NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Diabetes in children and young people

Date of Quality Standards Advisory Committee post-consultation meeting:
07 April 2016

2 Introduction

The draft quality standard for Diabetes in children and young people was made available on the NICE website for a 4-week public consultation period between15 February and 14 March 2016. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 20 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these systems and structures to be put in place?

3. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4: Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources required to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

5: The final quality standards should highlight a small number of priorities for improvement. Can you tell us what the 5 most important statements within this standard are?

Stakeholders were also invited to respond to the following statement specific questions:

6. For draft quality statement 2: To aid measurability how many times per year would children and young people receive this education programme?

7. For draft quality statements 3 and 4: These aim to be delivered at diagnosis - could these be merged into a single statement. Please detail your answer.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- General support for this quality standard with an overall consensus that all the draft statements are important.
- Suggestion to combine a number of statements - draft QS 1 and 8 on MDTs and 3 and 4 on insulin regimens and carbohydrate counting or combine draft QS 2, 3, 4 and 7 together on education.
- A number of editorial comments were received on a number of statements and underpinning information.

Consultation comments on data collection

- Local systems and structures are currently not in place to collect data for these quality measures but some networks have established data collection mechanisms.
- Units receiving or working towards receiving the Best Practice Tariff should be able to collect these data.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Children and young people presenting in primary care with suspected type 1 diabetes are referred on the same day to a multidisciplinary paediatric diabetes team.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Support that this statement aligns with a Scottish national initiative which aims to reduce diabetes ketoacidosis (DKA) at presentation of new onset type 1 diabetes to less than 10%.
- Support for early access to clinical psychologists at this early disease stage.
- Supported as an important area which is easy to measure. Auditing in Primary Care will be most effective.
- Concern raised on the term referral – does this imply telephone contact to seek advice from Paediatric diabetes services or a GP letter?
- Concern raised that children and young people do not need immediate referral to a team specialising in paediatric diabetes but to secondary care. However, immediate emergency care should be competently provided by a generalist paediatrician, with prompt appropriate onward referral to a specialist team.
- Concern raised on the structure measure stating ‘Evidence of local arrangements and written clinical protocols’ as being a resource burden and unnecessary.
- Suggestion to include proportion of patients with type 1 presenting in DKA (i.e. late diagnosis) in the process measure.
- Suggestion to state ‘suspected diabetes’ rather than specify diabetes type due to diagnosis difficulties.

5.2 Draft statement 2

Children and young people with type 1 or type 2 diabetes and their family members or carers are offered a continuing, structured diabetes education programme at diagnosis.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Support for education programmes for children and young people and their families.
- Support for structured education as the cornerstone of type 1 diabetes management and timely access for the individual and family.
- Concern raised on data collection as being challenging as there is not a unified structured education programme for children and young people.
- Suggestion to include advice on eye screening programmes and other safe evidence- based diabetic management tools in this statement.
- Suggestion not to merge this statement with draft statement 3 as they start at different care pathway points.
- Suggestion that continuing education should be ‘from diagnosis’.
- Suggestion to add ‘and prevention and management of hypoglycaemia’ to structure measure (c) add ‘or hypoglycaemic episodes’ to process measure (c) and add ‘and severe hypoglycaemia’ after ketoacidosis to outcome measure (d).
- Suggestion to include hypoglycaemic episodes to the audience descriptors.
- Suggestion to specifically state that the education programme is accessible in the statement.
- Concern raised on this statement’s measurability due to the variety of educational interventions and dependency on child’s age and ability.
- Suggestion to state the role of a key/ specialist/ hospital youth worker.
- Suggestion the National Paediatric Diabetes Audit (NPDA) does not specify offering the education programme at diagnosis.

- Stakeholders made the following comments in relation to consultation question 6:

- Concern raised on specifying a frequency of these structured education programmes as these are tailored to the individual’s need.
- A programme starting at diagnosis should be at least annually as standard with extra when needed.
- Structured education will be delivered on repeated occasions annually rather than in ‘blocks’ once or twice each year.
- An annual 2-day course along with information in each diabetes nurse specialist meeting as part of their transition plan.
- Children and young people receive intensive education initially during a 6 week period and, thereafter quarterly visits to diabetes clinics where education is delivered as part of care.

5.3 Draft statement 3

Children and young people with type 1 diabetes are offered multiple daily injection basal–bolus insulin regimens at diagnosis.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Support for this statement to reduce patients continually starting twice daily pre-mixed insulin.
- Suggestion to include insulin pump therapy.
- Support as measurable.

Stakeholders made the following comments in relation to consultation question 7:

- Support to combine draft statements 3 and 4. Both treatments should be offered together at diagnosis, with annual carbohydrate counting updates and as needed thereafter to achieve normal/near-normal blood glucose and HbA1c levels.
- Contrary argument to keep both statements separate as they are different treatment courses.

5.4 Draft statement 4

Children and young people with type 1 diabetes who are using a multiple daily insulin injection regimen and their family members or carers are offered level 3 carbohydrate-counting education at diagnosis, and at least annual repeated intervals thereafter.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Supported as a key component of Type 1 diabetes care.
- Concern raised that this statement requires considerable patient commitment and ongoing support.
- Concern raised that expert dietetic input is required.
- Concern raised on this statement's measurability as this can be ongoing and tailored to need.
- Suggestion to add paediatric dietitians trained in diabetes to the audience descriptor.

Stakeholders made the following comments in relation to consultation question 7:

- Support to combine draft statements 3 and 4. Both treatments should be offered together at diagnosis, with annual carbohydrate counting updates and as needed thereafter to achieve normal/near-normal blood glucose and HbA1c levels
- Contrary argument to keep both statements separate as they are different treatment courses.

5.5 Draft statement 5

Children and young people with type 1 diabetes are supported to achieve and maintain a HbA1c level of 48 mmol/mol (6.5%) or lower.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Supported as measurable.
- Concern raised that this statement is unlikely to be achieved safely without pump therapy and continuous glucose monitoring (CGM) technology which has significant resource implications.
- Concern raised on the achievability and consequential failure of this HbA1c level. This target will not be appropriate for all. Rather encouragement to obtain an HbA1c level which is as close as possible to this ideal target was supported.
- Suggestion to include individualised targets for those prone to frequent hypoglycaemia
- Suggestion that HbA1c level of 53 mmol/mol is more realistic and appropriate.
- Suggestion to state in the process measure the proportion who achieve the HbA1c level.
- Suggestion to include ‘risk/benefit allowance’ in this statement.
- Suggestion to define specific support.

5.6 Draft statement 6

Children and young people with type 1 diabetes who have frequent severe hypoglycaemia or an impaired awareness of their hypoglycaemic symptoms are offered ongoing real-time continuous glucose monitoring with alarms.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- A suggestion to re-word definition of severe hypoglycaemia.

