ACD comments

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 19/11/2007 @ 13:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	info@statmans.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	appears to be an adequate summary of suitable patients based on medical parameters
FORMFIELD2	A
FORMFIELD3	
FORMFIELD4	it may be prudent to have refresher courses for pump users. Is the reduced amount of insulin factored in to the cost calculations? No long acting & far less fst acting insulin is consumed. Are all pumps similar? did some pumps perform better than others?

FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	david statman
NOTES	
O	38197
OTHERROLE	father
PROCESS	1
ROLE	Carer

SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 20/11/2007 @ 16:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	louise.wong@srft.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	
FORMFIELD2	
FORMFIELD3	I do not believe the education the education is a one-off. There is the intense initial education & then there will always be on-going education. Some people initially will only want to use the basic functions of the pump but in time may want to use the more advanced features. Others, like all education , will forget certain things & need a recap session.
FORMFIELD4	

FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Louise M Wong
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional

SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 20/11/2007 @ 16:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	austin.blackburn@ntlworld.com
EXTENSIONID	extension:Guidance
FORMFIELD1	I think you need to make it clearer whether trouble with hypoglycemia means seizures/fits/unconsciousness. My sons diabetes team at Derriford Hospital interpret the current guidelines this way and in the absense of seizures use 7.5% as the magic figure to submit an application to the PCT for pump funding. As this document stands they will probably now only apply for patients with HbA1cs over 8.5% so even fewer patients will qualify. What do you actually mean by hypoglycaemia? Is it any level under 4mmol needing hypo treatment, symptomatic hypoglycemia or fits/seizures/unconsciousness. What about those with hypoglycemia unawareness?

FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Deborah Blackburn
NOTES	Had trouble getting an insulin pump for my now 3 year old, diagnosed at 11 months old.
O	38197

OTHERROLE	Parent of 3 year old insulin pumper with type 1 diabetes
PROCESS	1
ROLE	other
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 20/11/2007 @ 18:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	margomorriss@hotmail.com
EXTENSIONID	extension:Guidance
FORMFIELD1	Item 1.3 - what about other effects on quality of life being reasons for CSII, such as needle phobia, lumps and uncomfortable areas from injecting. Children over 11 being embarassed to inject in frount of friends. Not being able to vary the amount of insulin administered at particular times of day like you can on CSII by programing the pump. Depression caused by the above issues (and

	other issues) and a childs quality of life. Should these not be reasons to use CSII as well? As a parent we carb count all meals and correct any high blood sugars on MDI, but a child over 11 will not always have the confidence to do this themselves. My sons HBA1c is around 7.0 because of our vigilence and hard work, but our son would like more control himself using CSII would give him this - should those with reasonable control of their diabetes be excluded from gaining better control and more independence. Just because they are over 11 and can inject themselves at school should not exclude them from the other benefits of CSII.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations

FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Margo Morriss
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 20/11/2007 @ 18:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no

DATAPROTECTION	1
EMAIL	margomorriss@hotmail.com
EXTENSIONID	extension:Guidance
FORMFIELD1	Item 1.3: Why is the level set at less than 8.5%. I believe it used to be set at 7.5%. 8.5% seems way too high. You say futher down in this report that less than 7.5 is good control, but it is no way near normal. I know a young boy on CSII who is able to achieve an HBA1c of 5%. This is what I would like to be able to achieve for my son who has an HBA1c of 7% (and is probably still in honeymoon). Why should he not be given the tools to achieve a normal HBA1c too?
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL3	3|Appraisal Committees preliminary recommendations
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FORMLABEL5	5|Appraisal Committees preliminary recommendations

FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Margo Morriss
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 20/11/2007 @ 23:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit

CONFLICT	no
DATAPROTECTION	1
EMAIL	faurefamily@hotmail.com
EXTENSIONID	extension:Guidance
FORMFIELD1	1.3 A level of 8.5% is too high 1.4 What about people falling under community hospitals where there is no DSN and no interest in pump therapy? This is unfair on the diabetic persons in that catchment area.
FORMFIELD2	
FORMFIELD3	Does this education include the carers eg parents of a diabetic child and later in life the childs education? At present carers of children cannot do a DAPHNE course which is an important part of matching insulin to carbs.
FORMFIELD4	The healthcare professional needs to ensure that the schools also have the competence to use CSII therapy effectively.
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL4	4|Appraisal Committees preliminary recommendations

FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Fiona Faure
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 21/11/2007 @ 08:11

Submission data:

Form element	Submitted value
ACTION	article

BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	iain.cranston@porthosp.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	1.2 Given that in the first recommendations there was a limit set to the number of people thought to be appropriate for this therapy (2-3%) should one reading these recommendations assume this ceiling has now been lifted and that anyone reaching the criteria can be trialled on a pump (ie upto 50% of type 1 patients). If this is not the case it would be useful if an indication of a putative ceiling is included (5%, 10% or 20%?!) 1.5 QOL goals seem to be completely absent from this section - does that reflect the view of the committee that QOL improvement is not a valid goal? 1.6 given that with prolonged disease duration the insulin secretory reserve of people with type two diabetes may become identically deficient to type 1, I wonder if a statement regarding c-peptide negativity could clarify the statement ie
FORMFIELD2	
FORMFIELD3	Does this statement mean that other devices that are likely to become available will not be eligible until a future re-appraisal? In particular there are a number of single use pump devices that are already available in the US and Im informed will shortly become available in the UK. Pricing appears to be cost neutral overall (with a reduced start-up cost, therefor good for trials of therapy) and I feel sure many patients would prefer such devices - could a statement to the effect that devices which are EU / MDA approved, supported in the UK and

	broadly cost neutral with those already available could be considered to be covered within thi sguidance?
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	iain cranston
NOTES	
O	38197
OTHERROLE	Consultant Diabetologist - Pump services

PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 21/11/2007 @ 11:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	nicola.ward@royalsurrey.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	1.1 We select for CSII very carefully. Despite this people frequently become very used to CSII and take it for granted and the commitment to good management disappears. I think all people should sign a contract of some kind which is reviewed by both the diabetes team and the financing authority at regular (?6/12)intervals. Until this is done, taxpayers money is going to continue to be wasted.This has happened to 2 of the families that I look after

	and I would like to be able to either enforce good management or remove the pumps from these families. 1.3 An HbA1c cut off of 8.5% is much too high.This implies that 8.5% is the level at which it is no longer safe to be. In our clinic we strive for 7% or less according to current recommendations. 50% of the children are 7.5% or less but mey still have very erratic control. Of significance is post-prandial hyperglycaemia - often unrecognised, but which may be causing significant damage - there is evidence which demonstrates that post-prandial hyperglycaemia may cause significant endothelial damage. Even using MDI and low glycaemic index food it is sometimes impossible to erradicate this problem without causing iatrogenic hypoglycaemia.
FORMFIELD2	2.3 The first sentence should read complications not problems. A complication is completely different to a problem. Somewhere in 2.3 there should be a reminder that both Type 1 and Type 2 diabetes in early pregnancy are potentially catastrophic for the foetus unless well controlled PRIOR to pregnancy. Abnormalities can arise soon after cell differentiation commences which would be long before a woman would even know that she was pregnant. 2.5 I do not regard good control as an HbA1c of 7.5%. The DCCT (NEJM - 1993) indicates that 7%or less is associated with a significant reduction in long term complications. I am never happy with 7.5% and someone on CSII should be easily able to achieve an HbA1c of between 6 and 7%.
FORMFIELD3	3.2 Cannula may need resiting every 2 days - this should be mentioned because of cost implications to PCTs
FORMFIELD4	A meta-analysis of the available relevant evidence might give further clarification.A wider search, including trials in progress might reveal more work in this area.
FORMFIELD5	

FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	nicola ward
NOTES	I have a lot of experience using insulin pump therapy with children and pregnant women.
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 21/11/2007 @ 15:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	jane.bramwell@gwent.wales.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	Point 1.5 offers a very narrow view of measures of success of CSII. There should be QOL indicators for children and young people, where the insulin pump has made a significant impact on their emotional or social wellbeing, without necessarily demonstrating a fall in HbA1c. A very important measurable improvement would be a reduction in the number of episodes of Diabetic Ketoacidosis/reduced number of hospital admissions. This point also fails to suggest a timescale - is this a deliberate strategy?
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	

FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	Wales
NAME	E J Bramwell
NOTES	I am a Paediatric Diabetes Nurse Specialist, working in a team with a special interest in CSII therapy
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional

SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 21/11/2007 @ 15:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	Thomas.Ulahannan@glos.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	Hba1c of 8.5% represents a poor standard of care to aim for. GP QoF targets 7.5% and most specialist bodies recommend 7% or lower. 8.5% risks much greater microvascular disease and younger age type 1s are at great risk of this. the target should be 7%.
FORMFIELD2	interesting that this scetion quotes HbA1c of 7.5% as indicating good control- see comments above
FORMFIELD3	Accu Chek spirit has 6 year warranty as standard
FORMFIELD4	a serious issue to consider is if patients with severe hypoglycaemia and

	HbA1c<8.5% are denied CSII, they may to be considered for islet or whole pancreas transplant as the only option. as well as the great cost, there is a great shortage of donors. The 8.5% target is unwise.
FORMFIELD5	most pump services are up and running so this will not be a problem
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Thomas Ulahannan
NOTES	
O	38197
OTHERROLE	

PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 21/11/2007 @ 23:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	jason@hibbs.com
EXTENSIONID	extension:Guidance
FORMFIELD1	The key phrase here seems to be
FORMFIELD2	
FORMFIELD3	The cost of these pumps seems reasonable when the technology involved is considered. For the NHS, the cost will be offset in short term by far less wastage of insulin, less practitioner time spent treating diabetic episodes etc.

	and in the long term by greatly reduced complications for those sticking to CSII. Some models have a facilty for automatic blood sugar testing (with a separate canula) which is trasmitted to the unit wirelessly. This is the first step towards a commercially avaialable artificial pancreas, or at least Islets of Langerhans. This is the future of diabetes treatment (until a more permanent cure is refined and understood. The sooner type 1 DM sufferers are weaned onto pump therapy, the better.
FORMFIELD4	Thankyou for taking all of this into account. Some small observations:
FORMFIELD5	Please make this technology available to as many type 1 DM sufferers as possible, as soon as possible.
FORMFIELD6	Thankyou for all your work on these vital issues. It may be better, in my humble opinion, not to waste any more resources on
FORMFIELD7	Please endeavour to move this forward to coincide with the release of new models of pump and a more closed loop
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk

LOCATION	England
NAME	jason hibbs
NOTES	My daughter was diagnosed at 18 months. She contracted rotavirus in Watford General Hostpital directly after stabilising her blood sugar/acidosis (blood ph)/ketones etc.. Her mother has slept through only a handful of nights since then. She is now 5 years old.
O	38197
OTHERROLE	Well versed in paediatric endocrinology
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 22/11/2007 @ 12:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no

DATAPROTECTION	1
EMAIL	marco.chris@btconnect.com
EXTENSIONID	extension:Guidance
FORMFIELD1	Not enough consideration is given to quality of life. For children in particular and pump can really improve their quality of life by giving them independence and therefore giving them greater self esteem. Many children find it difficult to give themselves injections pumps make it much easier for the child to control the dosage themselves (or in can be programmed). This means that going to friends houses for tea is much easier and less embarrassing for the child as the carer does not need to go round to give the injection. This may sound minor, but for a child in their early years this is a big deal.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations

FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Marco Christoforou
NOTES	Please consider quality of life. In my view this is not given enough consideration but is very important to children. E.g. independence which avoid a childs self-esteme being reduced. Independance is gained because the child and control the insulin themselves. Many children find it very difficult to give themselves injections.
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 22/11/2007 @ 13:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	helen.thornton@sthk.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	I welcome the appraisal committees recomendations especially for children under the age of 11 where MDI may not be an option.
FORMFIELD2	I commend the recognition of the very vunerable & difficult group to manage...the under 5s
FORMFIELD3	3.2 could we not say 2-3 days as 3 days may be the norm but in some cases it can be every 2 which may cause queries on costs
FORMFIELD4	I agree with the recomendations especially in the delivery of small doses in children
FORMFIELD5	Implimentation for Paediatric teams may be difficult when they deal with more than 1 PCT for funding of pumps. I would like to see advised that Paediatric teams providing a pump service would have a funding stream from the PCTs to enable them to have a pool of pumps within secondary care then consumables set up on a case by case basis. This would enable

FORMFIELD7	Review date seems fine
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Helen Thornton
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 22/11/2007 @ 18:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	connormilton@yahoo.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations

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FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	Scotland
NAME	connor milton
NOTES	iam 14 and disapointed the nhs doesnt fund the isulin pump. i want one to have a healther and extended life without my parents paying alot of money i think everyone should have the best treat ment
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 23/11/2007 @ 08:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	david.jenkins@worcsacute.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	These are sensible and pragmatic suggestions that will be easily understood by patients and healthcare professionals. A pre-pump contract drawn up between the healthcare team and the patient may help withdrawal of pummp treatment if it proves unsuccessful.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations

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FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Dr. David Jenkins
NOTES	I am a Consultant Diabetologist who treats adult patients with diabetes.
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 23/11/2007 @ 10:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	louise.meakes@sbucks.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	children younger than 11???more clarity and its use in younger age groups is very effective due to improved absorbtion CSII could have a role in insulin resistant type 2 patients what about patients with poor sites, with wide areas of lypohypertrophy
FORMFIELD2	
FORMFIELD3	3.4 is very generalistic education is not one off but on going and with specific pump followup clinics to ensure this therapy is maximised as patints do have to have a commitment toit it is not an easy option for the person with diabetes
FORMFIELD4	no comment
FORMFIELD5	guide lines need to be very clear but not prescriptive key assessment for suitability for pump therapy is vital for its appropriate use and sucess
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations

FORMLABEL2	2|Appraisal Committees preliminary recommendations
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FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Louise Meakes
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 23/11/2007 @ 10:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	nandu.thalange@nnuh.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	The HbA1c standard of 8.5% is too high. The effect of such a target would be to exclude the patients most able to benefit from pump therapy - ie the ones with control that is suboptimal, but who are striving to achieve it.
FORMFIELD2	I agree with the statement that optimal control in uncomplicated T1 diabetes requires a HbA1c of <7.5% - and this should be the target for defining eligibility for treatment with a pump - not 8.5%.
FORMFIELD3	specific consideration needs to be given to concomittant use of glucose monitoring systems - eg Medtronics CGMS system.
FORMFIELD4	I think a period of MDI therapy, even for children under 11y is appropriate. Schools are under an obligation to promote the welfare of children with health needs to facilitate their inclusion. Our service routinely uses lunchtime injections, and works with schools to achieve this.
FORMFIELD5	

FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Dr Nandu KS Thalange
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 23/11/2007 @ 14:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	jackie.webb@heartofengland.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations

FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Jackie Webb
NOTES	4.38 Not to consider CSII in people with Type 2 diabetes is short termism approach. These individuals can be severly insulin resistant (especially those from ethnic minority backgrounds), they have significant difficulties self-managing their diabetes and maintaining an HbA1c<8.5%. Subsequently when the cost to the NHS, economic, personal and societal costs of the impact of developing complicatons is factored in the cost of CSII is less onerous.
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 23/11/2007 @ 16:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	sarah.gibson@cumbriapct.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	
FORMFIELD2	
FORMFIELD3	Education pre-pump start and initiation, for each patient is hugely time consuming. In order for the patient to receive adequate eduation and on-going support with their pump requires one-to-one time with a pump specialist (usually a diabetes specialist Nurse). For example, the appointment to start a pump usually takes between 2-3hours, daily telephone contact is required for the first week and weekly appointments there-after to make the necessary adjustments to the various insulin rates, assessing blood glucose levels in addition to training on the technical aspects of the pump functions. It can vary from patient to patient but generally can be up to 6 months before the patient is competant using their pump. The better the educational support, the better chances of maximising pump therapy. In my area most adjustments are made

	by the DSN not the Medical Team. An emphasis on Patient Education must be made.
FORMFIELD4	Regarding training costs incurred for patient education, I would contest that costs would higher. I dont know what their figure Â£240 relates to? My comments are based on my own clinial practice and experience. Pre-pump preparation approx 1hour. pump start 2-3hours. Appt for the first set change 60-90 minutes.Daily telephone contact for the first week and weekly 60 minute appts for the first 4-6 weeks and monthly thereafter until 6 months approx. This gives a rough idea, some patients need more, some a bit less. This is relating to DSN appointment only, not doctor or dietitian, which would be extra.
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk

LOCATION	England
NAME	Sarah Gibson
NOTES	
O	38197
OTHERROLE	Diabetes Specialist Nurse
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 26/11/2007 @ 10:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	paul.langridge@coch.nhs.uk

EXTENSIONID	extension:Guidance
FORMFIELD1	1.3 feel HbA1c level should be lower i.e 7.5% as in original document or taken out alll together. 1.4 I think trained team needed (not specialist team) otherwise will limit ability to provide. 1.5 include perceived improvement in quality of life, i.e. less anxiety re hypoglycaemia. Child having frequent hypos may find have higher HbA1c after use but better overall control.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk

LOCATION	England
NAME	paul langridge
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 26/11/2007 @ 17:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	Alexandra.Ward@ruh.nhs.uk

EXTENSIONID	extension:Guidance
FORMFIELD1	These recommendations are more appropriate for the patients that I see and would like to consider for pump therapy than the earlier appraisal. I support them.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England

NAME	Dr Alexandra Ward
NOTES	
O	38197
OTHERROLE	Consultant Diabetologist
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 26/11/2007 @ 19:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	jackie@jacombs.demon.co.uk
EXTENSIONID	extension:Guidance

FORMFIELD1	1.1 How is commitment and competence to be measured? and by who? 1.3 Why is an HbA1c of 8.5% being quoted as a target level when the previous level was 7.5%? This is a huge backward step. The American Diabetes Association now recommends an HbA1c of 6.5%, as the sort of level people should be aiming to achieve where possible. “Good control is indicated by a value of less than 7.5% (normal range for people who do not have diabetes is 4.5-6.1%)” Nice Guidance 2004 1.5. An HbA1c might be higher post pump if someone had been experiencing swings from high to low. Less fluctuation might mean a rise rather than a fall, but there may be less cell damage due to blood glucose excursions. Someone could have an HbA1c of 5.9% on five injections a day, but be experiencing terrible control and their life may be blighted by serious uncontrollable hypos. On other insulin regimens like MDI, treatment is not withdrawn if a patient fails to achieve the recommended HbA1c. You do not return to 2 injections a day. There should be patient care plans in place.
FORMFIELD2	
FORMFIELD3	Some of these costs are applicable to MDI (Basal bolus) regimens as well. The intial training, insulin, testing strips, blood glucose monitors. Patients moving on to basal bolus regimens also require additional medical support when a new regimen is initiated
FORMFIELD4	If you want evidence for improved quality of life using CSII, there are many thousands of pump users in the UK, from children to adults, who would be keen to testify what difference insulin pump therapy has made to their everyday experience.
FORMFIELD5	

