NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Diabetes in children and young people

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 03 December 2015

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for diabetes in children and young people. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE clinical guideline NG18

2 Overview

2.1 Focus of quality standard

This quality standard will cover the diagnosis and management of type 1 and type 2 diabetes in children and young people aged under 18. This quality standard will not cover children and young people with other forms of diabetes mellitus (for example monogenic diabetes and cystic fibrosis-related diabetes). Also, support for young women with diabetes who wish to conceive or who are pregnant is addressed by a separate clinical guideline and quality standard referral.

2.2 Definition

Diabetes is a long-term condition that can have a major impact on the life of a child or young person, as well as their family or carers. In addition to insulin therapy, diabetes management should include education, support and access to psychological services, as detailed in this guideline. Preparations should also be made for the transition from paediatric to adult services, which have a significantly different model of care and evidence base.

Type 1 diabetes is becoming more common in the UK, and since 2004 type 2 diabetes is also being diagnosed with increasing frequency. The 2013–14 National Paediatric Diabetes Audit[1] identified 26,500 children and young people (CYP) with type 1 diabetes and 500 with type 2. Much of the general care for type 2 diabetes is the same as for type 1 diabetes, although the initial management is different. In addition, the overweight and obesity associated with type 2 diabetes also bring an increased risk of renal complications, hypertension and dyslipidaemia.

Since 2004 there have been major changes to the routine management of type 1 diabetes, in an attempt to achieve much stricter targets for blood glucose control to further reduce the long-term risks associated with the condition. NICE clinical guideline NG18 (2015) is the first national guidance for children and young people to recommend attempting to reach a glycated haemoglobin (HbA1c) level near the normal range and near normoglycaemia. This tight control may be achieved by intensive insulin management (multiple daily injections or insulin pump therapy) from diagnosis, accompanied by carbohydrate counting. Newer technology such as continuous subcutaneous glucose monitoring may also help children and young people to have better blood glucose control, although this is not currently recommended for all children and young people with type 1 diabetes.

2.3 National Outcome Frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

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[1] National Paediatric Diabetes Audit report 2013–14. Royal College of Paediatrics and Child Health

Table 1 NHS Outcomes Framework 2015–16

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	***Overarching indicators*** 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare ii Children and young people ***Improvement areas*** **Reducing mortality in children** 1.6 i Infant mortality* ii Neonatal mortality and stillbirths
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Reducing time spent in hospital by people with long-term conditions** 2.3 ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care i GP services ii GP Out-of-hours services 4b Patient experience of hospital care 4c *Friends and family test* *4d Patient experience characterised as poor or worse* *I Primary care* *ii Hospital care* ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving people's experience of accident and emergency services** 4.3 Patient experience of A&E services **Improving access to primary care services** 4.4 Access to i GP services **Improving children and young people's experience of healthcare** *4.8 Children and young people's experience of inpatient services* **Improving people's experience of integrated care** *4.9 People's experience of integrated care***

Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development

Table 2 Public health outcomes framework for England, 2013–2016

Domain	**Objectives and indicators**
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators*** 2.11 Diet 2.17 Recorded diabetes
Alignment with NHS Outcomes Framework	

3 Summary of suggestions

3.1 Responses

In total 16 stakeholders responded to the 2-week engagement exercise 09/10/2015-23/10/2015.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the Committee.

Full details of all the suggestions provided are given in Appendix 3 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Diagnosis	CDC, SCM
Education and information for children and young people with type 1 or type 2 diabetes	CDC, DUK, JDRF, RCPH, SCM
Insulin therapy for children and young people with type 1 diabetes	JDRF, MLtd, , RCPH, SCM
Dietary management for children and young people with type 1 or type 2 diabetes	CDC, SCM
Blood glucose and HbA1c targets and monitoring for children and young people with type 1 diabetes	MLtd, RCPH,SCM
Hyperglycaemia, blood ketone monitoring and intercurrent illness in children and young people with type 1 diabetes	CDC, SCM
Psychological and social issues in children and young people with type 1 or type 2 diabetes	DUK, RCPH, SCM
Monitoring for complications and associated conditions of type 1 or type 2 diabetes	ICPH, RCO, RCPH, SCM
Diabetic ketoacidosis	RCPH, SCM
Service provision	DUK, RCPH
Transition from paediatric to adult care	DUK, IHHD, RCPH

CDC, Association of Children's Diabetes Clinicians
DUK, Diabetes UK
HQTD, HQT Diagnostics
ICH, Institute of Child Health
IHHD, Institute of Health and Human Development, University of East London
JDRF, Juvenile Diabetes Research Foundation
NHE, NHS England
MLtd, Medtronic Limited
RCO, Royal College of Ophthalmologists
RCPCH, Royal College of Paediatrics and Child Health
RCP, Royal College of Pathologists
SCM, Specialist Committee Member

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1370 were identified for QS topic. In addition, current practice examples were suggested by stakeholders at topic engagement (25 studies) and internally at project scoping (22 studies).