- A suggestion to define frequent severe hypoglycaemia.
- Concern raised on this draft quality statement encouraging more frequent device usage and its resource implications. Suggestion state upper or lower usage.
- Support for this statement as access to continuous glucose monitoring (CGM) is important for safe glucose control.
- A clear plan of action should be described in this statement.
- Suggestion to state the child or young person's inability to recognise or communicate symptoms of hypoglycaemia.
- Suggestion to include children and young people and carers with significant anxiety about nocturnal hypoglycaemia.
- Mixed support on the measurability of this statement.
- Remove NPDA from local data collection as it does not collect data on CGMs usage.

5.7 Draft statement 7

Children and young people with type 1 diabetes are offered blood ketone testing strips and a blood ketone meter.

Consultation comments

Stakeholders made the following comments in relation to draft statement 7:

- Strong support for this statement as vital for type 1 diabetes management.
- Supported as measurable.
- Concern raised that provision of ketone testing strips is not always recorded.
- A clear plan of action should be described in this statement.

5.8 Draft statement 8

Mental health professionals with an understanding of diabetes are core members of the multidisciplinary paediatric diabetes team.

Consultation comments

Stakeholders made the following comments in relation to draft statement 8:

- Strong support as access to psychological services is of great importance.
- Concern raised that employing psychologists with a diabetes interest might be a challenging in some areas.
- Concern raised on the cost implications of this draft quality statement.
- The mental health professional should have diabetes training and have a role in screening, treating and training and supervising staff.
- Suggestion that this statement could alternatively focus on a mental health assessment.
- Concern raised on this draft quality statement’s measurability as it may prove challenging with potential resource implications and decisions to be made as to where these services lie (adult or paediatric, primary or secondary care).
- Concern raised on the vagueness of this draft quality statement. ‘Core member’ needs to be defined with an expected time commitment of the core members.
- Concern raised that a mental health worker on the team could just be attending meetings and not have clinical responsibility. There needs to be more specification according to clinical workload.
- A specialist psychologist should be considered as a core team member of the team. Also GPs should be involved.
- Suggestion to state in the process measures the perceived need of the person with diabetes who should only be seen by a mental health specialist.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Transition between child to adult services
- Eye screening for diabetic retinopathy
- Oral healthcare
- Training doctors and clinicians in communication with children and young people.
- Active involvement of children and young people in the design, delivery and evaluation of services
- Peer education

- Integrated services of education, training and employment
- Wider use of technology outside of annual appointments and for recording and sharing HbA1c levels
- Scope extended to include care for children and young people with other forms of diabetes mellitus (such as monogenic diabetes or cystic fibrosis-related diabetes).

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	1	This is easily attainable. However, it is probably a question that needs to be posed to the Royal College of General Practitioners. Measure should also include proportion of patients with T1DM presenting in DKA (i.e. late diagnosis). Currently this is around 20-25% and has a detrimental effect on long-term outcomes. The problem is that the diagnosis of T1DM is NOT SUSPECTED in young children despite typical symptomatology. Greater awareness of childhood T1DM in primary care needs to be fostered. Should say suspected diabetes (and not go into which type -1/2/genetic etc.) because of the difficulties around diagnosis. Important standard, easy to measure. Harder to influence from Secondary Care – need to directly audit Primary Care to be most effective. Local teaching of Primary Care Teams and having a Network Guideline can help though.
2	Royal College of Physicians and Surgeons Glasgow	1	We strongly agree. There is a national initiative in Scotland to reduce diabetes ketoacidosis at presentation of new onset type 1 diabetes to <10%. As it currently stands at 25% this standard will drive improvements in care. There is an ongoing drive nationally to collect this information via SCI-diabetes the national IT tool for diabetes information in Scotland. We believe this should be readily measurable. We also agree that early access to clinical psychology is identified as important in this group at this early stage in disease
3	Royal College of General Practitioners	1	The RCGP agrees with this statement (JA) but has the following comments: 1. RCGP feels that children and young people do not need immediate referral to a team specialising in paediatric diabetes, they need immediate referral to secondary care. However, immediate emergency care should be competently provided by a generalist paediatrician, with onward referral to a specialist team soon, depending on the local circumstances. 2. On p7 the quality statement states under structure: 'Evidence of local arrangements and written clinical protocols to ensure that children and young people presenting in primary care with suspected type 1 diabetes are referred on the same day to a multidisciplinary paediatric diabetes team.' This is time consuming and complicated bureaucracy. The RCGP feels that that a local protocol to this effect is unnecessary as when a GP suspects or detects type 1 diabetes does anything other than make an immediate referral. (DJ)
4	South West Paediatric Diabetes Network; University	1	Measure should also include proportion of patients with T1DM presenting in DKA (i.e. late diagnosis). Currently this is around 20-25% and has a detrimental effect on long-term outcomes. The problem is that the diagnosis of T1DM is NOT SUSPECTED in

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
	Hospitals Bristol NHS Foundation Trust		young children despite typical symptomatology. Greater awareness of childhood T1DM in primary care needs to be fostered.
5	Royal Manchester Children's Hospital	1	This statement would be hard to measure as we do not currently collect this data. The National Paediatric Diabetes Audit or DQuINS require this information. We currently collect information for BPT, DQuINS, diabetes registry and NPDA. NPDA. This standard is difficult to interpret due to the clarity of the word referral – does this imply telephone contact to seek advice from Paed diabetes services or a GP letter. If this standard is more to do with missed / late diagnosis maybe it should include something about how GP's who suspect a child has diabetes doing same day testing of bloods/urine. This could help the discussions when referring to MDT. Currently when GP's take bloods from suspected CYP there is a delay in them getting the results back. Additionally, there is also a training issue for GP's in their recognition of the early sign and symptoms of T1 diabetes.
6	Diabetes UK	2	This statement should not be merged with Statement 3, as they are very different points. Structured education is an ongoing programme and should be updated annually in response to both the child's growing understanding of their diabetes, and their maturity. The rationale, structure and outcomes listed in Statement 2 relating to multiple daily injections (MDI) only apply to diagnosis. The National Paediatric Diabetes Audit (NPDA) does not make a distinction as to whether structured education occurs at diagnosis or not, and neither does it collect data about structured education at diagnosis. The audit question that it currently asks is whether a programme of structured education has been delivered to the patient during that audit year. It is thus incorrect to say that this measure is collected by the NPDA.
7	Royal College of Nursing	2	*Education and Information* This statement is measurable as indicated. Children and young (CYP) people would receive intensive education initially during a 6 week period and, thereafter quarterly visits to diabetes clinics where education would be delivered as part of care. As this is about continuing education, the statement should be 'from diagnosis' rather than 'at diagnosis'
8	Royal College of Nursing	2	Change last sentence to: The education should 'include' clear, individualised, annually updated advice on managing intercurrent illness or hyperglycaemic episodes 'which help' children and young people to avoid dehydration and diabetic ketoacidosis 'and prevention and management of hypoglycaemia'.
9	Royal College of Nursing	2	Add 'and prevention and management of hypoglycaemia' to Structure c) and add 'or hypoglycaemic episodes' to Process c). Add 'and severe hypoglycaemia' after ketoacidosis in Outcome d)
10	Royal College of Nursing	2	Change to '…management advice on what to do during intercurrent illness, hyperglycaemic episodes or hypoglycaemic episodes to …' in section for service providers, healthcare professionals and commissioners.
11	Royal College of Nursing	2	Final bullet point in topics for type 1 diabetes education programme should start with 'Prevention, detecting and managing…' Individualised, annually updated advice should say '…about type 1 diabetes during intercurrent illness, hyperglycaemic episodes or hypoglycaemic episodes.'
12	JDRF, the type 1 diabetes	2	Diabetes education is certainly a key area. For children and young people with T1D and their family members or carers, diabetes