FORMFIELD6	My child had an HbA1c of around 7.4% before starting pump therapy and suffered from extreme hyper and hypoglycaemia which resulted in seizures. Especially at night, as my daughter has no hypo awareness at all when asleep. Since going on a pump her blood glucose levels do not fluctuate so wildly and we are able to give a reduced basal rate during sleeping hours to try to prevent the serious nighttime hypos which occurred in the past
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Jackie Jacombs
NOTES	
O	38197
OTHERROLE	Founder of UK Children with Diabetes Advocacy Support Group

PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 26/11/2007 @ 21:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	carl.taylor@nhs.net
EXTENSIONID	extension:Guidance
FORMFIELD1	1.3 The NICE guidance on type 1 diabetes in children states that a HbA1c of less than 7.5% is the target. Why has a higher HbA1c level be chosen for insulin pump therapy? Many of the children I feel would benefit most from pump therapy have a HbA1c below 8.5%, but cannot achieve less than 7.5% without disabling hypoglycaemia.
FORMFIELD2	

FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Carl Taylor
NOTES	
O	38197
OTHERROLE	Consultant Paediatrician

PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 26/11/2007 @ 22:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	oliverdouble@sardobi.freeserve.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	I am shocked that the acceptable HbA1c in this document is quoted as 8.5%.In previous NICE guidelines an HbA1c of 7.5% was what was considered acceptable and necessary to reduce complications. In the US this level is below 6.5%. What evidence has been used to justify this? My children have HbA1c of 7.4%. They need pumps for the variable basal rate. My 8 yr old would only need to have better quality of life to keep his pump. My 11 year old would ahve

	to prove a better HbA1c - though his reflects lots of lows during the night and day to keep it so low. His HbA1c may go up as he achieves balance and avoids hypos and swings. He would be safer but criticised for it and may lose his pump. Is this fair? How would you test us for commitment and competence? In a clinic not embracing pump therapy this could be used as a stick to beat the patients and carers amd refuse pumps to many.
FORMFIELD2	The definitions here are great. They stress the desperate need for good glycaemic control especially in those diagnosed young. They seem to disagree with the recommendations in the first section. You talk about the severe complications and address the psychological effects of this disease on the whole family and the patient. Are not these reasons enough to be given a choice of treatment which suits you, though it may not show startling reductions in HbA1cs? Childrens needs are so so difficult to manage, especially the young going into and through puberty. The previous statements do not allow for this most crucial time to be shown good guidance and be given every opportunity to learn for yourself how to keep your body healthy. How can a young person learn with the threat of loss of pump were they to make any mistakes which raise HbA1c? You even say in para 2.5 that acceptable HbA1c is 7.5%. Is the previous 8.5% a typo which might cost us dear?
FORMFIELD3	I would argue that many of these costs are also appropriate to those starting basal/bolus therapy. Also, they do not give the comparitive savings acknowledged by the Working Party on Pump therapy (2007), which prove savings year on year on the care required for complications and in-patient treatments over the years of using pumps. If medical insurance companies are willing to fund pumps in the States, there can be no better indication that pumps save money if viewed in a bigger picture. Should this not be reflected in your guidance or this information will merely hinder those professionals wishing to

	implement pump therapy from within PCTs as yet proving to be reticent to intiate it.
FORMFIELD4	The one thing missing from the studies is a report into how well adult users of pumps maintain theri HbA1cs and avoid complications if they have been started on CSII therapy from being a child. Does the use of the pump and ability to maintaing good healthy levels imrpove if the user has been exposed and educated in pumps from an earlier start? I would aslo ask you to define reasonable in terms of lengh of time to see differences when moving to CSII in clinics or PCTs ant-pump this time period could be used to disuade or even bar manmy from the therapy. These guidleines are vital tools for those seeking a better quaility of life. You have to ensure they give us tools to help rather than giving other the tools to prohibit the use of such modern technologies. Many clinics spend very little time or money on the mental health issues around Type 1. would hate to have to prove my childrens anxiety about hypos if it was the only criteria upon which to base a claim for pumps therapy. It could tie you up for many many months whilst your child suffers long-term problems. I still question the HbA1c of 8.5%. This is being set prohibitively high for financial reasons not clinical!
FORMFIELD5	I think these guidelines will set back the push forward for new technologies particularly for young people wanting to access CSII. I hope inadvertantly you will have made the task of proving need and qualifying criteria for CSII far more difficult when faced with many PCTs who are reluctant to embrace these new technologies. You will find more and more patients will be exercising theri patietn choice to move to areas where pump therapy is progressive and not restricted. I have moved to a clinic over an hour and a half away to be able to have pumps for my children. When this country is so far behind the standards of Sweden, France, USA, Italy and many of the worlds developed nations in

	terms of diabetes care, is it right to advocate a raising of the HbA1c seen as needed to prolong health and life? I feel ashamed when I speak to friends in other countries and have to describe the appeal for a referral I had to lodge to have my children considered for insulin pumps. I was successful, despite their lack of hypo awareness over-night and frequent hypos during the day, because I was able to quote from NICE guidelines. This document means I would not be successful again. Is that right?
FORMFIELD6	You have not referenced Making Every Young Person with Diabetes Matter (April 2007) Why change HbAic values to 8.5% when these other publications have it lower?
FORMFIELD7	I would say this needs reviewing sooner in the light of the comparitive price reduction for new technologies. Would the report not give scope to the demands for the Pump companies to reduce theri UK proces to bring them in-line with the costs in the USA. We pay more for the same technology here - why? This committee night have a louder voise to ask these questions. Also newer technologies - such a sensor pumps - will be here soon. The committee may have new guidance to add if the newer technologies provide life-chanign advances in therapy ie. artificial pancreas trial etc etc
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations

FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Jacqueline Double
NOTES	Sit as a user rep on the Every Young person with Diabetes Matters Working Party
O	38197
OTHERROLE	Parent of two childrenw ith type 1 diabetes
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 26/11/2007 @ 22:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit

CONFLICT	no
DATAPROTECTION	1
EMAIL	elizabeth.harpum@ntlworld.com
EXTENSIONID	extension:Guidance
FORMFIELD1	1.3 The figure of 8.5% is too high given that the DCCT study showed that 7.5% was the point at which significant reduction of diabetic complications occurred.Children in particular should be better protected from the longterm complications of diabetes by having a lower target HbA1c. Women planning pregnancy are advised to aim for a much lower HbA1c and this should be reflectd in the guidance. 1.5 Children experience great difficulty in maintianing good control through growth spurts and puberty, and this should be reflected in the guidelines. They should not be threatened with a return to injection therapy when they may be working very hard at their control but be struggling with effects of hormones and rapid body changes.
FORMFIELD2	2.4 Children often get little support in school in managing their diabetes, which increases stress on the child and family. All children should receive support in measuring blood glucose and taking appropriate action,administering insulin and ensuring food intake and exercise are balanced.
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	

FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Elizabeth Harpum
NOTES	
O	38197
OTHERROLE	Health Professional
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 27/11/2007 @ 09:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	margomorriss@hotmail.com
EXTENSIONID	extension:Guidance
FORMFIELD1	1.3. Diabetes UK state the following: The target for HbA1c is 6.5 per cent or below since evidence shows that this can reduce the risk of developing diabetic complications eg nerve damage, eye disease, kidney disease and heart disease. Individuals at risk of severe hypoglycaemia should aim for an HbA1c of less than 7.5 per cent. Any parent of a child with diabetes desperately wants to reduce their childs chances of developing these terrible complications. Could the people making these decisions about who should have the best care and tools to manage diabetes (CSII therepy) imagine leaving their own children on 8.5% without making strenuous efforts to correct this. Stenuous efforts to do so involve regularly checking blood sugars through the day and night to try to keep levels low and giving extra injections of insulin to bring down high blood sugar levels. By having the HBA1c set at such a high level seems to penalise children whose parents are making these efforts and preclude them from receiving the tool that could help them have a better quality of life now and a better chance of a long life. Surely having a pump should not just be about these figures

FORMFIELD2	
FORMFIELD3	
FORMFIELD4	4.1.2 There are many adults and children (not just in the UK but around the world) who have had their lives improved by CSII. I know this because I have spoken to them myself via email and their experiences should be taken into account. Why is an HbA1c of 8.5% being quoted as a target level when the previous level was 7.5%? This is a huge backward step. The American Diabetes Association now recommends an HbA1c of 6.5%, as the sort of level people should be aiming to achieve where possible. Why is the UK so far behind in their care of diabetes than the rest of Europe and the United States? The quality of life for the children 11 and over should be considered too. My son gets embarassed when with his friends - if they have snacks or food he has to get out an insulin pen, put a needle on it, calculate the amount of insulin needed to cover the food and inject (not much fun for a lad trying to fit in with his peer group, making him feel self conscious and different). He would much prefer to have a pump that he could use to bolus for the food he has eaten rather than having to inject himself. Surely these psycological issues are just as important as percentages.
FORMFIELD5	
FORMFIELD6	You dont seem to have mentioned the Making Every Young Person with Diabetes Matter document, which certainly doesnt have the tone that youngsters as young as 11 should fit the same criteria as adults in terms of reviews of their care etc.
FORMFIELD7	2011 seems a long way away considering how technology moves on and the fact that pumps should get cheaper over time. Pumps are much cheaper in USA