Of these studies, 12 were assessed as having potential relevance to this topic and the suggested areas for quality improvement identified by stakeholders (see

Appendix 3). A summary of relevant studies is included in the current practice sections for each suggested area of improvement.

4 Suggested improvement areas

4.1 Diagnosis

4.1.1 Summary of suggestions

A stakeholder highlighted the importance of early diagnosis and referral of CYP with type 1 diabetes by healthcare professionals and primary care in line with NICE clinical guideline NG18 recommendation 1.1.2. This could reduce the life-threatening acute type 1 diabetes complication of diabetic ketoacidosis (DKA) at diagnosis, increase earlier admission to an appropriate service and improve communication between primary and secondary care.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Diagnosis	**NICE NG18 Recommendation** 1.1.2

Diagnosis

NICE NG18 – Recommendation 1.1.2

Refer children and young people with suspected type 1 diabetes immediately (on the same day) to a multidisciplinary paediatric diabetes team with the competencies needed to confirm diagnosis and to provide immediate care. **[2004, amended 2015]**

4.1.3 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

Education and information for CYP with type 1 and 2 diabetes

4.1.4 Summary of suggestions

Stakeholders supported ongoing structured education programmes as being vital for CYP with type 1 and 2 diabetes to self-manage their condition and therefore potentially prevent the risk of long-term complications. Improved communication within these programmes was also reported as important with tailored information for the CYP and parents or carer to understand accessible appropriate treatments.

4.1.5 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Education and information for children and young people with type 1 and 2 diabetes	**NICE NG18 Recommendations** 1.2.1, 1.2.2,1.3.1 and 1.3.2

*** Please note where possible this paper presents merged recommendations on CYP with type 1 and 2 diabetes**

Education and information for children and young people with type 1 and 2 diabetes

NICE NG18 – Recommendation 1.2.1 and 1.3.1

Offer children and young people with [type 1 or 2] diabetes and their family members or carers (as appropriate) a continuing programme of education from diagnosis. Ensure that the programme includes the following core topics:

- insulin therapy, including its aims, how it works, its mode of delivery and dosage adjustment
- blood glucose monitoring, including targets for blood glucose control (blood glucose and HbA1c levels)

- the effects of diet, physical activity and intercurrent illness on blood glucose control
- managing intercurrent illness ('sick-day rules', including monitoring of blood ketones [beta-hydroxybutyrate])
- detecting and managing hypoglycaemia, hyperglycaemia and ketosis. **[new 2015]**

NICE NG18 – Recommendation 1.2.2 and 1.3.2

Tailor the education programme to each child or young person with [type 1 and 2] diabetes and their family members or carers (as appropriate), taking account of issues such as:

- personal preferences
- emotional wellbeing
- age and maturity
- cultural considerations
- existing knowledge
- current and future social circumstances
- life goals. **[new 2015]**

4.1.1 Current UK practice

The 2013-14 National Paediatric Diabetes Audit [2] reported that only 45% aged under 25 are receiving some form of structured education on an annual basis with significant regional variation reported between the South West (11%) and North West (62%). The Audit recommended that regional diabetes networks should develop regional and national structured education programmes to help prevent wide variation in treatment target outcomes and ensure that every CYP with diabetes receives optimal care wherever they live. Further investigation by this Audit is however required for more accurate assessment as the findings specifically on education were based on poor data quality with 45% of data missing.

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[2] 2013-14 National Paediatric Diabetes Audit Royal College of Paediatrics and Child Health

4.2 Insulin therapy for children and young people with type 1 diabetes

4.2.1 Summary of suggestions

National variation in insulin pump access was reported. In response, stakeholders supported insulin therapy options and pump use as beneficial to type 1 diabetes management in CYP. In particular, continuous subcutaneous insulin infusion (CSII or pump therapy) was supported by a stakeholder to significantly reduce HbA1c levels in CYP with type 1 diabetes.