ID	Stakeholder	Statement number	Comments[1]
	charity		education is necessary for understanding how to successfully manage the disease day-to-day. We support continued inclusion of a quality statement related to diabetes education. But for this key area to be accurately reflected, we believe the issue of access to education must be acknowledged. Continuing structured diabetes education programmes are necessary but not sufficient. More children and young people with diabetes need access to self-management courses and more needs to be done to make these courses available to parents who work and for children and young people who study. The 2013-2014 National Paediatric Diabetes Audit shows that only 45.2% of children receive diabetes related education on an annual basis. Additional data indicate that this number varies significantly by region. For example, data shows that in one area only 11.1% of children with diabetes receive structured diabetes education while in another area 62% of children receive it. One potential explanation for this outcome is lack of accessible programmes. By making access to diabetes education programs a priority, more children would receive optimal care regardless of their residence in the coming years. An improvement to the text would be: "children and young people with type 1 or 2 diabetes and their family members or carers are offered an accessible, continuing, structured diabetes education programme at diagnosis." This change not only reflects the importance of offering structured diabetes education programmes, but also reflects the importance of making sure such programmes are accessible to children and young people with diabetes and their family members and carers.
13	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	2	The NPDA does not distinguish whether this is 'at diagnosis 'or not . The National Paediatric Diabetes Audit (NPDA) does not collect data about structured education at diagnosis. The audit question being asked currently by the NPDA is about whether a programme of structured education has been delivered to that patient during the audit year. It is therefore incorrect to say that this measure is collected by the NPDA. In outcome a) it states that the quality of life is measured by the NPDA. Currently this is not the case. The NPDA does not measure the satisfaction with the education intervention. The NPDA currently conduct a patient experience questionnaire but this is not specific to an education programme. The on going conduct of this experience measure depends on whether the NPDA gets future funding from HQIP. Structured education will be delivered to individual patients on repeated occasions annually rather than in 'blocks' once or twice each year. The specifics of the Structured Education is mentioned so is auditable.
14	Royal College of Physicians and Surgeons Glasgow	2	We strongly agree. This is of vital importance. in particular the recommendation that all children have written advice on dealing with intercurrent illness. Structured education is the cornerstone of type 1 diabetes management and timely access for the individual and their families as well as ongoing support during transition and into adult care should be mandatory. Access to this at diagnosis including insulin intensification and carbohydrate counting are required to optimise care and in turn outcomes in the short, medium and long term. Collecting data in on this in paediatrics may be challenging as there isn't a unified structured education programme. This will be less of an issue in adult care as there are several accredited education programmes across

ID	Stakeholder	Statement number	Comments[1]
			Scotland and recording of this information is updated quarterly via the reporting system from Managed Clinical Networks.
15	Royal College of General Practitioners	2	This statement may be hard to measure because of the variety of educational interventions which depend on mentoring and coaching from a young person's diabetic specialist multi-disciplinary team. It isn't a "one size fits all" but should be personalised according to language, educational ability, age, context. It might be better to state assignment of a key worker or specialist worker? (JA)
16	Royal College of General Practitioners	2	The RCGP believes that it is not appropriate to set the frequency of education required as a standard. The interval will depend entirely on the extent to which individual patient and their families are willing and able to learn and then put into practice their learning. It has to be personalised, some will need only one session and will then back it up with their own education from the internet, books etc.; others will need much more frequent sessions. The effectiveness can be assessed partly by measuring the extent to which patients adhere to the (intermediate) outcome of low HbA1c. (DJ)
17	South West Paediatric Diabetes Network; University Hospitals Bristol NHS Foundation Trust	2	Structured education will be delivered to individual patients on repeated occasions annually rather than in 'blocks' once or twice each year.
18	Royal Manchester Children's Hospital	2	All children and young people with type 1 or type 2 diabetes and their families/carers are offered a continuing, structured education programme at diagnosis. This programme of work is delivered by members of the MDT using tools designed by the team – Diabetes Information Pack Type 1 & Type 2 with individualised tutorials and used in conjunction with the Goals of Diabetes. Education is annually updated in annual review clinic using the age/developmental appropriate Goals of diabetes and includes sick day management and hypoglycaemia. These sessions are evidenced based and documented in patient's notes. Children and parents/carers have copies of all the information. Link workers are provided for those families who have difficulty speaking or reading English. (Sample of educational tutorials, Goals of diabetes and DIP 1 & 2 provided)
19	Royal College of Nursing	3	*Intensive Insulin Therapy for Type 1 Diabetes* This statement is measurable as indicated. 'and insulin pumps soon after diagnosis' to be added at the end.
20	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	3	We would go as far to make clear statement on: - Pump therapy for under 5 years as in NICE TAG - The Statement should say "Children and young people with type 1 diabetes should be offered…." It needs to be more directive - The statements in 3 and 4 can be combined. T1DM should be intensively managed from diagnosis with MDI and Carbohydrate counting in order to achieve normal/near-normal blood glucose and HbA1c levels - Important and easy to audit
21	Royal College of Physicians and Surgeons Glasgow	3	We agree. This is becoming standard practice in most units. Some patients continue to start twice daily pre-mixed insulin and this recommendation should reduce this. Should also be easily measured.A recent Scottish wide meeting of paediatric and adult teams agreed that basal bolus regimens from diagnosis should be the norm. There are some exceptions and the evidence base for the best initial regimen is lacking. We hope to use data from our early intensification work in Scotland to assess if one starting insulin regimen in superior to others in terms of achieving optimal glycaemic control at 6 and 12 months post diagnosis as well as