	- why not here? Can pressure /insentives be brought to bear to bring down prices and therefore increase the amount of people that can be given the chance of a more normal life, and a healthier one at that.
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Margo Morriss
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 27/11/2007 @ 14:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	lfcrbest@gmail.com
EXTENSIONID	extension:Guidance
FORMFIELD1	1.1 how will competence be measured? By who? 1.3 why is 8.5% now being quoted? The american diabetes assciation recommends 6.5% Is this figure a mistake? 1.4 for those in areas where this does not exist, will there be a centre of excellence to go to or is it a postcode lottery? 1.5 a rise in hba1c following pump therapy does not automatically mean glycaemic control is not improved i.e. where the previous hba1c was only lower at the expense of hypoglycaemia
FORMFIELD2	
FORMFIELD3	3.4 Some of these costs are applicable to MDI Basal bolus regimens as well. The initial training, insulin, testing strips, blood glucose monitors. Patients moving on to basal bolus regimens also require additional medical support when a new regimen is instigated. Long term cost of chronic ilnesss due to poor

	control?? Impact on quality of life is significant if not measurale.
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	helen lacey
NOTES	
O	38197
OTHERROLE	

PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 27/11/2007 @ 16:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	kate@fazakerley.org
EXTENSIONID	extension:Guidance
FORMFIELD1	In 1.3, how can an HbA1c of 8.5% be described as adequate control when the previous level was 7.5%? The Association now recommends an HbA1c of 6.5%, as the sort of level people should be aiming to achieve where possible.
FORMFIELD2	
FORMFIELD3	3.4 Some of these costs are not in addition to MDI therapy. Any type 1 diabetic

	will require insulin, lancets, test strips and glucometers and medical support whether they are using a pump or not.
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Kate Fazakerley
NOTES	
O	38197
OTHERROLE	

PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 30/11/2007 @ 10:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	donna.ross@nice.org.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	Just a test
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	

FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	donna.ross@nice.org.uk
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer

SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 30/11/2007 @ 11:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	bill.lamb@cddft.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	I have real concerns about the omission of adolescents and young adults as a group. They are a very difficult group to manage and have the worst metabolic control. There is NO evidence that MDI improves their long term control, the few RCTs are too short lived and there is much observational evidence to suggest that they do better on CSII. Also most individuals with repeated admissions for DKA have been shown to have greatly reduced admission rates on CSII. The increased baseline HbA1c to 8.5% conflicts with evidence suggesting that metabolic control improves as a whole for those with HbA1c >7.5% There is also a real ethical issue here. If an individual is on CSII, it has

	greatly improved the quality of their life, yet not satisfied some arbitary unvalidated targets, are you really suggesting stopping what for the patient is an effective treatment. Youll be legally challenged I think. Its not our diabetes! Would you stop somebody from using insulin if they didnt control themselves properly? Finally there are well documented cases of type 2 diabetes especially with very high insulin needs responding very well to CSII. Exclusion is not justified on any evidential basis
FORMFIELD2	It has been clearly demonstrated by the findings of the DCCT that there is no threshold effect of HbA1c and complication rates, and that the lowest HbA1c acheivable without unacceptable hypoglycaemia should be the target. Lowering HbA1c does increase the risk of severe hypoglycaemia, it is well recognised that CSII reduces the risk of severe hypoglycaemia. Therefore CSII should be available to individuals who have so-called acceptable control (HbA1c<7.5%) who want to further intensify their diabetes control but are unable to do so without hypoglycaemia. Are we seriously telling patients that they dont have to have better results than 7.5% or indeed 8.5% as is to be recommended by this advice?
FORMFIELD3	It is probably a myth that individuals on CSII get catheter infections. Careful observation shows that most of these episodes are reactions (a better term than infection) to the catheter and are influenced by the type of insulin infused. The greatest incidence of reactions is to insulin Lispro, but also occurs with both insulin aspart and glulisine. It is a very individual response. True infections are uncommon.
FORMFIELD4	I do not feel that the committee have adequately addressed the needs of adolescents and young adults. The evidence for benefit of MDI as the only intervention over the long term in this group has not been demonstrated. It is clear from the observational studies that adolescents do particularly well on

	CSII. As a clinician I have known of many children over the age of 11 who will NOT self inject at school. Furthermore our own observations suggest that the MAJORITY of school aged adolescents on MDI regularly miss their lunchtime injection, and this is in a clinic in the lowest decile for HbA1c results in the UK. Given that this is the group of individuals who are at greatest risk of inadequate control, but also at greatest risk of hypoglycaemia with intensification(DCCT evidence)then to set the criteria for CSII as the same for mature adults is discriminatory and frankly wrong. They should be treated almost as a seperate category of high risk and CSII available as an option for all. Remember only 50% of patients offered CSII will take it.
FORMFIELD5	Well we know how effective these methods have been in raising awareness, availability and uptake of CSII in the UK. Still the lowest in the developed world!
FORMFIELD6	
FORMFIELD7	Should be reviewed sooner than this as both the technology and expertise in CSII are changing rapidly. No later than 2010
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations

FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Dr W H Lamb
NOTES	I have received payments for lecturing on insulin pumps both from the NHS and insulin pump manufacturers
O	38197
OTHERROLE	
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 30/11/2007 @ 16:11

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no

DATAPROTECTION	1
EMAIL	niall.furlong@sthk.nhs.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	I do not think that an HbA1c of <8.5% is necessarily acceptable when people are having major problems with hypoglycaemia, particularly in pregnancy or if they have established complications? Given the importance of tight glycaemic control,why should such suboptimal control be acceptable when CSII can facillitate improved glycaemic control with a reduced risk of hypoglycaemia.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations

FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Niall Furlong
NOTES	
O	38197
OTHERROLE	Consultant diabetologist
PROCESS	1
ROLE	NHS Professional
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 01/12/2007 @ 02:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no

DATAPROTECTION	1
EMAIL	nice.j.josleas@xoxy.net
EXTENSIONID	extension:Guidance
FORMFIELD1	I am disappointed that MDI therapy is considered to have failed at a HbA1c of 8.5% or less even though good control is usually considered to be 7.5% or below and some authorities recommend even lower levels. This seems a backwards step from the previous guidance which used the clinically more appropriate 7.5%. Disabling hypoglycaemia is mentioned but not patients whose blood glucose (BG) levels fluctuate widely throughout the day resulting in an adequate HbA1c at the cost of a poor quality of life and probably future complications as a result of the hyperglycaemic episodes? Research has found that the mean difference between an individual's (adults) lowest and the highest hourly basal rate on a pump was 127% and ranged from 25 to 300% when optimised to reduce these BG fluctuations (King & Armstrong, A Prospective Evaluation of Insulin Dosing Recommendations in Patients with Type 1 Diabetes at Near Normal Glucose Control: Basal Dosing). A flat basal insulin injection cannot hope to match the basal insulin requirements of many of these patients. Research has also shown that juveniles (aged <20) have an even more pronounced and sustained night time peak in basal insulin needs.
FORMFIELD2	
FORMFIELD3	Im not sure why insulin, lancets, test strips and glucometers are included in this list as these items will be needed even without a pump. Some costs will also go down, e.g. insulin pen needles. We carried out more tests during multiple daily injections because blood glucose levels fluctuated more and were less predictable than during pump use. If control is poor enough to consider

	prescribing an insulin pump then further education will obviously still be required even if a pump is ultimately considered unsuitable for the patient. Education should therefore not be seen as an additional cost caused by pumps. We have needed less help from clinic staff since the one day of pump training we received compared to the help we needed using multiple daily injections. We needed much more help from staff with day to day management because of the more unstable blood glucose control my daughter had. Before the pump my daughter suffered seizures twice but this has not been a problem since using the pump so we have also had less need of help from the ambulance service.
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk

LOCATION	England
NAME	Jocelyne Underhill
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 01/12/2007 @ 09:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	langdon812@btinternet.com

EXTENSIONID	extension:Guidance
FORMFIELD1	I am worried that HBA1cs will be used to remove some off pump therapy even if the quality of life has improved on the pump.
FORMFIELD2	Good that the danger of hypoglycaemia recognised.
FORMFIELD3	
FORMFIELD4	I am worried that if my son wants a pump his good HBA1c will be used to prevent this, even though he is having worrying hypos.
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England

NAME	julie langdon
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 01/12/2007 @ 14:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	SARAH-MILLS1@sky.com
EXTENSIONID	extension:Guidance

FORMFIELD1	
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	How do you intend to finance these recommendations when most trusts only have funding for just a few pumps a years (some trusts have not facilities which requires an out of area referral). Its all very well having these guidelines but funding at a local level is extremely difficult not just for the pump but for DSN time to support the introduction and support of a pump. As a parent I can only say that I wish we had been encouraged to look at a pump earlier rather than struggle on for so many years not improving HbA1c - god only know that damage we may have done. The local issue has always been funding and no amount of guidelines will changing this practice. As a parent I feel a pump should be available to every child who wants one as the payback in years to come with better control at a younger age I am convinced will cover the extra expenses.
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations

FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	sarah mills
NOTES	
O	38197
OTHERROLE	Mother
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 01/12/2007 @ 15:12

Submission data:

Form element	Submitted value
ACTION	article

BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	mary.f.moody@btinternet.com
EXTENSIONID	extension:Guidance
FORMFIELD1	The HBA1C level of 8.5% is not the optimum level for the avoidance of complications. The Diabetes Control and Complications Trial found that intensively treated patients had lower average blood glucose levels than conventionally treated patients even when they had the same HbA1c. It was concluded that the lower average BG levels may explain the link between intensive treatment and both increased hypoglycemia and decreased microvascular complications compared with conventional treatment. A second study looked at data from the DCCT and compared how well average BG predicted cardiovascular disease compared to HbA1c. The conclusion that,
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations

FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	Scotland
NAME	Mary Moody
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 04/12/2007 @ 14:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	fiona.hunt@midlothian.gov.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	HbA1C of 8.5% is too high as the risk of ciomplications at even 7.0% is significantly greater. this limit should be reduced. As stated further down the document good control is judged to be when the HbA1C is 7.5% or lower in section 2.5. The OR should be made clearer in 1.3 so that it is clear a patient only needs to meet one, not both of the requirements.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations

FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	Scotland
NAME	Fiona Hunt
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 06/12/2007 @ 12:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	adrian@teknocat.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	Currently the UK has lower usage of CSII than most other European Countries. CSII was first initiated in the UK and is a proven method for improving control, lifestyle and productivity of diabetic patients - hence the high usage of pumps in virtually all other Westernised Countries. The upfront costs of CSII are comparatively low compared with the costs of complications of diabetes. Why is it that Diabeic patients are being discriminated against? Does a cancer patient have to prove that they have tried all other possible methods of pain contol before being allowed to use a pump to deliver their pain medication? This appraisal is yet another short term cost cutting excercise which will be very costly for Diabetics throughout the UK and is a wasted opportunity to improve the treatment options available for this chronicaly sick group of people who have to live with discrimination throughout every path of their lives without the NHS employing similar tactics. Point 1.3 needs to have the criteria relaxed. Diabetes is all about failure - failure to achieve correct blood sugar results so often and with so little encouragement. Now the NHS is failing us too.

FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Adrian Miller
NOTES	
O	38197

PROCESS	1
ROLE	Patient

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 06/12/2007 @ 12:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	rosemaryhumby@aol.com
EXTENSIONID	extension:Guidance
FORMFIELD1	para 1.3 - the limit of less than 8.5 is most unwise. Where is the evidence to substantiate a move to such a high limit? To run at an HBa1c as high as 8.4 (or even lower than this) is inviting long term health complications as well as an low quality of life. Certainly I would consider my health to be in danger if my blood sugars were running this high! 1.5 - HbA1c levels may well stay the same after starting on a pump despite the fact that overall control has

	significantly improved. Lots of high sugars and lots of low sugars can lead to quite a respectable HbA1c. I think people with diabetes are well able to judge whether their control has improved with the addition of a pump.I personally would not put up with the inconvenience of a pump if it did not significantly help my control!Targets are in my view quite inappropriate here - it is impossible to set targets which are meaningful. A decrease in hypos could be accompanied by too many hyperglycaemic episodes, yet the target would still be met. I think the targets set out here are quite simply a nonsense.
FORMFIELD2	2.5 So if good control is indicated by an HbA1c of less than 7.5, where does the 8.5% level mentioned above come from??
FORMFIELD3	3.4 insulin is not an additional cost as it is also needed for injection regimes. Same applies to lancets, test strips and glucometers.
FORMFIELD4	4.1.2 - my quality of life is without doubt significantly better whilst using an insulin pump. I have been on a pump for just over 7 years. My HbA1c levels are largely unchanged pre/post pumping, but my overall control is much better, with far fewer excursion outside the range (about 5-10) within which I try to keep my blood sugars. 4.3.11 I return to the same point - my HbA1c has not improved on a pump despite my having significantly better control and fewer excursions outside an acceptable range. Frequency of hypos is not something which can be measured scientifically by a clinician in any event. So the use of these targets, linked to pump withdrawal, is a nonsense which I would most strongly oppose.
FORMFIELD5	none, except that I believe many individuals who would benefit from an insulin pump are still having problems getting one. In other words, what is set out above is not happening in practice.

FORMFIELD6	none.
FORMFIELD7	If the target/withdrawal principles are to be included, and also the 8.5% ceiling, both of which I strongly oppose, then review would be required much sooner than 2011.
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	rosemary humby
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient

SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 06/12/2007 @ 17:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	type1tom@aol.com
EXTENSIONID	extension:Guidance
FORMFIELD1	You state in 2.5 below that a good HbA1c level is 7.5. Why is the limit for failing MDI set at 8.5? This is even more curious when the 7.5 limit is considered too high by many people. Patients should not need to have tried all variations of MDI if it is obvious that just changing the type of insulin will not resolve the problem causing the high HbA1c level. There is no mention of quality of life issues as a possible condition for starting CSII. Diabetics have to live with their diabetes, not just survive it, and allowance should be made for considering these issues.
FORMFIELD2	This last statement that good control is indicated by an HbA1c level of less than

	7.5% conflicts with the statement at 1.3 above. There is evidence that even the 7.5% figure is too high, and that the value should be less than 7%.
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Tom Falconer
NOTES	Currently using a pump.
O	38197

OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 06/12/2007 @ 19:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	joparsons.parsons@btinternet.com
EXTENSIONID	extension:Guidance
FORMFIELD1	1.3 1.3 Due to A1cs being based on a total advarage of glucose in the blood over 3 months reoccuring hypos can lower this advarage giving a false impression so highering the target range could be derogatory. Quaility of life should also include patients employment and effects of MDI within a work pattern and also reflect the interaction of both work and social life effect on a

	individual quaility... 1.5 Measuring improvements of A1cs and hypo alone to obtain whether a improvement has been acheived, is problematic in many ways... This leaves a very open ended interperations of this guideline, due to lack of time scale and that of good results achieved could end with the patient being left with the stress andworry of having there therapy removed giving a negetive effect or unfair time scale...
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk

LOCATION	England
NAME	joanne parsons
NOTES	Hoping to go to pump therapy
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 06/12/2007 @ 23:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	lornawhite32@googlemail.com

EXTENSIONID	extension:Guidance
FORMFIELD1	It would be wonderful if this therapy could be made available to more people. I struggled to gain any sort of control for 44 years until I tried a pump, which completely revolutionised it for me. The guidelines suggest it should only be for people who have problems, and yet it could make a significant difference to the development of problems for many people. Why is it not appropriate for Type 2, when some type 2s have as many difficulties as type 1s? I agree it needs to be properly introduced and explained, and the person using it needs to be competent to use it (or the parent/carer in the case of a child). An HbA1c of less than 8.5 does not necessarily mean someone does not have a problem - it is after all an average, and could be achieved despite significant highs and lows.
FORMFIELD2	What about MODY? This puts young peoples health at risk, and they will have diabetes for a long time in all probability.
FORMFIELD3	However large the cost appears to be, it must be measured against the cost of treating diabetic complications, hospital admissions etc. It is likely that the long term results of CSII make these events less likely, or at least delay them. Quality of life is also considerably improved.
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations

FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Lorna White
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Public
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 07/12/2007 @ 08:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	kldpjd@supanet.com
EXTENSIONID	extension:Guidance
FORMFIELD1	As a parent of a child with diabetes my aim is to make her blood sugar levels mimick those of a person without diabetes. This means the HbA1c needs to be near to 5.5%. Insulin pumps have been shown to reduce HbA1c and used to be issued to people who could not get their HbA1c below 7.5%. I cannot understand the reasoning behind increasing this threshold to 8.5%, which is LOWERING STANDARDS, unless it is to save money in the short term. Poor control will lead to more long term complications and cost more in the long term. This country should be embracing new technologoes which improve quality of life and save money in the long term.
FORMFIELD2	If good control is acknowledged as being below 7.5%, then why has the threshold for pump therapy been raised to 8.5%. Studies have shown that blood glucose control in children with diabetes in this country is very poor, with 85% not achieving an HbA1c below 7.5%. In America, the recommendation is to have an HbA1c below 6.5%. Surely we should be decreasing the threshold, not increasing it.
FORMFIELD3	As said previously, costs could be recouped by a lessening in future

	complications, provided that adequate training and support is given
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	Wales
NAME	Karen Dunford
NOTES	
O	38197
OTHERROLE	

PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 07/12/2007 @ 12:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	inputpaeds@hotmail.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	1.1 why aged 11 cut-off point? Research has shown adolescents & toodlers in particular benefit most from CSII, both ages being difficult to control diabetes for different reasons.Additionally,1.1 who decides MDI is inappropriate, I worry this can be used as a get-out clause to effectively bar CSII for some children if funders have financial/budgetary concerns, if staff are not trained or available, or if consultnat does not believe in CSII. The 8.5% recommendation

	is atrocious, it may well be money/biggest effective result driven, but consideration should be given to DCCT research proving 6.05% is the target to aim for to reduce long term complication prosepects. My son has had HbA1c 6-7.3% over past 5 years, at age 17 he has retinopathy, bleed in left eye.Denying children of all ages CSII as their HbA1cs may be 8.5% & over is going to condemn many more children to earlier complicationsd, especially those who have been diagnosed young. This will not be cost effective for future nations health, short term savings against long term complications. 1.5 HbA1cs cant continually drop, & arent actually proof of good control, it should be removed completely, its a nonsense, escape clause
FORMFIELD2	Please remember some children with diabetes die every year, dead-in-bed syndrome is still with us, how many of those who died had been using a pumpat the time of their death? or even a sensor? One we know of was on injections, and had had a severe hypo only 2 months before she was founf dead-in-bed. My onw sone has no glucagon response, which should be anotrher consideration for having a pump, and sensor, especially of the child also has hypo unawareness, or is too young to be able to recognise and tell. Unfortunately we still hear of have clinicians who think hypos are not dangerous, or tell parents that if your child hypos in her sleep, it will wake them up. Oumps and education are needed more than ever to try and prevent any more dead-in-bed deaths they devatstae the whole extended family for ever, and leave them feeling guilty. Pumps should be looked at for th is reason as well. As for good control being under 7.5%, this may reflect constant glucose swinigs, from 1mmol to 30+ mmols, especially with children on injections, experience of this, when son was in this position, yet the HbA1c, showing the average, did not tell the full story,HbA1c OK, control crap!
FORMFIELD3	The difficuloty is, that intensive education should actually be offered to all

	people with diabetes, not just those going onto CSII. The reality is, education isnt available to all. we have had no education since August 2000 from the hospital, pump or otherwise. Lancets, test strips etyc are also required for injection users! Its been shown those on pumps actually need less ongoing support from the diabetes team following sucessfull initiation of CSII, they get to self-manage!
FORMFIELD4	4.24 The cost of hospitalisation appears too low, my sojns costs when we were on hoiliday for paramedics and ambulance for severe hypo which afected his heart rythmm, was over Â£1000, and that did not involve an overnight stay. This was the first and only time since using CSII he had such a severe life-threatening episode (which started at 4am and the hypo did not awaken him, I tried, in vain, to). I give myself nightmares wondering what the situation would have been on injections.
FORMFIELD5	In addition to NICE technology appraisals being implemted, NICE shoyld also be able to implement thehir guidelines, specifically those on management of diabetes (2004)and the National diabetes audit should have to include questions and indformation in its audit on CSII details from all hospitals, numbers on pumps, clinical targets etc, and numbers fullfilling criteria for pumps who have not been offered CSII and reasons why not. How are we ever going to improve care for childrenwith diabetes in the UK if we dont ask the relevant questions and act on the results?
FORMFIELD6	As before, these NICE guidelined contain good stuff, unfortunately they are not enforcable and in may places are certainly not used. They may be referred to as good practice, but as I have been told by a senior nurse on one ocassion,
FORMFIELD7	By the time this review comes into effect I assume it will be 2008, so 2011 is 3 years. It is a long time if the HbA1c requirement increases to 8.5%, perhaps it

	should be shortened to see how disastrous an effect this will be, supported by ongoing national monitoring of effect via National Audit. What I fail to understand is why diabetic pump users are subject to this close scutiny, discriomination and intervention in the UK, when other pump users for other purposes, ie thalasaemia, asthma, chronic pain control, are not they dont have their own NICE technology assemments, so why do diabetics?
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Deborah Beskine
NOTES	I am mother of son with type 1 diabetes I ahve studeied nursing course on childhood and adolescent diabetes
O	38197
OTHERROLE	nurse
PROCESS	1

ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 07/12/2007 @ 13:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	tcp123456@hotmail.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	Like the USA, I think the only criteria needed for pump use should be personal choice and capability of carb counting. Multiple injections should be regarded as second rate treatment not a primary treatment. Also people with type 2 diabetes are successfully treated with the pump in the USA and elsewhere in the world.
FORMFIELD2	
FORMFIELD3	Pump therapy may be more costly to manage, but ultimately it could save the

	NHS millions of pounds to reduce diabetes complications later.
FORMFIELD4	Adolescents have body image problems and have different priorities during teenage years than diabetes control. My son lost over one stone in weight after pump therapy and while I am trying to leave him to deal with his diabetes control to become an independent adult, his management isnt as strict as mine. Do you want to penalize him if his HbAlc happens to be elevated during this training time? Also as teenagers and students generally sleep late in the mornings, injections would be missed. The insulin is delivered continuously whether they are awake or not.
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England

NAME	Tina Cappuccini-Pearce
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 07/12/2007 @ 14:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	max.finn@tiscali.co.uk
EXTENSIONID	extension:Guidance

FORMFIELD1	I can not understand why the Hba1c guideline has been set at 8.5%, when it has been well documented by the DCCT trial that a HBa1C of above 7.5% can cause long term complications. In fact, in that study, anything above 6.5% leads to an increased risk of complications. To take away an insulin pump just because the HbA1c has not come down is cruel. My son wears his pump 24 hours a day, he has grown up with it and it is part of him, to take it away would be devastating for him. Instead those who struggle with an HbA1C should be given extra support, not punished. What kind of message does that send children? Injections are a punishment for not complying with a pump?!
FORMFIELD2	
FORMFIELD3	The insulin is not a cost specific to the pump. The cartridges used to provide insulin injections actually cost more than the vials of insulin used to fill the reservoirs for a pump.
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations

FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	marie betts
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 07/12/2007 @ 16:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit

CONFLICT	no
DATAPROTECTION	1
EMAIL	marion@explc.com
EXTENSIONID	extension:Guidance
FORMFIELD1	1.3 The level of 8.5 is concerning especially as ideal level when child is charted looks at 6 - 7.5. Why has level been raised? 1.4 trained teams are ideal but supportive and knowledgeable teams are fine, for nearly 3 years we have had little contact with the DSN or dietician and now only meet every 6 months for a review and daughter is 13 years old. 1.5 Having a child who has had diabetes for 10+ years I find this comment very disappointing, my daughter had a good Hb level but this was achieved by erratic levels which greatly affected her day to day life as well as ours, this was supported by having use of a CGMS. For us the Hb did reduce but for some the difference may be marginal but may mean better quality of day to day life, less trauma due to the concerns of hypers and hypos. How can such a simple statement be used fairly??
FORMFIELD2	Agree in the main to 2.3 & 2.4, however it confuses me why many health departments nationally do not start carb counting at diagnosis, and do not mention the inflexability of some regimes, options should be discussed, eg twice daily injections versus MDI. These things seem to be age related, I believe full and accurate information should be given at diagnosis and reviewed quite quickly to help support the families in the best regime for them to suit their lifestyle. Why should diabetes be allowed to restrict when more flexibility is available at the outset even in terms of MDI. Make the complications clear and fully support the family, dont hide information, people take this on at different levels over different time frames. 2.5 Why is 7.5 being quoted when

	8.5 is the level to be considered for CSII, are we looking at just cost here? Levels have to be a lot higher to achieve an Hb of 8.5
FORMFIELD3	3.4, our daughter has a pump and we happily supply all batteries, the insulin, lancets, test strips and meters are the same whatever regime you use though there may be more test strips used. We had two hospital appointments, one to view pumps available and agree on best pump and one to commence pumping, the health team during our visits have learnt a great deal from us. We did have DSN support for the first week of pumping. We have now reduced our annual visits from 4 to 2 so this reduces costs.
FORMFIELD4	
FORMFIELD5	cost savings for reduced hospital visits must be considered. My daughter has only visited her GP for minor things like tonsillitis in the last 10 years, we have medication at home in case there is a site infection, we have had one in nearly 3 years. With CSII for us and a supportive view to her health care by us and my daughter she is a happy and healthy individual who just haappens to have diabetes. This has been helped greatly in recent year by her pump as hormonal teenagers are very volitile in many ways. I would suggest that your studies are conducted on less stable individuals as adults of 30 - 40 should be much easier to control than growing children.
FORMFIELD6	
FORMFIELD7	As noted before a fairer more even study may produce more accurate results which would put children in a fairer light. A review in 2009 may be appropriate.
FORMLABEL1	1|Appraisal Committees preliminary recommendations

FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Mrs M Malik
NOTES	N/A
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 07/12/2007 @ 19:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	pr@bradfordgrammar.com
EXTENSIONID	extension:Guidance
FORMFIELD1	I have just been informed that my 8 year old son may not be able to get a pump because we are working like trojans to maintain a good level of sugars and because of this he has to suffer 7 or 8 injections. If we just didnt care and his HbA1c was high he would be eligible for funding. This is ridiculous and very upsetting for a little boy who hates injecting but copes because of our support. Your guidlines need to change. It has just ruined his Christmas learning he might not get funding.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations

FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Patricia Reddish
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 08/12/2007 @ 15:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	angela17@btinternet.com
EXTENSIONID	extension:Guidance
FORMFIELD1	
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations

FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Angela Dudley
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 13:12

Submission data:

Form element	Submitted value
ACTION	article

BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	melissa.ford@mac.com
EXTENSIONID	extension:Guidance
FORMFIELD1	How do you define competence and commitment? These are subjective terms. Please give measurable criteria to ensure consistency. A1C benchmark of 8.5% is TOO HIGH. All current standards of care published by say 6.5%-7.0%. The Diabetes Control and Complications Trial (DCCT), showed in 1994 that an A1C above 7.0% is correlated with higher rates of diabetes complications. If a prospective pump users established diabetes care team is not trained to initiate and supervise insulin pump therapy, the patient must be referred to a specialist team for evaluation before pump therapy may be denied. Non-specialist teams may not deny patients who wish to be evaluated for pump therapy access to specialist teams. In the case of patients whose A1Cs were below the benchmark before starting pump therapy, an increase in A1C – so long as the A1C remains within range of the benchmark, is acceptable as it signals a reduction of hypoglycaemia episodes. CSII therapy is not recommended for people with type 2 diabetes unless MDI has failed. Patients diagnosed with type 2 diabetes whose diabetes whose diabetes is not under control despite compliance with insulin therapy may be evaluated for CSII
FORMFIELD2	Sec 2.4: Diabetes mellitus is a chronic condition in which both morbidity and treatment affect quality of life. For patients on conventional insulin therapy (2-3 injections/day) or MDI (3+ injections/day) daily life activities may need to be arranged around a relatively inflexible structure of meal times and insulin

	injections. Sec 2.5 Causes of beta-cell dysfunction in patients with type 2 diabetes are under investigation as the United Kingdom Prospective Diabetes Study (UKPDS) showed that seven years after diabetes diagnosis many patients produce only half as much insulin as non-diabetic individuals. Insulin requirements change depending on food intake, hormonal changes, stress levels, exercise or illness. Many type 2 diabetes patients can achieve control of their diabetes using a basal insulin and oral medications but all type 1 diabetes patients and many type 2 diabetes patients require both bolus and basal insulin. The Diabetes Control and Complications Trial (DCCT) showed conclusively that in type 1 diabetes, achieving good control of blood glucose through an intensive regimen, including frequent SMBG, reduces the risk of complications. UKPDS showed similar findings in type 2
FORMFIELD3	Starlet is not currently (9 Dec. 2007) approved by any regulatory agency and Animas just launched the IR 2020 in the UK - please confirm available insulin pump models with ALL manufacturers before the final guidance is published. The pump is programmed to deliver basal rates of insulin throughout a 24-hour period, with boluses (doses) programmed separately at meal times and to correct glycaemic excursions. The main advantage of modern insulin pumps is that they can deliver different basal rates of insulin at different times of the day and night. It is recommended that the disposable cannula is removed and replaced every 72 hours (3 days). All insulin users, whether on MDI or a pump, require insulin, lancets, test strips and glucometers for monitoring. In the cases of young children going on to pump therapy, their parents or guardians receive education and support.
FORMFIELD4	Include word isophane as synonym for NPH. Sec. 4.1.4: what number & types of centres specifically? Sec. 4.1.7: The time of puberty was also identified as a difficult time to control diabetes because of fluctuations in sex and growth

	hormones, which dramatically affect insulin sensitivity throughout adolescence. Children also have a greater lifetime risk of complications because complications are more likely the longer the duration of diabetes, and an early onset makes for a potentially longer time lived with diabetes. Sec. 4.2.4: is it really only Â£413 when someone needs to take a day or two off work? Reduced productivity is a cost. Sec. 4.2.6: severe hypos cost only Â£65?? 4.3.1: effective use of NHS resources includes prevention of expensive diabetes complications!!
FORMFIELD5	Sec. 4.3.6: ...for whom, despite a high level of care, it has been impossible to maintain a HbA1c level of less than 7.5%, or who experience disabling hypoglycaemia at an A1C below 7.5%. Sec. 4.3.10: Additionally, the use of effective insulin pump therapy would require replacing the cannula every at least every 72 hours and programming the pump (similar degree of difficulty to operating a mobile phone). Sec. 4.3.11: reasonable time period? What is it? What about people who lose control for a short time after getting control? 4.3.12: Furthermore, the whole package of care provided to all people with diabetes, including pump users, should include....
FORMFIELD6	6.1 given that the Exubera product has been discontinued by Pfizer I am not sure that it is relevant anymore!
FORMFIELD7	What will happen when new models of insulin pumps are released to the market before 2011? Will they be available to patients or will pump companies be allowed to distribute only the models of pumps that were on-market as of the date this guidance becomes effective? Please clarify. It would be a severe injustice to UK patients with diabetes if they are not allowed access to incremental improvements in insulin pump technology because this was not specified.

FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Melissa P Ford
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 13:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	05CLD@kings-school.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations

FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Charlie Dalton
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 19:12

Submission data:

Form element	Submitted value

ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	h.cope@hotmail.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	1.1 The age of 11 is completely arbitary and neither scientifically nor evidence-based. 2- dose and MDI regimes are more likely to result in severe hypoglycaemic events yet
FORMFIELD2	2.3 All children therefore have severe hypoglycaemic episodes. 2.3/2.5 One of the main drawbacks of 2-dose and MDI regimes is the unpredictability of action of insulin, both in duration and quantity. The sensitivity of children to insulin and the small doses thay are on increase the margin of error to unacceptable levels when insulin is injected. One drop remaining on the insulin needle after injection may be 50% of a dose. Injection pens allow adjustments in 1/2 unit increments only. The statement
FORMFIELD3	3.2 The only insulin delivered is rapid-acting delivery is much more precise doses can be measured to 1000ths of a unit ability of setting variable basals is extremely useful and not applicable to MDI. Maximum bolus can be set, much safer than an insulin pen. Technology is improving all the time for instance Medtronic now do a pump which can receive readings from CGSM. 3.4 Most of these costs (should) apply to any other insulin regime.
FORMFIELD4	4.1.8 The Committee might wish to recommend that further RCTs of CSII

	therapy are undertaken for its future reference. When an intensive insulin regime is recommended by the care team, its mode of delivery (MDI or CSII) must also be a clinical decision in consultation with the patient. Unfortunately, the proposed guidelines will be seen as a backwards step by the diabetes community, with reference to arbitary ages and HbA1C levels. The supporting documentary evidence submitted by the small numbers of insulin pump users in the UK and the specialist diabetes teams that use them have been given insufficient weight in this appraisal.
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Helen Cope

NOTES	
O	38197
OTHERROLE	Doctor Senior management MRC and Wellcome Trust now full time carer to child with type 1
PROCESS	1
ROLE	Carer
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 19:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	d.battson@btopenworld.com
EXTENSIONID	extension:Guidance

FORMFIELD1	These seem like good recomendations.
FORMFIELD2	Parents of all children with type 1 should be offered the insulin pump.
FORMFIELD3	The consumable costs can vary a lot depending on many factors.
FORMFIELD4	The quality of life issue ie: the flexibility of life when using a pump is so important as it does give a feel of what it would be like to be normal.
FORMFIELD5	Within 3 months should be a maximum time.
FORMFIELD6	Overall a good consultation document.
FORMFIELD7	The date should be brought forward to the September of 2010
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	david battson
NOTES	

O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 20:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	arleneosman@btinternet.com
EXTENSIONID	extension:Guidance
FORMFIELD1	My HBA1C was 7.9 when I commenced on pump therapy . With the suggested 8.5 level then I would not have been considered. I am eternally grateful that I was selected for pump therapy . It has changed my life. I have control over my

	life and I am not constantly worried by high blood sugar readings. My HBA1C is now 7.1 so therapy has had an impact on my long term health and my risk of complications is now minimal which I think is very important to me and to the financial burden that I will now not cost NHS.
FORMFIELD2	It states that rate for pump is 0.6 per kg I am using far less insulin than this. I have halved the amount of insulin that I require since starting pump. The least amount of insulin necessary to treat must be advantageous . Insulin is weight gaining and I am now able to loose weight as a result of using less insulin.
FORMFIELD3	Long term savings that are made by reduction in complications should also be considered.
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations

FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	Wales
NAME	Arlene Osman
NOTES	
O	38197
OTHERROLE	Pharmacist
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 21:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1

EMAIL	bary.squire@hotmail.com
EXTENSIONID	extension:Guidance
FORMFIELD1	I consider it to be totally inappropriate to set targets for people. Targets will only create STRESS, stress will have the wrong effect and only produce worse results and the whole situatioon will become a vicious circle. Providing other people like me with an Insulin Pump will I am sure save the NHS money and give back to many diabetic patients a reasonable quallity of life once again. I am very seriious about this matter and my wife who suffered hell for many years will back me up.
FORMFIELD2	
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations

FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Barry Squire
NOTES	i have been using an Insulin Pump for over 7 years and it has proved to be my salvation. For the 6 years prior to starting insulin pump therapy at least once a year I was an in-patient at the local hospital, in between these sessions Paramedics were called to my home 4 to 5 times a year. Since starting to use a pump, paramedics have not been called at all nor have I been an in-patient for any problem directly related to my diabetes.
O	38197
OTHERROLE	Fully retired former garage mmmmmmanager
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 21:12

Submission data:

