NICE Clinical Guideline: Diabetes in children (partial update)

Stakeholder scoping workshop notes

Quality Standards

- Many of the adult's quality standards are subtly inappropriate for children and young people, for example the adult's quality standard on structured education centred around Dose Adjustment For Normal Eating (DAFNE) evidence which does not apply to children. One stakeholder noted that new evidence on structured education for children and young people called 'Choice' was about to be published in Northern Ireland
- There was agreement among some stakeholders that the quality standard for children and young people needed to include a statement that would ensure that clinicians offered same-day diagnostic testing and referral to children and young people in whom diabetes was suspected. Discussion on this topic highlighted that, although recognition remains a problem in some areas, stakeholders were generally more concerned that despite correctly identifying signs and symptoms, health care professionals are still not acting quickly enough on their suspicions and instead asking patients to return at a later date, rather than carrying out immediate testing. It was noted that this was a particular problem in relation to children and young people with type 1 diabetes as they require more urgent care
- The same stakeholders also agreed that the pregnancy advice for young women should be included in the children's and young people's quality standard as some health care professionals still felt uncomfortable about discussing this important issue and a statement would help to reinforce better practice
- Glucose monitoring strategies and transition were also identified as topics for the quality standard – see below
- It was noted that key areas for children that are covered in the adult's quality standards include education, chronic health care planning and acute health care planning. Some quality standards are already established in paediatrics: for example specialist diabetes teams are already standard practice in paediatric diabetes (quality standards 11-13). Quality standard 10 (footcare) is not a major issue for children, although regular footcare reviews are an important part of annual review (quality standards 3 and 8). Quality standards 1 and 2 (education), which overlap with quality standard 6 (insulin dosage and education), were thought to be important for children and young people, as were quality standards 8 (annual assessment for complications) and 9 (psychological assessment)
- It was noted that quality standards 5 (medications), 10 (footcare) and 7 (preconception care) were not thought to be as important to children and young people, although advice on the need for contraceptives should be included in any recommendations/ quality standard on education

- It was felt that families should be included/mentioned in any recommendations/quality standards – it is important to include the family perspective in the diabetes in children quality standard and recommendations
- It was noted that there are no quality standards on support from schools and nurseries – for example on how to manage injections/pumps/etc. in schools. This could also include other settings – afterschool clubs, babysitters, etc.
- It was noted that there are no quality standards on other types of diabetes (MODY, etc.)
- It was noted that the term 'specialist diabetes team' is not defined in the quality standard

Key clinical issues that will and will not be covered (sections 4.3.1 - 4.3.2 of draft scope)

General comments

- Some stakeholders suggested that monitoring for retinopathy and nephropathy should be added to 4.3.1.h (screening for dyslipidaemia and coeliac disease in type 1 diabetes) as there has been an increase in the number of children under 5 diagnosed with these conditions. Many centres are monitoring those under 12 – the stakeholders questioned the evidence for the cut-off at this age in the current guidance
- Some stakeholders suggested that it is unclear how the transition experience questions will translate into recommendations. Is this the best way to frame this question? Perhaps look at more concrete outcomes? The Youth Health Talk module on T1D may be useful here
- It was noted that the National Paediatric Diabetes Audit launches in June-September and may be useful. It publishes in early 2013 and is chaired by Deborah Christie. The National Diabetes Audit and National Diabetes Inpatient Audits may also be relevant
- It was noted that it would be useful to make recommendations on the creation/mandatory use of national diabetes registers and the cost implications of poor diabetes care in the young

Key clinical issues that will be covered

Topic a: The use and diagnostic accuracy of antibody tests for distinguishing type 1 and type 2 diabetes in children and young people