A stakeholder also highlighted the importance of tailored diabetes care such as equal access to insulin pumps to meet every child's needs to achieve optimal control and improve life expectancy.

Another stakeholder also suggested raising the importance of diabetes technology with CYP, parents and diabetes MDTs in line with NICE Technology Appraisal 151 [TA151][3] (2008) which outlines criteria for recommending insulin pumps use specifically for children and young people aged over 12.

4.2.1 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Insulin therapy for children and young people with type 1 diabetes	**NICE NG18 Recommendations** 1.2.18, 1.2.19 (KPI), 1.2.20, 1.2.22, 1.2.25, 1.2.30

Insulin therapy for children and young people with type 1 diabetes

NICE NG18 Recommendation 1.2.18

Take into account the personal and family circumstances of the child or young person with type 1 diabetes and discuss their personal preferences with them and

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[3] Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus NICE technology appraisal guidance [TA151] (2008)

their family members or carers (as appropriate) when choosing an insulin regimen. **[new 2015]**

NICE NG18 Recommendation 1.2.19 (KPI)

Offer children and young people with type 1 diabetes multiple daily injection basal–bolus insulin regimens from diagnosis. If a multiple daily injection regimen is not appropriate for a child or young person with type 1 diabetes, consider continuous subcutaneous insulin infusion (CSII or insulin pump) therapy as recommended in continuous subcutaneous insulin infusion for the treatment of diabetes mellitus[4] . **[new 2015]**

NICE NG18 Recommendation 1.2.20

Encourage children and young people with type 1 diabetes who are using multiple daily insulin injection regimens and their family members or carers (as appropriate) to adjust the insulin dose if appropriate after each blood glucose measurement. **[2004, amended 2015]**

NICE NG18 Recommendation 1.2.22

Provide all children and young people with type 1 diabetes who are starting continuous subcutaneous insulin infusion (CSII or insulin pump) therapy and their family members or carers (as appropriate) with specific training in its use. Provide ongoing support from a specialist team, particularly in the period immediately after starting continuous subcutaneous insulin infusion. Specialist teams should agree a common core of advice for continuous subcutaneous insulin infusion users. **[2004, amended 2015]**

NICE NG18 Recommendation 1.2.25

Offer children and young people with type 1 diabetes a choice of insulin delivery systems that takes account of their insulin requirements and personal preferences. **[2004]**

NICE NG18 Recommendation 1.2.30

If a child or young person with type 1 diabetes does not have optimal blood glucose control (see recommendations 1.2.54 and 1.2.67):

- offer appropriate additional support such as increased contact frequency with their diabetes team, and

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[4] Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus NICE technology appraisal guidance [TA151] (2008)

- if necessary, offer an alternative insulin regimen (multiple daily injections, continuous subcutaneous insulin infusion [CSII or insulin pump] therapy or once-, twice- or three-times daily mixed insulin injections). **[new 2015]**

4.2.2 Current UK practice

The 2013 Insulin Pump Audit[5] reported a low uptake of 19% of UK paediatric patients aged under 18 undertaking insulin pump therapy. A stakeholder noted that this uptake was significantly below NICE [TA151][6] which concluded that 50% of type 1 diabetes paediatric population may benefit from this therapy. Insulin pumps were supported by NICE TA151[6] as a cost-effective use of NHS resources.

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[5] Insulin Pump Audit Public Health England (2013)

[6], Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus NICE technology appraisal guidance [TA151] (2008)

4.3 Dietary management for children and young people with type 1 and 2 diabetes

4.3.1 Summary of suggestions

Stakeholders highlighted the importance of improving dietary management in CYP with type 1 and 2 diabetes. In particular, level 3 carbohydrate counting from diagnosis was supported. A stakeholder suggested that families of children who start on a multiple daily insulin regimen need to learn how to carbohydrate count so that their insulin dosage is adjusted with food and blood glucose levels are maintained appropriately.

Information on reducing glycaemic index for the general population overall was also supported by stakeholders as this could reduce obesity levels and improve understanding on overall health and wellbeing options.