ID	Stakeholder	Statement number	Comments[1]
			hypoglycaemia rates.
22	Royal College of General Practitioners	3	The RCGP welcomes this statement but should not be merged with statement 4. (JA)
23	Royal Manchester Children's Hospital	3	RMCH start all newly diagnosed children and young people on basal bolus insulin regimens at diagnosis with carbohydrate counting. This initially includes children under 5 years whilst we train the family on insulin pump therapy. For the small number of children and young people that basal bolus does not work for or who chose otherwise alternative methods of insulin management are offered. i.e Insulin pump therapy or twice daily insulin injections. (see carb counting sheets provided in addition to sample of carb booklet)
24	Royal College of Nursing	4	*Level 3 Carbohydrate-Counting with Type 1 Diabetes* This statement is less measurable. It is considered that this type of education is usually ongoing and can also fluctuate depending on the needs of the child. Records may not be as specific as required in terms of this quality statement.
25	Royal College of Nursing	4	Change to '…in line with individualised insulin-to-carbohydrate ratios.'
26	Royal College of Nursing	4	Change to '**Healthcare professionals** (such as paediatric dietitians trained in diabetes) offer level 3 carbohydrate counting….' As they are the ones who provide this education, with some input from the nurse specialists but not usually the consultants.
27	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	4	Teaching carbohydrate counting requires expert dietetic input. Many diabetes teams are under-resourced with regard to dietetic provision and this will need to be addressed if this statement is to be met. Important measure as it ensures dietetic input and funding persists where present – easy to audit.
28	Royal College of Physicians and Surgeons Glasgow	4	We strongly agree. This is one of the key components of T1DM care and should be introduced at diagnosis and repeatedly thereafter. Worth noting that statements 2,3 and 4 cover the same key areas and 3 and 4 could be combined.
29	RCGP	4	The RCGP agrees that this should be the aim but it is too hard to measure unless done tokenistically. It requires considerable commitment and ongoing support. It is not a "take it and leave it option". (JA)
30	South West Paediatric Diabetes Network; University Hospitals Bristol NHS Foundation Trust	4	Teaching carbohydrate counting requires expert dietetic input. Many diabetes teams are under-resourced with regard to dietetic provision and this will need to be addressed if this statement is to be met.
31	Diabetes UK	5	This is unlikely to be achieved safely without the use of pump therapy and continuous glucose monitoring (CGM) technology. It is highly unlikely to be safely achieved by just using MDI. This would, however, have significant resource implications. This target will also not be suitable for every child and young person. There needs to be more emphasis on individual targets where necessary. It is furthermore important that families do not see themselves as failures for not attaining this level, but understand it rather as an aspiration by which the child or young person is encouraged to obtain an HbA1c level which is as close

ID	Stakeholder	Statement number	Comments[1]
			as possible to this ideal target. There ought to be an explanation of what support is needed in order to achieve an HbA1c level of less than 48mmol/mol.
32	Royal College of Nursing	5	*HbA1c Targets for Type 1 Diabetes* This statement is measureable as indicated. Wording should be changed to 'From diagnosis, children and young people with type 1 diabetes are supported to achieve and maintain a HbA1c level of 48 mmol/L (6.5%) or lower without disabling hypos, or individualised lowest achievable HbA1c target'. This is because there is evidence that achieving optimal glycaemic control during the first year after diagnosis leads to better long term outcomes, and is in line with NICE guideline NG18.
33	Royal College of Nursing	5	The definition for HbA1c is incorrect. It could be reworded to something like 'The amount of glucose that has been joined to the red blood cells over the last 2 or 3 months. It is an indication of how high the blood glucose levels have been during that time.'
34	Association of British Clinical Diabetologists	5	ABCD recognises and supports the desire to reduce mean clinic HbA1c concentrations in an attempt to improve outcomes. While for many young people, particularly those on multiple daily injections or insulin pumps, it will be possible to achieve the 48 mmol/mol or lower standard, it will not be possible for all. Individualised targets for those prone to frequent hypoglycaemia, will need to be agreed as set out in the guideline. The standard states 'supported to achieve and maintain an HbA1c level of 48 mmol/mol or lower', but the metric will be the proportion achieving that target. A balancing metric of proportion of the clinic population experiencing one or more episodes of severe hypoglycaemia in the past year might help to interpret the overall quality of blood glucose control for a service.
35	JDRF, the type 1 diabetes charity	5	Success may be difficult to achieve on this quality standard. Data from the 2013-2014 National Paediatric Diabetes Audit show that very few children and young people (18.4%) have been able to reach an HbA1c level at or below 58 mmol/mol, which is a higher threshold than the threshold in the proposed quality statement. Additionally, the 2013-2014 audit indicate that the national average HbA1c is 71.6 mmol/mol, which provides further evidence that an HbA1c level of 48 mmol/mol is likely unattainable for all but a few children and young people. One barrier to achieving this quality standard is fear of hypoglycaemia. The Diabetes Control and Complications Trial (DCCT) established intensive insulin therapy as standard treatment in type 1 diabetes and identified severe hypoglycaemia as the chief adverse event associated with intensive insulin therapy. The DCCT demonstrated that intensive insulin therapy results in a threefold risk of hypoglycaemia. This increased risk of hypoglycaemia (and the associated fear) has been demonstrated to be a barrier to the treatment of type 1 diabetes, and as a result a barrier to achieving recommended HbA1c levels. Hypoglycaemia is only one barrier to achieving recommended HbA1c levels. Human growth and development in this population also makes glucose control challenging. To achieve and maintain an HbA1c level of 48mmol/mol, children and young people with type 1 diabetes must have access to tools that facilitate safe glucose control, such as continuous glucose monitoring (CGM), including sensor augmented pump therapy with and without low glucose suspend. Clinical data shows that individuals with T1D using real-time continuous glucose monitoring (CGM) achieve lower HbA1c levels compared to those solely relying on self-monitoring blood glucose (SMBG) methods. These