- Some stakeholders considered this to be a low-medium priority only – could potentially be dropped from scope
- Other stakeholders described this is an interesting topic but of fairly low priority in relation to some other topics because the tests are not reliable enough to direct clinical decision making on their own but just make up one part of the overall diagnostic picture. Realistically the results of these tests are more relevant/useful several year later when insulin control has been established to help figure out if a child or young person who was originally diagnosed with type 1 diabetes does

in fact have a rarer type of diabetes, for example Maturity Onset Diabetes of the Young – MODY • The same stakeholders noted that when diagnosis is uncertain is better to assume type 1 and treat with insulin (and then find out later that it is type 2 when it becomes apparent that insulin therapy is not completely essential) because this approach carries less risk than assuming it is type 2 and the type 1 child developing diabetic ketoacidosis (DKA). Using these tests would be more likely to encourage bad practice because they might wrongly encourage clinicians to rule out type 1
Topic b: Structured education programmes and behavioural interventions to improve adherence in children and young people with type 1 diabetes
• Some stakeholders noted that this was a very high priority topic to look at in terms of making recommendations but it is unlikely that there will be any evidence in a young population. Suggest that evidence is sought from Germany where structured education seems to be effective and then extrapolated for the NHS • Other stakeholders described this as a high priority for clinical and health economic review because this will be relevant to such a high proportion of the overall type 1 population. It will also therefore be likely to have a high cost impact and so should be the subject of a health economic review
Topic c: Multiple daily injections vs. mixed insulin in children and young people with type 1 diabetes
• Stakeholders agreed that this is a very important topic, probably the highest priority for the update, because there is a lot of variation in practice • However, it was noted that the wording of the questions needs to be reviewed to make very clear that the clinical concern is not about the device/technology used to deliver insulin but rather the outcomes associated with different frequencies/intensity of different insulin regimens • See also comments on topic f
Topic d: Metformin in addition to insulin in children and young people with type 1 diabetes
• It was noted that this is less of a priority than topics a-c because even if it is shown to be effective then it is unlikely to benefit many patients (stakeholders quantified this as approximately 1 in 100). If resources were not limited though it would be useful to undertake the review as this is an area where there is variation in practice and there may be new evidence available (some small studies from the USA). It was also noted that although the use of this intervention is not entirely contingent on obesity status (it is also used for children and young people who are highly resistant to insulin), it is more likely to be used in groups with high BMI, and because obesity is becoming more common, the use of this intervention therefore may also become increasing relevant/common
Topic e: Glucose monitoring strategies in children and young people with type 1 diabetes, including blood glucose targets and methods of monitoring (continuous, frequent or infrequent)

- With regard to targets for blood glucose – it was noted that there is already good guidance about this published by the International Society for Paediatric and Adolescent Diabetes (ISPAD) and it is unlikely that there will be any new evidence available that will conflict with this advice. Stakeholders were aware however that some centres did not treat to targets, which they considered to be bad practice
- With regard to monitoring strategies – it was noted that this is an extremely important area because there is significant variation in practice and there are problems with access to treatment throughout the country. This should not only be reviewed but also be considered for the quality standard. It is a large and complex topic though and this is not reflected in the current wording of the question. As with the question on different insulin regimens (see topic c above), the question should not be limited to/focus too much on the use of specific continuous blood glucose monitoring devices, but rather on establishing what the optimal frequency for monitoring is. Key issues for stakeholders were the lack of availability of blood glucose testing strips (their view was that children and young people should have access to as many as they want), which it was felt was reinforced by a lack of clear guidance on the minimum number of tests that should be carried out each day. Stakeholders also agreed that giving children and young people choice about what equipment they used to measure blood glucose levels was likely to be beneficial although they were unsure if there would be any evidence to support this assertion. They noted that the type of monitoring strategy used would be likely to have an impact on the management of diabetes in schools which is currently excluded from the scope
- Some stakeholders suggested that the question on blood ketone monitoring should be moved to this section and should look at the use of blood ketones in sick day rules and the prevention of DKA (i.e. as an outcome) –see below for more details
- It was noted that 'frequent glucose monitoring' is the standard glucose monitoring regimen in type 1and everything should be compared to this
- It was noted that it is important to define 'frequent', 'infrequent' etc. carefully in terms of number of tests per day
- It was noted that automated bolus calculators should be included as a comparator (there is a recent study from Denmark on this)

Topic f: Dietetic advice including glycaemic index and carbohydrate counting for children and young people with type 1 diabetes

