healthcare Professionals.
1	NICE	13	1.1.1	We recommend the addition of excessive tiredness.
2	NICE	14	1.1.6	We feel that the characteristics monogenic diabetes are not fully represented in this point and recommend that ISPAD guidelines are used https://www.ispad.org/sites/default/files/resources/files/4-the_diagnosis_and_management_of_monogenic_diabetes_in_children_and_adolescents.pdf
3	NICE	15	1.2.1 1.2.2	We welcome the detail on content of a continuing education programme and that this should be tailored to the individual.
4	NICE	16	1.2.9	We feel that this point should be expanded to recommend accessible communication methods for these groups of people eg. written/audio information, use of interpreters etc.
5	NICE	18	1.2.19	We welcome the recommendation to consider family circumstances and personal preference when choosing an insulin regimen.
6	NICE	19	1.2.20	We agree with the recommendation of personalizing the injection regimen for newly diagnosed children and

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				<p>young people and that generally multiple daily insulin injections from diagnosis should be offered. However we feel that the guidance should address insulin regimens for children and young people with established diabetes and recognise that in certain circumstances neither MDI nor CSII would be appropriate, and a BD regimen may be necessary to gain compliance with treatment.</p>
7	NICE	19	1.2.22	<p>We recommend that what constitutes a specialist team in terms of CGMS should be specified.</p>
8	NICE	21	1.2.37	<p>We welcome introduction of carbohydrate counting from diagnosis as allows greater flexibility in food choices, timing and amounts. We would like to see an explanation of “level 3 carbohydrate counting”.</p>
9	NICE	22	1.2.42	<p>We are concerned that the recommendation around low GI diets is misleading as some low GI foods are high in fat, which could lead to weight gain. We recommend that what constitutes a healthy balanced diet is made clearer.</p>
10	NICE	23	1.2.50	<p>We would recommend adding the possibility of needing to monitor blood glucose levels during exercise as well as before and after, depending on length of time spent exercising.</p>
11	NICE	25	1.2.55	<p>We find the use of the terms “fasting BGL” and “before meals” confusing as this target seems to relate to the same thing. If this is the case we recommend clarification eg. to say “on waking and before meals...” If “fasting” refers to on waking, should “5-7 for young people intending to drive the following morning” read “5-7 for young people intending to drive that morning”? The guideline must state how long after meals the targets should be reached, eg 1 hour/2 hours. The guideline must suggest a bedtime target for blood glucose level and strategies to avoid night time hypoglycaemia as this is a major concern for parents.</p>
12	NICE	25	1.2.57	<p>We welcome the recommendation to ensure that children and young people do not experience problematic hypoglycaemia or undue emotional distress when attempting to achieve blood glucose and HbA1c targets, but would like to see strategies that can be employed to manage this.</p>
13	NICE	25	1.2.58	<p>We welcome the awareness of potential conflict between children and young people and parents and the need to agree a compromise</p>
14	NICE	25	1.2.59	<p>We are concerned about the recommendation of 5 or more tests a day and question how children and young people will be able to achieve the new lower HbA1c targets on 5 tests a day. We appreciate that “at least” is stated but feel the figure 5 will be the one that is remembered. We note that in the adult Type 1 guidance, 10 or more tests a day may be appropriate in certain circumstances. We appreciate that some of the circumstances applicable to adults will not be the same for children, but the recommendation must take into account the effect of growth and development on blood glucose level, the risks associated with hypos in children and potential of driving in older teenagers, and recognise that a higher number of tests per day may need to be the norm. We are concerned that the recommendation of “at least 5 tests a day” may result in a restriction of test strips as GPs may only prescribe enough for 5 tests a day, which</p>