ID	Stakeholder	Statement number	Comments[1]
			studies also note that individuals that use CGM in addition to SMBG show reduced rates of both severe hypoglycaemia and hypoglycaemia exposure. Without access to the proper tools, proposed HbA1c levels cannot be achieved safely. Moreover, there are concerns that using HbA1c as the sole indicator of glucose control could side-line other important indicators of safe glucose control. While a good indicator, HbA1c is not perfect. Evidence shows that some patients are given overwhelmingly positive feedback from their clinicians about their diabetes control because their HbA1c levels meet targets, even if their overall blood glucose levels are dangerously variable such that they experience significant hypoglycaemia and hyperglycaemia. HbA1c can be influenced by a number of factors including red blood cell count, non-diabetic medications, antioxidant agents, and genetic variants. Because HbA1c is imperfect, other indicators of glucose control, including time in normal glycaemic range, are emerging and there is increasing evidence that this indicator could in fact be a better measure of the risk of long term complications. Hypoglycaemia, including severe hypoglycaemia, is also an important diabetes indicator and often is a barrier to achieving treatment goals. If HbA1c is prioritised as a key indicator without explicit reference to these other indicators then it is possible there could be unintended consequences – clinical blind spots could be created as targets are geared towards achieving ideal median HbA1c levels.
36	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	5	This is a good aspiration. It is unlikely to be achieved safely without the use of pump therapy and CGM technology. It is highly unlikely to be safely achieved on MDI and caution in this area is needed. This means that teams will have to deliver more pump and sensor training which will have resource implications. It is important that families do not see themselves as failures for not attaining this level. How to evidence "supported to achieve HbA1c <48"? Is an advice leaflet adequate evidence? Is more evidence then this required – if so what – clinic letters? Does it mean individual plans separate to clinic letter discussions?
37	Royal College of Physicians and Surgeons Glasgow	5	We agree. However, this is a very ambitious target that may prove challenging to achieve. It is readily measurable and at present in Scotland we have regular reporting on glycaemic control. If need be this could be revised to indicate the % of individuals achieving an HbA1c of <48mmol/mol. At a national meeting recently it was felt a target of 53 mmol/mol may be more realistic and indeed appropriate. We feel it is worth noting that all glycaemic targets should be individualised.
38	Royal College of General Practitioners	5	The RCGP agrees that optimal control is the best if severe hypoglycaemic episodes can be avoided. The statement should include the risk/benefit allowance. (JA)
39	Diabetes UK	6	This quality statement should add that children and young people with Type 1 diabetes who have the inability to recognise or communicate symptoms of hypoglycaemia (for example, because of cognitive or neurological disabilities, or because of their age), are also offered ongoing real-time CGM with alarms. It should additionally include children and young people with Type 1 diabetes who have significant anxiety about nocturnal hypoglycaemia. This statement may be hard to implement as funding for continuous CGM has not been agreed. Furthermore, the proportion of children and young people with Type 1 diabetes who would be eligible under this quality statement is unclear, as are the criteria for discontinuing CGM if there is shown to be a lack of benefit or if glycaemic control demonstrably improves. These factors increase the likelihood that this quality statement will be hard to implement.
40	Royal College of Nursing	6	*Continuous Glucose Monitoring*

ID	Stakeholder	Statement number	Comments[1]
			This statement may be less measurable generally as a consequence of poor compliance in terms of wearing glucose monitoring equipment which can often present in CYP; can be difficult to collect reliable data.
41	Royal College of Nursing	6	For **Severe hypoglycaemia** – 'A hypo which makes it hard…' For Ongoing real-time continuous glucose monitoring with alarms – '….glucose all the time without them having to do lots of finger-prick tests' . This needs to be added as most of the Continuous Glucose Monitoring (CGM) devices need to be calibrated with capillary blood glucose tests.
42	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	6	Again for many units this may have resource implications. The NPDA does not collect data on the usage of CGMS. Hypoglycaemia incidence is calculated from the HES and PEDW data but this is for all children with diabetes and not just those on CGMS. The NPDA does not measure quality of life. This should include children and carers with marked anxiety about nocturnal hypoglycaemia and young children who are unable to communicate their symptoms of hypoglycaemia. Whilst the concept is good, I have concerns about how this may be applied. Where will the funding for CGMS come from? In addition, how about the staffing levels to support the increase workload that comes with it (with extra staff support needed)? This measure will result in a requirement for an increase in spending for many units– has this been costed? This statement may be hard to measure because: 1 – funding for continuous CGM has not been agreed at any level therefore locally and at a network level we have no guidance. 2 – clarity of definition of who should be considered is insufficient – potentially any young child has impaired sense of hypo therefore unsure proportion of clinic patient eligible. 3– criteria for discontinuing CGM if lack of benefit or if control improves also unclear
43	Royal College of Physicians and Surgeons Glasgow	6	We agree. Should be readily measured. A recent Health Technology Assessment highlighted the benefits of sensor augmented pump therapy in individuals with recurrent severe hypos. It is important to note that this should be part of a stepwise approach to type 1 diabetes management with structured education and then technologies such as insulin pump therapy +/- continuous glucose monitoring systems (CGMS) in those who require it. Advancing technologies should be part of mainstream T1DM management and used in those individuals who are likely to benefit and fulfil evidence based criteria. As there are significant advances in pump therapy and CGMS, including the likely introduction of 'closed loop' systems in the near future, it may be worth attempting to 'horizon scan' this guidance by highlighting that in those individuals who despite optimised insulin regimens continue to have recurrent severe hypoglycaemic episodes they get timely access to technologies such as CGMS. It is important pumps and CGMS are not considered in isolation but as part of the advancing technologies to manage T1DM. The number of individuals using CGMS should be measurable via SCI-diabetes. Cost implications of this need to be considered also.

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44	Royal College of General Practitioners	6	The RCGP agrees with this statement if it is subject to there being a clear plan of action. Perhaps the statement should say this. (JA)
45	Royal College of General Practitioners	6	Children and young people might prefer a clever device that monitors continuously and avoid finger pricks. I assume it is much more expensive. The intention of limiting their issue to those who have *'…frequent severe hypoglycaemia or an impaired awareness of their hypoglycaemic symptoms'* seems reasonable. The RCGP notes that the statement includes a definition of severe and impaired awareness, but not frequent. Without a definition it is quite possible that many more will be issued than is entirely justified. Interesting that the quality statement wishes to encourage more frequent issue of such devices, and is not concerned about the potential for excessive issue. Should there be a benchmark for upper, as well as lower rates of issue? (DJ)
46	South West Paediatric Diabetes Network; University Hospitals Bristol NHS Foundation Trust	6	This should include children and carers with marked anxiety about nocturnal hypoglycaemia and young children who are unable to communicate their symptoms of hypoglycaemia.
47	JDRF, the type 1 diabetes charity	6	Access to continuous glucose monitoring (CGM) is important for safe glucose control. We support a quality standard related to use of CGM. Access to CGM is necessary for children and young people who have severe hypoglycaemia and hypoglycaemia unawareness. It is also necessary for children and young people that continue to have hyperglycaemia. Robust evidence supports the use of CGM to reduce hyperglycaemia and to improve glucose control. While hypoglycaemia is a significant concern, data from the 2013-2014 National Paediatric Diabetes Audit suggests that perhaps greater focus should be placed on reducing hyperglycaemia. The 2013-2104 audit data show that fewer than 20 percent of children and young people achieve target HbA1c levels and that the average HbA1c level in this population was 71.6 mmol/mol. Moreover, audit data indicate that an alarming number of young people are already showing early signs of complications. Specifically, in the 2013-2014 audit, 7.1% of young people aged 12 years and above showed increased risk of developing kidney disease in the future and 14.1% showed early signs of increased risk of blindness. Finally, nearly 30 percent of all young people with T1D have high blood pressure. These data demonstrate the need for access to tools like CGM for improving glucose control. Through continuous measurement and reporting of glucose as well as alerts, real-time CGM allows children and young people with T1D and their family members or carers to respond more quickly to changes in blood glucose. Through this quality statement, NICE recognizes the benefits of CGM for preventing hypoglycaemia through its ability to identify when blood glucose is falling or is below the normal range. However, NICE overlooks that the benefits of CGM also apply when blood glucose in rising or has gotten too high. This Quality Statement narrowly focuses on CGM as a tool for preventing hypoglycaemic outcomes. It should be expanded to reflect CGM's ability to reduce hyperglycaemia and, as a result, its ability to delay or reduce micro- and macro-vascular complications.
48	Royal College of Nursing	7	*Blood ketone monitoring in type 1 diabetes* This statement may be less measurable. The distribution of ketone testing strips is not always recorded – although the provision of a ketone meter normally is perhaps negating the questions of measurability. '<u>, and education on how to prevent, detect and manage ketones</u>' to be added at the end of the quality statement.