- Stakeholders agreed that this is a very important topic. There is currently massive variation in practice, lack of access is a problem, is a relatively new area and current guidance is not very detailed and it was also a research recommendation in the previous guideline
- It was noted that while glycaemic index is used very occasionally on its own if carbohydrate counting has not been possible, in practice these are not usually seen as alternatives. Instead glycaemic index is used as an adjunct to

carbohydrate counting which is a more basic approach and the first line option and this should be reflected in the wording of the question • It was noted that this topic is intrinsically linked to the effectiveness of different insulin regimens as these dietetic strategies are only relevant to children who are on intensive insulin regimens, not those on mixed insulin or twice daily insulin injections. Stakeholders advised that the wording of this question should be amended to make this clear and adequate consideration should be given to the role of such dietetic advice when formulating the questions for topic c
Topic g: Management of diabetic ketoacidosis in children and young people with type 1 diabetes, including the use of blood ketone monitoring
• Stakeholders agreed that blood ketone monitoring is a high priority for clinical review as part of the overall consideration of different methods of monitoring and maintaining glycaemic control (see above) but a review of different DKA management strategies is not a high priority because there is good existing guidance on this published by the British Society for Paediatric Endocrinology and Diabetes (BSPED) and this advice is also incorporated into the ISPAD guidance. As this is quite well known within the clinical community this topic could potentially be dropped • It was noted that this question needs to be re-phrased as two questions, one about the effectiveness of blood ketone monitoring at home to prevent hospitalisation and another about the effectiveness of blood ketone monitoring during a DKA episode for reducing the length of inpatient stay
Topic h: Recognition of dyslipidaemia and coeliac disease in children and young people with type 1 diabetes
• Stakeholders agreed that this was a high priority for clinical review because there is variation in practice • Regarding coeliac disease – it was noted that the changes to the current diabetes guideline that were made as a result of the new NICE coeliac guidance recommending that testing for coeliac disease should occur only at diagnosis is clinically wrong and both the diabetes and the coeliac guidelines need to be updated. • It was noted that there is an ongoing study on the use of HLA subtypes in diagnosing coeliac disease – not specifically in children with diabetes but it could be relevant. • It was noted that it is important to consider the long-term effects of dyslipidaemia as it is unlikely there will be any evidence in the age groups considered in this guideline • It was noted that in order to ensure that the advice on both dyslipidaemia and coeliac testing is clinically relevant the questions need to be reworded to reflect when these tests are first useful – testing for coelic disease should occur at diagnosis and every three years thereafter, whereas testing for dyslipidaemia at diagnosis is not useful as lipid levels are likely to be abnormal at this stage anyway and so results will only be meaningful later down the line • It was noted that as with the complications of type 2 diabetes, this should begin with an investigation of the prevalence of different complications before determining the effectiveness of different recognition strategies

• There was also no clear consensus among stakeholders about whether to treat/how to treat children and young people who receive abnormal lipid test results. This may have an impact on the usefulness of the current question – without evidence of treatment efficacy, the effectiveness of recognition cannot be properly evaluated • Some stakeholders did however agree that it would be appropriate for the recommendations on the management of dyslipidaemia to be undertaken as part of the lipids guideline so long as the population of the guideline was expanded to include children and young people and there was adequate paediatric input within the guideline development group
Topic i: Transition care for children and young people with type 1 diabetes
• Some stakeholders described transition is a crucial stage of management of diabetes. 16-25 year olds with type 1 diabetes are a particularly vulnerable group and in stakeholder experience poor practice at this time correlates with bad long term outcomes • The same stakeholders were aware that there is some evidence about the effectiveness of structured transition in a general context and believed that some of this may be diabetes specific • Some stakeholders noted that the current recommendations were already good and would be unlikely to change as a result of a further review, although this may be an important topic for the quality standard • It was noted that there is a possible gap with regard to psychological care – this is a problem because current service structures in adolescent mental health stop at 16 and adults services only start at 18 meaning that there is a gap in service provision at this crucial stage • It was noted that if this is included, the question needs to be reworded as it is not useful in its current form. The TCATS(?) study on models of transition care may be useful for this. There is a Diabetes UK report 'Making Every Young Person With Diabetes Matter' which may also be useful here
Topic j: Structured education programmes and behavioural interventions to improve adherence in children and young people with type 2 diabetes
• It was noted that there is new evidence from the USA (large multicentre study) that would be relevant to this topic. Nevertheless some stakeholders felt that this was of lower priority than other topics relating to type 2 diabetes – see below • Other stakeholder said that this was a high priority for clinical review because this will be relevant to such a high proportion of the overall type 2 population. Unlike with type 1 though the total number of children receiving this treatment is likely to be quite small so the cost impact may not be as high and health economic analysis may not be as crucial
Topic k: Metformin monotherapy for children and young people with type 2 diabetes
• Some stakeholders said this is the primary pharmacological management strategy for children and young people with