Form element	Submitted value

ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	caroline.batistoni@virgin.net
EXTENSIONID	extension:Guidance
FORMFIELD1	The use of an A1c value is somewhat meaningless. Since an A1c is an average, it is possible to obtain a value much lower than 8.5% via huge swings, which make patients feel awful and decrease QoL/productivity, even without recurrent hypos. 8.5% is also a startlingly high number, given complication risk associated with that level, the recommendations following DCCT and the fact that previous guidance used 7.5%. It is acknowledged later in this guidance that good control is represented by a value under 7.5%. Using 8.5% does a disservice to those regularly achieving 8% Para 1.5 implies that if there is no improvement in glycaemic control, the pump will be withdrawn. It is not clear over what time period this applies. As a CSII user for 6yrs, Ive seen great improvement in my control and my life. My A1cs have improved greatly over time, but my last A1c was higher than the previous one and Id had more hypos. It is not possible to see improvement indefinitely. This guidance seems inappropriate to long term users of CSII. QoL is also an important outcome measure which is not addressed in Para 1.5, nor is a reduction in the anxiety about hypoglycaemia mentioned as an indication in 1.3
FORMFIELD2	Para 2.4 is an accurate appraisal of QoL issues, and illustrates their importance. The inflexibility of an MDI regime would make it impossible for me to do my

	job as an NHS dentist, and is also unworkable for many people who fulfill important job roles that demand flexibility and good control. Work can be difficult aside from the issues caused directly by complications. I feel these issues are important enough that they should be considered an indication for CSII on their own.
FORMFIELD3	
FORMFIELD4	
FORMFIELD5	
FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Caroline Batistoni

NOTES	Using insulin pump therapy funded by the NHS for the last 6 years.
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 09/12/2007 @ 21:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	caroline.batistoni@virgin.net
EXTENSIONID	extension:Guidance
FORMFIELD1	The use of an A1c value is somewhat meaningless. Since an A1c is an average,

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FORMFIELD4	
FORMFIELD5	

FORMFIELD6	
FORMFIELD7	
FORMLABEL1	1|Appraisal Committees preliminary recommendations
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FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Caroline Batistoni
NOTES	Using insulin pump therapy funded by the NHS for the last 6 years.
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 10/12/2007 @ 21:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	splith@helper3000.net
EXTENSIONID	extension:Guidance
FORMFIELD1	8.5% is far too high and it should be recommended for teenagers because it is not possible for us to get control on injections because of growth sperts and go to bed late / get up late, which can be dealt with on a pump, but not on injections. The part about training is a complete joke I have never had it.
FORMFIELD2	If normal people have a maximum HbA1c of 6%, why is the target for diabetics 8.5% and a good control 7.5%, this is rubbish and a complete contradiction. Im now 17 years old and have never had an HbA1c over 7.5% since I used a pump but I now have long term complications in my eye which will affect my sight so even 7.5% is not good enough. Alslo the HbA1c doesnt mean your levels are actually always low, it usually means an aveerage and you have highs and lows. So it doesnt really mean anything to have this HbA1c unless you know what it

	is made up from.
FORMFIELD3	Ive used a pump for 7 years and have never ever had a site infection.I BUY MY OWN BATTERIRES, THATS NO PROBLEM, i ALSO BUY BaTTERIES FOR OTHER THINGS i USE. Education? I dont get any, I was trained with my mum and dad by a nurse in August 2000 and then she left and we have never had any help since, we have to try ourselves and when things go wring there is no one who really can help as out nurse doesnt do pumps and the hospital dont do downloading them.
FORMFIELD4	Actually, as slomeone who has used injections and pumps, there is a big diffrence between quality of life, on injections my life was actaully total crap and I never went out except to school and I was always having hypos or being forced to eat stuff when I wasnt hungry and didnt want to. All that stuff above, its not for real man!! Know what I mean? Any kid can use a pump, its easier than a mobile phone, we all learn computers at school and get to make them. You poeple doing this must be much older than me if you think its hard to use a pump. You should try injections, now thats hard init? pumops do really little amounts of insulin, injections dont, and sometimes they leak out your skin, or hit lumps and stuff and you go unconscious. I cant understand what all the fuss is about pumps, all children should have one so should teenagers, cos they protect us from dying from really bad hypos. I hypo slower with my pump so I can do something about it, if Im awake of course.
FORMFIELD5	Dont know what to say about this one. It would be nice not to have to travel a long way for my clinic but like they dont do pumps right here right now.
FORMFIELD6	? dont know about this stuff either
FORMFIELD7	Dont know about this one either. Does it mean pumps have to be looked at

	again in 3 years time? why? theyre just pumps, although having ones that play games and mobile phone fopr help would be good too. when do you look at injections again? Do you check these out every 3 years too?
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
FORMLABEL4	4|Appraisal Committees preliminary recommendations
FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	Jamie McCrae
NOTES	
O	38197
OTHERROLE	
PROCESS	1
ROLE	Patient
SUBACTION	reviewform

Form type: guidance notes: ACDDiabetes@nice.org.uk

Submission date: 10/12/2007 @ 22:12

Submission data:

Form element	Submitted value
ACTION	article
BTNSUBMIT	Submit
CONFLICT	no
DATAPROTECTION	1
EMAIL	mccrae5@hotmail.co.uk
EXTENSIONID	extension:Guidance
FORMFIELD1	Pumps are essential for children and teenagers who have bad hypos. All chidlren seem to have hypos at some time and its really frighteneing as a dad to watch this and think your child is dying. Soemtimes the glucagon doesnt work and an abulance has to take your child to hospital.Having a pumps reduces how serious hypos are. Having a teenager, and its really hard during this age for the parents and their youngster, everything changes. When my son is gowing, when he is ill, when he is moody, and sometimes for no known reason at all, his blood sugar levels are all over the place.His HbA1c has gone up and down a lot during the last few years as he has grown and started to go out with his mates. Bweing able to eat pizza and be like them has been better by having a pump and may have helped stop his HbAS1c going as bad as it might have, but 8.5% is much too high. If he had not had a pump, I think he might have died from a

	hypom(he had one that affected his heart), like someone my partner knows whose daughter died from a hypo one morning this year and she was only 12 years old and was on injections. Having a pump is not about HbA1c in real life, its about living the best you can.
FORMFIELD2	My son has had short term problems and now has eye problelms although he has had so called good Hba1cs, and someone he was at school with is also 17 and they found out this year he has kidney problems from his diabetes and its serious. He didnt have a pump, always had injections.Surely if normal poeple without diabetes are 4-6% Hba1c, then we should be aiming at 4-6% for our children and teenagers with diabetes to get to? why is it acceptable for them to be 8.5% when we knwo that means they will get long-term complications? Using the glucose sensor is also a good idea and can save lives, it alarms for hypos so is useful for children who have no awareness of hypos
FORMFIELD3	Never known any site infections happen but there have been problems when my son bleeds at canula sites. But then, on injections, he could eat his meal, have his ionsulin injected afetrwards, and within minutes have a seizure, and collapse unconscious, bruised from where he fitted.This doesnt happen with a pump as the insulin goes in slowly. The m,atter of education,the bck up is very poor, almost non-existant, and certainly the only emergency help or advice is to call an ambulance. You might think we get education and all that stuff, well, in my experience, nothing has been available for the past 6 plus years, we just have to muddle through or phone the pump company. I used to work in plastics and would have thought some of the consumeables should be a lot cheaper than they are. I think they are cheaper abroad.
FORMFIELD4	Im just a dad, and all that research stuff, well, I only know about my son and about others from other parents,its easier for family life having your child on a pump, easier to go out, be spontaneous, less emergency supplies to carry, better

	qulaity of life, more able to take part in school activities more able to benormal and less arears for schools to discriminate against your child for having diabetes.Injections arent cool fopr kids, especially if they have to go to matrons office to get them, and as teens find diabetes embarrassing and may try to hide it and not take their insulin if its by injection. Using a pump isnt just about getting good HbA1c although thats an added benefit, its about your child getting thier personailty back and being able to live the best life and get the best use of education they can.Highs and lows stop them being able to learn the same, their brains need to be normal blood levels so they can get exams the same as their mates, and be able to get jobs.
FORMFIELD5	Thats good, our local health poeple didnt seem to have that stuff in place when our son originally wanted a pump. Does that mean that if youre auditing implementation, you will now enforce it? It is certainly needed.
FORMFIELD6	Thats a lot of guidances, but I underst6and that you dont actually enfoce them, if you did my son would have had education, would have a pump nurse, diet and exercise advice and podiatrist, none of which he gets, in fact they dont even look at his diary. You need to look at making sure we get the basics as well as pumps, there is so much missing from care for our children with diabetes you wouldnt believe it.To date, care received over the majority of the past 9 years has been severely lacking, despite all those guidelines you show. They are just that, guidelines, no one we have seen in clinics has actually taken any notice whatsoever of them.
FORMFIELD7	Thoughts are, why review in 3 years, is this review faulted? It is looking at financuial aspects especially, so is it a cut back and are you looking to check if you can get away with reducing access to pumps through the 8.5% and making people get targets? Would a sooner review be better? if something major change? or a later review? What was wrong with the previous report of 2003?

	Pump technology has improved so the HbA1c level should be reduced, but its gone up instead. So Im not sure about this one. If iot says 8.5%, I would review it sooner rather than later, but where will you get any real evidence from, as its those who arent on pumps and who dont make a fuss or underatand seriousness of diabetes this is going to affect most, and in years to come when longterm complications may be irreversible.
FORMLABEL1	1|Appraisal Committees preliminary recommendations
FORMLABEL2	2|Appraisal Committees preliminary recommendations
FORMLABEL3	3|Appraisal Committees preliminary recommendations
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FORMLABEL5	5|Appraisal Committees preliminary recommendations
FORMLABEL6	6|Appraisal Committees preliminary recommendations
FORMLABEL7	7|Appraisal Committees preliminary recommendations
FORMRECEIVER	ACDDiabetes@nice.org.uk
LOCATION	England
NAME	robert mccrae
NOTES	
O	38197
OTHERROLE	dad
PROCESS	1

ROLE	other
SUBACTION	reviewform