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49	Royal College of Nursing	7	Change first sentence to: 'Insufficient insulin can lead to increased ketone levels.' Also, 'The risk of diabetic ketoacidosis is increased if a child or young person….'
50	Royal College of Nursing	7	Add ', and education on how to prevent, detect and manage ketones' to the end of sentence in the sections for service providers, healthcare professionals and commissioners.
51	Royal College of Nursing	7	Change last sentence to 'When people are unwell or have high blood glucose levels and not enough insulin, their body makes ketones, and…'
52	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	7	Should be easy to audit.
53	Royal College of Physicians and Surgeons Glasgow	7	We strongly agree. This is a mandatory requirement for appropriately managing type 1 diabetes. Ketone strips have an associated cost (more expensive than glucose strips) but are far better than glucose or urine ketone testing in monitoring response to therapy of mild ketosis at home and may reduce admissions, as well as identifying DKA requiring admission. A very useful development if implemented. This standard should also include that individuals are aware of the significance of ketone monitoring and the action they will take in the presence of ketones and during intercurrent illness. This can be readily measured from prescribing data.
54	Royal College of General Practitioners	7	The RCGP agrees with this statement if it is subject to there being a clear plan of action. (JA)
55	Diabetes UK	8	This quality statement is too vague. It needs to explain the phrase "core member" and additionally needs to set out exactly what the time commitment is which is to be expected of the core members. However, it is imperative that all children and young people with Type 1 diabetes are screened for their emotional health and wellbeing.
56	Royal College of Nursing	8	*Access to mental health professionals with an understanding of type 1 or 2 diabetes* This statement is measurable as indicated.
57	Royal College of Nursing	8	Add 'Psychological (such as anxiety, depression, behavioural, eating and conduct disorders and family conflict)…'
58	Royal College of Psychiatrists, Liaison Faculty	8	This statement is at risk of being little value but costly. The mental health professional should have training in diabetes and should have a role in screening, treating patients and carers and training and supervising staff. Perhaps the standard should be that the person and their families with diabetes have a mental health assessment.
59	Royal College of Paediatrics and Child Health and National Children and Young People's Diabetes Network	8	We are not convinced that this is the case nationally. There is the best practice tariff requirement but we do not think that core membership is as expressed in NICE. The wording is too vague; it needs to say what is meant by core member and in particular what is the time commitment expected of core mental health professional. It needs a Job expectation to go with it. The NPDA does not breakdown the psychology input measure by diabetes type. The number of children with Type 2 Diabetes is

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			small and the NPDA is not authorised to publish data on patients if < 5 in the category for anonymity reasons The NPDA does not report on quality of life. Important measure as will help maintain funding for psychology in diabetes – which most units now have access to, but may be at risk of losing if Best Practice Tariff ever stops. Percentage of patients with access to psychology in diabetes – could be clarified further? Not all will need to see psychology each year so will never be 100%. Should it be "has timely access if judged by diabetes MDT to require it"? Or "have potential access should they need it"? Important that all children and young people are screened for emotional health and wellbeing.
60	Royal College of Physicians and Surgeons Glasgow	8	We strongly agree. This is a welcome statement and one that should be fully supported. There is no doubt that access to psychological services is of great importance and should continue to be available through transition into young adulthood. Measurement of this statement may prove challenging and there may be resource implications and decisions made as to where these services lie (adult or paediatric, primary or secondary care). The Scottish Diabetes Group funded PID PAD (Psychology in Diabetes, Psychology and Diabetes) project provided useful insights into the challenges around providing mental health support within diabetes services and further information may be available from the Scottish Diabetes Group as to the projects outcomes.
61	Royal College of General Practitioners	8	The RCGP feels that this statement doesn't match the intention which is that children or their parents have access to the mental health worker with a knowledge of diabetes. A mental health worker on the team could just be attending meetings and not have clinical responsibility. There needs to be more specification according to clinical workload. (JA)
62	Royal College of General Practitioners	8	The RCGP agrees that a specialist psychologist should be consider as a core member of the team. However, the approach looks like ignores any help, expertise, local knowledge or knowledge of the family that general practitioners could bring to bear on the subject. Apart from rapid referral, the RCGP feels that GPs aren't involved anywhere. On p33 it states 'Numerator – the number in the denominator who receive timely and ongoing access to mental health professionals …' This would imply that every person with diabetes should be seen by a mental health specialist, regardless of perceived need. (DJ)
63	NIHR CLAHRC North Thames	Additional area	The quality standard omits one significant area of concern identified in evidence relating to the quality of transitions from paediatrics to young adults services. A SMART (i.e. Ready, Steady Go) transition plan should be informed by and inform the three quality areas identified in this consultation exercise.
64	NIHR CLAHRC North Thames	Additional area	Other: missing from the quality standard equality and diversity considerations is the mention of training doctors and clinicians to be able to listen and hear the voices of CYP as well as training practitioners in how to effectively communicate with CYP communication avoiding ageist discrimination of young patients. The quality standard also leaves out the active involvement of CYP in the design, delivery and evaluation of services, which ignores their expert knowledge as patients. In addition, as part of their on-going education, the value and benefits of peer support and mentoring initiated or facilitated by the health care team is omitted by the quality standard. Peer education is evidenced as a positive methodology to compliment practitioner led advice and support for CYP with diabetes. Linked to the above improvements in the quality standard is a plan methodology for transitions. This includes pre-transition where the focus is firmly placed on self-advocacy (i.e. a 10 minute slot to have one-to-one conversations-discussion with the clinician away from parents and carers) and also a co-produced and co-owned transition plan