type 2 diabetes so it is priority for review • Other stakeholders said this was a medium to low priority in comparison to other topics due to the number of children who were likely to require this treatment and if a new review is undertaken, insulin may need to be included as well. 'Usual care' is weight loss and exercise (lifestyle interventions)
Topic l: Glycaemic control monitoring strategies for children and young people with type 2 diabetes, including blood glucose, HbA1c, weight/BMI and frequency of monitoring
• Stakeholders agreed that this is an important topic for children and young people with type 2 diabetes as well as those with type 1. As with the type 1 question, this question should not be limited to/focus too much on the use of specific monitoring devices, but rather on establishing what the optimum frequency for monitoring is. It was however noted that CGM devices were not used in this group of children and young people. • It was noted that unlike in type 1, there is also no clear consensus on what the optimum HbA1c/blood glucose targets for children and young people with type 2 diabetes are so further questions need to be added to address this • It was noted that blood pressure monitoring should be added as an intervention
Topic m: Management of diabetic ketoacidosis in children and young people with type 2 diabetes including the use of blood ketone monitoring
• Stakeholders agreed that this is also an important topic and should be included in the update, however, the management of type 1 diabetes and type 2 diabetes does not differ in relation to DKA so it should be possible to undertake a single review/make overarching recommendations for both groups in this case • As above, it was noted that the management of DKA is low priority because it is covered by other guidelines but the use of blood ketones is high priority and should be moved to the glucose monitoring topic
Topic n: Recognition of renal disease/nephropathy in children and young people with type 2 diabetes
• Stakeholders agreed that this is also an important topic and should be included in the update because there is significant variation in practice • It was noted that the list of possible complications should be expanded to include retinopathy, hypertension, dyslipdaemia, fatty liver • Regarding dyslipidaemia and retinopathy; it was noted that these are likely to be the same for type 1 and type 2 so could cross-refer from one to the other rather than doing a separate review • As with the complications of type 1 diabetes, stakeholders felt that it was reasonable to refer to other guidelines/expert clinical judgement for the management of complications for type 2 diabetes beyond recognition
Topic o: Transition care for children and young people with type 2 diabetes

- Stakeholders agreed that this is likely to be the same as in type 1 so a separate review is not required – just look at all children with diabetes
- See also comments on topic i

Clinical issues that will not be covered

- Some stakeholders suggested that the following topics/areas should be included and were more important that the topics on antibody tests, DKA management and metformin in type 1 diabetes
    - 4.3.2.e. The management of type 1 diabetes in schools/non-family settings should be included
    - 4.3.2.j. Care during surgery should be included – in particular the use of pumps during surgery as there is variation in practice
- The same stakeholders also suggested that treatment for children and young people with type 2 diabetes who have failed to maintain glycaemic control with metformin should be included (i.e. treatment with insulin should be included as well as treatment with metformin)
- Other stakeholders said that the exclusion of post metformin treatment options for children and young people with type 2 diabetes (topic p on draft scope) was discussed but stakeholders concluded that this was an appropriate exclusion
- It was noted that the draft scope did not include anything on the management of diabetes in children and young people with eating disorders. It was noted that this problem may be more prevalent in an adult population but this needed to be balanced against the fact that it is very dangerous (10 deaths in 15 months in the adult population was cited). It was noted that current guidance is helpful in raising awareness of this problem but lacks specific instructions about what healthcare professionals should do in terms of treatment for this subgroup
- It was noted that one of the current recommendations about the use of oral glucose solution for the treatment of severe hypoglycaemia was wrong and potentially dangerous (the current recommendation does not make clear that this treatment should not be used if the child or young person is unconscious). Comment was also made that recommendations on the treatment of mild to moderate hypoglycaemia may also be incorrect (the current recommendation about consuming carbohydrates recommends a higher dose than is found in other guidance). Changes to the recommendations on the management of hypglycaemia may involve changing recommendations that are about delivering care in schools. Stakeholders did not reach a consensus as to whether these problems meant that the whole area of hypoglycaemia management needed to be included in the scope though
- It was noted that the exclusion of management in schools may not be practical in light of other included topics – see bullet directly above and topic e