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				will not be sufficient for many children and young people. We therefore think the recommendation should state that testing up to 10 or more times a day may be necessary for some children and young people.
15	NICE	27	1.2.68	Whilst we appreciate this target may be ideal in helping to avoid long term complications, we are concerned that the lower Hba1c target is potentially unachievable, especially give the recommendation for 5 tests a day. We feel that this lower target will also potentially increase the risk of hypoglycaemia, which parents and children and young people tell us is of great concern to them. It could also dis-incentivise children and young people who are already struggling to meet the current target of 53 mmols/mol. The guideline must also put greater emphasis on the need to set individual targets through discussion with the child and family.
16	NICE	28	1.2.73	The guidance should also add that children, young people and their family members should be educated in how to interpret blood ketone results and action to be taken if blood ketones test positive.
17	NICE	29	1.2.79	This point of the guidance is not fully in line with current ISPAD recommendations https://www.ispad.org/sites/default/files/resources/files/12_-_assessment_and_management_of_hypoglycemia_in_children_and_adolescents_with_diabetes.pdf and should be clarified to reflect these. Oral complex carbohydrate may not be required for all children and young people following immediate treatment of hypoglycaemia especially for those on pumps and some on MDI. The guideline must be changed to reflect this.
18	NICE	30	1.2.85	The word “consider” should be removed - diabetes teams must refer children and young people who have frequent hypos and/or recurrent seizures.
19	NICE	32	1.2.95 1.2.97	We feel that the guideline should be consistent with the Paediatric Diabetes Best Practice Tariff which states: “Each patient must have an annual assessment by their MDT as to whether input to their care by a clinical psychologist is needed, and access to psychological support, which should be integral to the team, as appropriate”. The guideline should be altered to reflect this.
20	NICE	34	1.2.108	We feel that monitoring programmes work best when they are kept simple, and so are concerned that the differing times for monitoring for complications and associated conditions are confusing to parents and there is a risk that they will be forgotten. Long term complications are a real concern to parents, particularly for parents who have a child diagnosed very young. We would therefore suggest that the monitoring programme is simplified, perhaps to monitoring for all complications and associated conditions every year from one year post diagnosis.
21	NICE	35	1.2.111	While we are aware of the rarity of retinopathy in children under that age of 12, see comment 16
22	NICE	36	1.2.112	While we are aware of the rarity of nephropathy in children under that age of 12, see comment 16
23	NICE	36-46	1.3	We feel that the recommendations for Type 2 diabetes in children and young people need to far more detailed, in particular in terms of treatment both for the Type 2

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				diabetes itself (as there is no mention of treatment strategies if metformin is ineffective) and for the treatment of any complications and associated conditions. We recommend that this part of the guideline is reviewed, and reflect the ISPAD/ADA guidelines https://www.ispad.org/sites/default/files/resources/files/3-type_2_diabetes_in_the_child_and_adolescent.pdf / http://care.diabetesjournals.org/content/38/Supplement_1
23	NICE	46	1.4.1	We would like to see this statement changed to: "Measure capillary blood glucose at presentation in children and young people without known diabetes who have increased thirst, polyuria, recent unexplained weight loss or excessive tiredness and any of the following:"
24	NICE	49	1.4.17	We suggest this statement specifies a paediatric high dependency unit.
25	NICE	50	1.4.27	We suggest that perhaps there is no place for a bolus unless there is severe haemodynamic collapse. We would also question whether 3% saline might be considered if hyponataemia is present.
26	NICE	52	1.4.43	We suggest that plasma osmolality is considered as a factor in the decision to change fluids.
27	NICE	54	1.4.55	We suggest that assessment of the ECG trace should specify to review for evidence of hypo/hyperkalaemia.
28	NICE	58	1.5.9-1.5.13	This section must be expanded to include all aspects of transition such as preparation, education, appropriate timing for transition, the need for joint paediatric and adult clinics/joint clinics/young person's clinics/transition clinics, liaison between paediatric and adult teams etc.

Please add extra rows as needed.

Please email this form to: DiabetesChildrenUpdate@nice.nhs.uk

Closing date: 4 March 2015

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