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			which functions as a living document to focus structure dialogue and measure progress towards improved self-care, knowledge and adherence to treatment. Finally, appointment scheduling and locations are key to engage disengaged CYP. More flexibility should be built into how integrated services are provided which do not negatively impact of CYP education, training and employment and should consider the wider use of technology outside of annual appointments and for recording and sharing Hab1c levels. Caution should be paid to setting Hab1c levels at 6.5 might serve has an additional barrier to attend clinic but average numbers are 10 and above.
65	Royal College of Nursing	Additional area	Are there any plans to develop a quality standard to cover care for children and young people with other forms of diabetes mellitus (such as monogenic diabetes or cystic fibrosis-related diabetes)?
66	Royal Collede of General Practitioners	Additional area	In 2012 Barbara Young, Chief Executive at Diabetes UK advised urgent improvement were needed in this area because the UK is currently one of the worst-performing countries in Europe in terms of blood glucose levels for children with diabetes. It is disappointing that new technology such as insulin pumps is not included in these quality standards as or some children these pumps are extremely useful in helping to manage blood glucose levels, and many do not currently have the option to use them. The RCGP is also concerned that the standards only apply to the care of those aged under 19 and do not include guidance on preparing young people with diabetes for their move to adult services. This is a problem because we know that too many young people are already falling into the gap between services. The NHS needs to make sure that the new quality standards do not ignore the need for a continued level of care throughout this transition between child to adult services. (MH)
67	Royal College of Nursing	General	*Last sentence of first paragraph* The move to adult services is a transfer not a transition. Better wording would be 'Support should be provided during transition and preparation for transfer from children's to adult services, which have a different model of care and evidence base'.
68	Royal College of Nursing	General	Add NG43 **Transition from children's to adults' services for young people using health or social care services** to the list of current policy documents Possibly include more information about transition in the whole document or a statement.
69	British Infection Association	General	The BIA is content with this Quality Standard. Thank you.
70	Royal College of General Practitioners	General	The RCGP feels that this is a specialist care. However the document reflects the implication that many of these aspects developed in the statements are not already completely standard, most particularly statements 2 and 3. (DJ)
71	Institute of Child Health — Eyes and Vision Group	General	We believe that the draft quality standard reflects some of the key areas for quality improvement. However, a critical component of the care pathway for diabetes in children and young people was not considered. Eye screening for diabetic retinopathy should be part of the quality standard not only because it is in line with the Public Health Outcomes Framework for England 2013-16, and it would contribute to the reduction of preventable sight loss, but also because it is the only annual screening recommended by NICE guideline which is not covered by the paediatric diabetes best practice tariff. Additionally, the inclusion of eye screening uptake as a quality standard may help to ensure the integration between paediatric diabetes care — where children and young people with diabetes mellitus are diagnosed and looked after — and the national eye screening programme which is responsible for identifying and inviting eligible diabetic children and young people to an eye screening exam. The lack of integration between these two points of care may be one of the reasons for the low proportion of eligible children and young people recorded as having an eye screening exam reported by the last National Paediatric Diabetes

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			Audit. We believe that if the quality standard for diabetes in children and young people recognises that “a person-centred, integrated approach to providing services is fundamental to delivering high-quality care to children and young people with diabetes”, eye screening should have been included as a quality standard.
72	Faculty of General Dental Practice (UK)	General	Despite the section on *“coordinated services”* stating that *“a person-centred, integrated approach to providing services is fundamental to delivering high quality care to children and young people with diabetes”* (p4), the Quality Standard as a whole does not mention other health conditions which may be influenced by being diabetic, nor the full range of health care professions who can help support the management of diabetes. There is significant evidence that diabetics are at increased risk of certain oral health conditions, in particular periodontal conditions, and there is also some evidence that good oral hygiene habits can influence the control of diabetics. However, as dentists are not included in the multidisciplinary paediatric diabetes team (p9), we would recommend that referral for dental check-ups be included among the quality indicators for the management of diabetes in children.
73	NHS England	General	I think the Quality Standards are very useful. I am however a bit surprised not to see any reference to insulin pump therapy, which features quite heavily in NICE NG18 published last August, and is an important part of management now for many children with Type 1 diabetes.
74	Department of Health	General	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
75	ACDC (Association of Children’s Diabetes Clinicians]	General	ACDC committee feel that all the quality standards are reasonable and mirror our original comments. We are happy to support their implementation
76	HQT Diagnostics	General	General Practitioners should test for Fatty Acids and supplement to achieve: • Omega-3 Index: >8%...Is my Omega-3 high enough ? • Omega-6/3 Ratio: <3:1…Is my Omega-6 low enough to reduce Inflammation ? Re-test after 3 months to confirm Fatty Acid levels and other standard tests for Diabetes Increasing Omega-3 is relatively easy by eating oily fish like salmon etc REDUCING Omega-6 involves changes to diet and lifestyle, which requires a reduction in consumption of oils made from Sunflower, Corn and Soyabeans Refer to Dietitian (www.bda.co.uk) or registered Nutritional Therapist (www.bant.org.uk) This is being used widely in Germany to treat both Type1 and Type2 Diabetes

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			Poly Unsaturated Fatty Acids (PUFA) are involved in glucose level control and insulin sensitivity Evidence: http://www.expertomega3.com/omega-3-studies http://www.expertomega3.com/omega-3-studies/metabolism http://www.fatsoflife.com/ http://www.hqt-diagnostics.com/ http://www.greenvits.eu/collections/omega-3
77	HQT Diagnostics	General	General Practitioners should test 25(OH)D for all Diabetes patients and supplement Vitamin D to be between 100-150 nmol/L Review blood tests after 3 months Vitamin D appears to both prevent and treat Diabetes Vitamin D is a significant factor in insulin sensitivity A general MINERAL multi-vitamin should be considered, since this provides important co-factors such as Magnesium and Zinc Evidence: http://www.vitamindwiki.com/Overview+Diabetes+and+vitamin+D http://www.vitamindcouncil.org/health-conditions/ http://www.greenvits.eu/collections/other/products/vita-min-multivitamin
78	Royal College of Nursing	Question 1	Yes, but there is no statement regarding transition, this is a key area for quality improvement.
79	Association of British Clinical Diabetologists	Question 1	The draft QS appears accurately to reflect the key areas for QI.
80	Royal College of Nursing	Question 2	No, local systems and structures are currently not in place to collect data for the quality measures, although we are aware that some networks have established data collection mechanisms. As indicated for each statement, they could be established consistently with extra funding for data input and collection. There will be many children and young people who are supported but may not be able to achieve a HbA1c of 48 or lower and so the measurement of this particular standard needs careful consideration.
81	Association of British Clinical Diabetologists	Question 2	Those units receiving or working towards receiving the Best Practice Tariff should be able to collect these data.
82	NIHR CLAHRC North Thames	Question 2	Question 2 *Are local systems and structures in place to collect the data for the proposed quality measures?* No consistent system is in place to collect data away from the Diabetes Audit information. If not, how feasible would it be for these systems and structures to be put in place? Very feasible to collect routine data on CYPs DNAs, DKAs, A&E admissions, A&E admissions resulting in overnights stays as well as A&E as per GP. However, an agreed framework should be design, tested and rolled out to ensure reliability and comparability across CCG areas.
83	Royal College of Nursing	Question 3	The Children and Young People’s Diabetes Team in Leeds have two part-time psychologists who are part of the Multi-Disciplinary