4.3.1 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Dietary management for children and young people with type 1 and 2 diabetes	**NICE NG18 Recommendations** 1.2.33 ,1.2.34, 1.2.37 (KPI), 1.2.42 and 1.2.43

Dietary management for children and young people with type 1 diabetes

NICE NG18 Recommendation 1.2.33

Support children and young people with type 1 diabetes and their family members or carers (as appropriate) to develop a good working knowledge of nutrition and how it affects their diabetes. **[new 2015]**

NICE NG18 Recommendation 1.2.34

Explain regularly to children and young people with type 1 diabetes and their family members or carers (as appropriate) how healthy eating (including eating foods with a low glycaemic index, fruit and vegetables, and appropriate types and amounts of fats) can reduce their risk of cardiovascular disease, and support them to adjust their food choices accordingly. **[new 2015]**

NICE NG18 Recommendation 1.2.37 (KPI)

Offer level 3 carbohydrate‑counting education from diagnosis to children and young people with type 1 diabetes who are using a multiple daily insulin injection regimen or continuous subcutaneous insulin infusion (CSII or insulin pump) therapy, and to their family members or carers (as appropriate), and repeat the offer at intervals thereafter. **[new 2015]**

NICE NG18 Recommendation 1.2.42

Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that a low glycaemic index diet may help to improve blood glucose control and reduce the risk of hyperglycaemic episodes. **[new 2015]**

NICE NG18 Recommendation 1.2.43

Offer children and young people with type 1 diabetes and their family members or carers (as appropriate) advice and education to promote a low glycaemic index diet. **[new 2015]**

4.3.2 Current UK practice

A stakeholder reported that level 3 carbohydrate counting from diagnosis still remains highly variable between UK diabetic units.

The Paediatric Diabetes Team at Southport and Ormskirk NHS Trust[7] developed a 360 degree educational approach to carbohydrate counting for health care professionals, carers and CYP with type 1 diabetes. Joint drop-in specialist nurse and diabetes dietitian clinics were arranged weekly, dietitian home visits and school visits were initiated, and large group carbohydrate counting education workshops were implemented. Surveys concluded that patient or carer and staff knowledge and their confidence were significantly improved by this education.

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[7] 360 degree approach to carbohydrate counting education from diagnosis in paediatric diabetes- Paediatric Diabetes Team, Southport and Ormskirk Hospital NHS Trust (2015)

4.4 Blood glucose and HbA1c targets and monitoring for children and young people with type 1 diabetes

4.4.1 Summary of suggestions

Blood glucose targets

Achievement of glycaemic control for CYP with severe hypoglycaemic episodes was reported as important by a stakeholder as this can have a significant impact on healthcare resources and both the CYP and their parent or carers' quality of life.

Blood glucose monitoring

Ongoing real-time continuous glucose monitoring (CGM) for CYP with type 1 diabetes was highlighted as important by stakeholders. It was noted that hypoglycaemic episodes and subsequent hospital admissions can be avoided with the use of CGM particularly when used in conjunction with insulin pump therapy[8]. Also increasing CGM uptake in appropriate CYP could positively help to both prevent severe hypoglycaemia and the fear associated with this complication. Long term CGM was supported as positively enabling CYP to monitor their blood glucose levels and improve their glycaemic control.

HbA1c targets and monitoring

A stakeholder highlighted that HbA1c is the most important measurable outcome in CYP with type 1 diabetes with an ideal HbA1c target level of 48 mmol/mol (6.5%) or below to minimise the risk of long term complications. Shared HbA1c targets between MDT members and CYP was also supported as significantly influencing metabolic outcomes.

A stakeholder however raised concern in currently measuring this target's achievement. They suggested by adding this as an audit measure to the National Paediatric Diabetes Audit would enable comparisons across centres in which CYP are cared for.

4.4.1 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

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[8] Type 1 diabetes: Integrated sensor-augmented pump therapy systems for managing blood glucose levels (The MiniMed Paradigm Veo System and the Vibe and G4 PLATINUM CGM system)
Publication anticipated date: January 2016

Table 8 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Blood glucose targets	**NICE NG18 Recommendations** 1.2.54 -1.2.57
Blood glucose monitoring	**NICE NG18 Recommendations** 1.2.62 (KPI) - 1.2.64
HbA1c targets and monitoring	**NICE NG18 Recommendations** 1.2.67 (KPI)- 1.2.70 and 1.2.72

Blood glucose targets

NICE NG18 Recommendation 1.2.54

Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that the optimal target ranges for short-term plasma glucose control are:

- fasting plasma glucose level of 4–7 mmol/litre on waking
- a plasma glucose level of 4–7 mmol/litre before meals at other times of the day
- a plasma glucose level of 5–9 mmol/litre after meals
- a plasma glucose level of at least 5 mmol/litre when driving[4] . **[new 2015]**

NICE NG18 Recommendation 1.2.55

Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that achieving and maintaining blood glucose levels towards the lower end of the target optimal ranges will help them to achieve the lowest attainable HbA1c. **[new 2015]**

NICE NG18 Recommendation 1.2.56

Ensure that children and young people with type 1 diabetes do not experience problematic hypoglycaemia or undue emotional distress when achieving, or attempting to achieve, blood glucose and HbA1c targets. **[new 2015]**

NICE NG18 Recommendation 1.2.57

Be aware that there may be conflict between children and young people with type 1 diabetes and their family members or carers about blood glucose and HbA1c targets, and that an agreed compromise may be needed. **[new 2015]**

Blood glucose monitoring

NICE NG18 Recommendation 1.2.62 (KPI)

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

- frequent severe hypoglycaemia or
- impaired awareness of hypoglycaemia associated with adverse consequences (for example, seizures or anxiety) or
- inability to recognise, or communicate about, symptoms of hypoglycaemia (for example, because of cognitive or neurological disabilities). **[new 2015]**

NICE NG18 Recommendation 1.2.63

Consider ongoing real‑time continuous glucose monitoring for:

- neonates, infants and pre-school children
- children and young people who undertake high levels of physical activity (for example, sport at a regional, national or international level)
- children and young people who have comorbidities (for example anorexia nervosa) or who are receiving treatments (for example corticosteroids) that can make blood glucose control difficult. **[new 2015]**

NICE NG18 Recommendation 1.2.64

Consider intermittent (real‑time or retrospective) continuous glucose monitoring to help improve blood glucose control in children and young people who continue to have hyperglycaemia despite insulin adjustment and additional support. **[new 2015]**

HbA1c targets and monitoring

NICE NG18 Recommendation 1.2.67 (KPI)

Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that an HbA1c target level of 48 mmol/mol (6.5%) or lower is ideal to minimise the risk of long-term complications. **[new 2015]**

NICE NG18 Recommendation 1.2.68

Explain to children and young people with type 1 diabetes who have an HbA1c level above the ideal target of 48 mmol/mol (6.5%) and their family members or carers (as appropriate) that any reduction in HbA1c level reduces the risk of long-term complications. **[new 2015]**

NICE NG18 Recommendation 1.2.69

Agree an individualised lowest achievable HbA1c target with each child or young person with type 1 diabetes and their family members or carers (as appropriate), taking into account factors such as daily activities, individual life goals, complications, comorbidities and the risk of hypoglycaemia. **[new 2015]**

NICE NG18 Recommendation 1.2.70

Support children and young people with type 1 diabetes and their family members or carers (as appropriate) to safely achieve and maintain their individual agreed HbA1c target level. **[new 2015]**