Other comments

- It was noted that the following topics are covered in other guidelines and should be cross-referred to:
  - 4.3.2.t. Management of complications and co-morbidities other than diabetic ketoacidosis
  - 4.3.2.u. Specific diet/exercise/lifestyle advice for children and young people with type 2 diabetes
  - 4.3.2.x. Bariatric surgery – this should be cross-referred to and clearly highlighted in the diabetes in children guideline
- It was noted that there was a variation in screening/monitoring practices between paediatric and adult diabetes care – for example children have annual thyroid screening but adults do not. This should be harmonised. The issue of the evidence behind the age banding (12+) on the screening recommendations was raised again and it was suggested that this should be lower. It was also suggested that an additional question should be included on whether early diagnosis/recognition of retinopathy etc. leads to better HbA1c later on – this might need to be extrapolated from the evidence for adults
- Editing issues: it was noted that it would be useful to cross-refer to or reproduce the recommendations in the existing type 1 adults' guideline on management of complications (e.g. microalbuminuria etc.) as these are relevant for children as well although currently excluded from the scope apart from management of DKA

GDG composition

- It was felt that a GP might not be necessary. One nurse should have a DGH background as well as one of the paediatricians.
- Ideally the lay representatives should include people with experience of type 1 and type 2, and a parent/carer, although some stakeholders questioned how relevant type 2 (lay?) input into the GDG would be given the size of the type 2 section compared to the type 1 section. It might also be useful to have ethnic minority groups represented. The PPIP representative said that the Black and Ethnic Minority Diabetes Association (BEMDA) would be sent GDG advertisements but that would not guarantee receipt of applications to joint the GDG.
- A pharmacist expert advisor might be useful for the topics on mixed insulin and metformin in type 2
- An expert advisor would be useful for the education topics – particularly someone from the Department for Education who deals with implementation of health guidelines in schools. It was felt that someone from the Department for Education would be more useful than a teacher or headteacher as they would be more effective in getting any recommendations implemented in schools
- Public health input might be useful, although it was noted that this might be more relevant for the type 2 adults' guideline
- A nephrology expert advisor was suggested

- Some stakeholders were unable to comment on this due to time constraints

Other sections of the draft scope

Outcomes

- General points:
  - Different outcomes are relevant for type 1 and type 2 diabetes
  - There is some crossover between outcome categories – for example, hypoglycaemia requiring third-party assistance (e.g. in hospital) is both a measure of glycaemic control and a complication
  - The adverse effects outcome is perhaps too specific and may be confusing – the group wanted to add hypoglycaemia as an adverse effect of metformin in type 1 diabetes. It might be simpler to remove any reference to metformin and specific adverse effects
  - BMI should be added as an outcome for type 2 diabetes
- Notes on specific outcomes:
  - 4.4.a. This should be preprandial glucose not postprandial glucose. For questions on continuous glucose monitoring the outcome should be the area under the curve (AUC) rather than preprandial glucose
  - 4.4.c Quality of life should include school attendance (this may be a specific outcome on its own as well, for example in the adherence questions). This should also be expanded to include quality of life for parents and carers (EQ5D)
  - 4.4.d. Complications should include DKA episodes, instances of neuropathy, retinopathy and nephropathy
  - 4.4.g. Patient satisfaction should include patient experience
- Some stakeholders were unable to comment on this due to time constraints

Equalities and population

- There are equalities issues to consider in terms of language and cultural barriers to diabetes education (for example education may not be available in non-English languages or in formats suitable for the deaf/blind or those with learning disabilities). Those with learning disabilities and visual impairments may also have difficulty in self-management (e.g. injecting)
- Some stakeholders were unable to comment on this due to time constraints

Healthcare setting

- This was not discussed due to time constraints

Epidemiology and current practice

- This was not discussed due to time constraints

Summary

- Some stakeholders stated that insulin regimens and carbohydrate counting are the most important topics for the guideline update
- Other stakeholders prioritised setting of care (schools etc.), care transition and education
- Broader themes were:
    - The need for joined up thinking in terms of transition care and glycaemic target setting in the children's and adults' guidelines
    - The need to consider diabetes as a lifelong illness and extrapolate from adults' guidelines where there is a lack of paediatric evidence
- The need to recognise that there has been an intensification of treatment since the publication of the last guideline was also noted