ID	Stakeholder	Statement number	Comments[1]
			Team (MDT). They have developed a comprehensive psychology screen for children and young people and parent/carers and routinely attend the MDT clinics as well as meeting families soon after diagnosis and offering individual appointments.
84	NIHR CLAHRC North Thames	Question 3	Question 3 *Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard?* If so, please submit your example. Yes, available on request. Newham CCG Youth Diabetes Project Business Plan in combination to Barts Health Trust and Newham CCG Draft Transition Plan.
85	Royal College of Nursing	Question 4	If statement 5 is measured by the number achieving a HbA1c of 48 or lower, it will not be achievable in most cases. Extra resources will be needed for statements 5 and 6 (6 could be very expensive), and possibly statement 2 if courses such as Kick-off and WICKED are to be offered. There may be cost savings by a reduction in admissions for DKA with statements 1, 2 and 7 and severe hypos with statement 6 and possibly with poor control due to psychosocial difficulties with statement 8. Long term cost savings with a reduction in complications of diabetes could be achieved by all of these, particularly statements 2, 5 and 8. There are no opportunities for disinvestment, but could be in future if complications are reduced.
86	Association of British Clinical Diabetologists	Question 4	Employing psychologists with an interest in diabetes might prove challenging in some areas. It is important that local work force plans include psychologists with the skills needed in the children and young people's teams. In some centres psychology services are sub-contracted from a community mental health trust as part of a block contract with the acute trust, and support for the children and young people's diabetes service is not ring-fenced. The existence of the best practice tariff should make it easier to employ staff with the correct skills, as provider income will rise if all the criteria are met. There is a lack of clarity regarding the proportion of children and young people who might be expected to benefit from sensor-augmented pumps, and therefore the predicted cost to the purchasers. However deployment of this technology would be expected to save money in unplanned admissions to hospital with DKA or hypoglycaemia.
87	NIHR CLAHRC North Thames	Question 4	Question 4: *Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources required to deliver them?* Yes. *Please describe any resource requirements that you think would be necessary for any statement.* *Mental Health Support for CYP and Parents and Carers should be consistently built into all teams alongside educational packages that are not solely delivered by DNS. A dedicated hospital youth worker to coordinate training and/or residential camp would be an added value to involve CYP in their own self-care and in fulfilment of the identified quality standard.*
88	Royal College of Nursing	Question 5	They are all important. Statements 1, 3, 4 and 7 should be part of routine care but are not in all areas. Statement 6 may not be possible due to financial implications and inadequate numbers of trained and experienced staff. The 5 most important to be offered to all are statements 1, 2, 3 & 4 combined, 5 and 8.
89	Association of British Clinical Diabetologists	Question 5	ABCD believes the eight draft quality statements could be reduced to six by combining QS 1 and 8, and QS 3 and 4. QS 1 and 8 Children and young people presenting in primary care with suspected type 1 diabetes are referred by telephone on the same day to a multidisciplinary paediatric diabetes team that includes a mental health professional with an understanding of diabetes. QS 3 and 4 All children and young people with diabetes and their family members or carers are offered a structured education programme at diagnosis Since children and young people with type 1 diabetes are offered multiple daily injection basal-bolus regimens at diagnosis, they and their family members or carers should be offered level 3 carbohydrate-counting education.

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90	NIHR CLAHRC North Thames	Question 5	Question 5 *The final quality standard should highlight a small number of priorities for improvement. Can you tell us what the 5 most important statements within this standard are?* *8, 7, 3, 2 and 5*
91	Royal College of Physicians and Surgeons Glasgow	Question 5	The five most important statements are: 1,2,4,7,8
92	Royal College of Nursing	Question 6	If at diagnosis, then once per year should be the standard, with extra as needed.
93	Association of British Clinical Diabetologists	Question 6	QS 2 All children and young people with diabetes and their family members or carers are offered continuing structured diabetes education *at least annually*.
94	NIHR CLAHRC North Thames	Question 6	Question 6 For draft quality statement 2: *To aid measurability how many times per year would children and young people receive this education programme?* *They should be offered a summer camp (i.e. two-day course each year) along with an incremental building up of information in each DNS meeting as part of their transition plan. A key officer should be designated responsible for the education although delivered across the team*
95	South West Paediatric Diabetes Network; University Hospitals Bristol NHS Foundation Trust	Question 7	These statements can be combined. T1DM should be intensively managed from diagnosis with MDI and Carbohydrate counting in order to achieve normal/near-normal blood glucose and HbA1c levels
96	Royal College of Nursing	Question 7	Yes, basal-bolus insulin with level 3 carbohydrate counting should be offered together at diagnosis, with carb counting updates annually and as needed thereafter.
97	NIHR CLAHRC North Thames	Question 7	Question 7 For draft quality statements 3 and 4: *As quality statements 3 and 4 aim to be delivered at diagnosis could these be merged into a single statement*. Please detail your answer. Keep both statements separate as they pertain to different courses of treatment and emphasis type one only when statement two could be open to type two.
98	Royal College of Physicians and Surgeons Glasgow	Question 7	Arguably statements 2-4 and indeed 7 could be added together as structured education from diagnosis which includes a basal bolus regimen, carbohydrate counting and ketone monitoring should be standard care in type 1 diabetes right from diagnosis.

Registered stakeholders who submitted comments at consultation

- Association of British Clinical Diabetologists
- Association of Children’s Diabetes Clinicians
- British Infection Association
- Department of Health
- Diabetes UK
- Faculty of General Dental Practice (UK)
- HQT Diagnostics
- Institute of Child Health- Eyes and Vision Group
- JDRF, The Type 1 diabetes charity
- National Children and Young People’s Diabetes Network
- NHS England
- NIHR CLAHRC North Thames
- Optical Confederation and Local Optical Committee Support Unit
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Physicians and Surgeons
- Royal College of Psychiatrists, Liaison Faculty

- Royal Manchester Children’s Hospital
- South West Paediatric Diabetes Network, University Hospitals Bristol NHS Foundation Trust