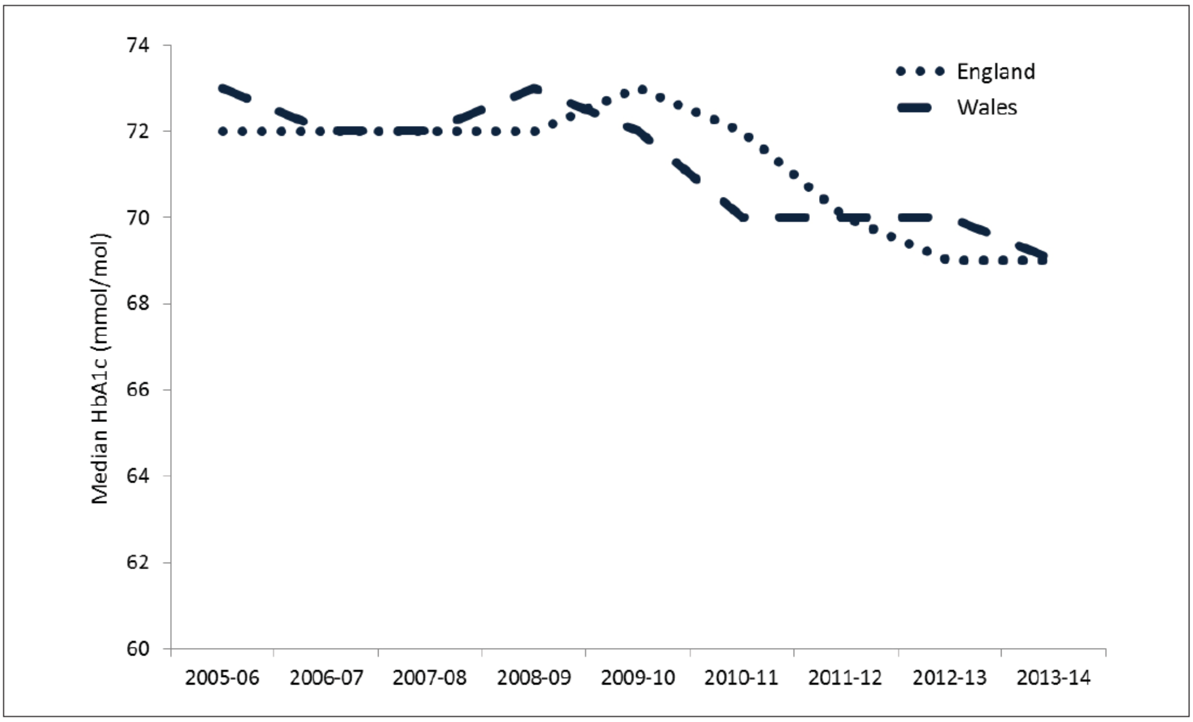
NICE NG18 Recommendation 1.2.72

Diabetes services should document the proportion of children and young people with type 1 diabetes in a service who achieve an HbA1c level of 53 mmol/mol (7%) or lower. **[new 2015]**

4.4.1 Current UK practice

The National Paediatric Diabetes 2013 Audit[9] concluded that there has been a steady improvement in HbA1c control in England and Wales over the last four years. In 2013-14 the national average HbA1c was 71.6 mmol/mol a reduction from 73.0 mmol/mol in 2012-13. Please see Figure 1 below.

Figure 1: Change in median HbA1c for England and Wales (2005-6 to 2013-4)



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[9] 2013-14 National Paediatric Diabetes Audit Royal College of Paediatrics and Child Health

4.5 Hyperglycaemia, blood ketone monitoring and intercurrent illness in children and young people with type 1 diabetes

4.5.1 Summary of suggestions

A stakeholder highlighted that blood ketone monitoring in CYP with type 1 diabetes is important to prevent the complication of diabetic ketoacidosis (DKA) during hyperglycaemic episodes and intercurrent illness. Ensuring all CYP with this condition are also offered regular blood ketone test strips and advice on testing, interpreting the result and undertaking preventative action to prevent DKA was reported by stakeholders.

4.5.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Hyperglycaemia, blood ketone monitoring and intercurrent illness in children and young people with type 1 diabetes	**NICE NG18 Recommendations** 1.2.73 and 1.2.74 (KPI)

Hyperglycaemia, blood ketone monitoring and intercurrent illness in children and young people with type 1 diabetes

NICE NG18 Recommendation 1.2.73

Provide each child and young person with type 1 diabetes and their family members or carers (as appropriate) with clear individualised oral and written advice ('sick-day rules') about managing type 1 diabetes during intercurrent illness or episodes of hyperglycaemia, including:

- monitoring blood glucose
- monitoring and interpreting blood ketones (beta-hydroxybutyrate)
- adjusting their insulin regimen
- food and fluid intake

- when and where to seek further advice or help.

  Revisit the advice with the child or young person and their family members or carers (as appropriate) at least annually. **[new 2015]**

NICE NG18 Recommendation 1.2.74 (KPI)

Offer children and young people with type 1 diabetes blood ketone testing strips and a meter, and advise them and their family members or carers (as appropriate) to test for ketonaemia if they are ill or have hyperglycaemia. **[new 2015]**

4.5.1 Current UK practice

Klocker et al (2013)[10] supported blood ketone testing as being more effective than urine testing in reducing current emergency department assessment, admission and time to recovery from DKA, as well as potentially lowering healthcare cost.

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[10] Blood β-hydroxybutyrate vs. urine acetoacetate testing for the prevention and management of ketoacidosis in Type 1 diabetes: a systematic review- Klocker et al (2013) Diabet Med. 2013 Jul;30(7):818-24

4.6 Psychological and social issues in CYP with type 1 and 2 diabetes

4.6.1 Summary of suggestions

Stakeholders highlighted that CYP with diabetes are more likely to have problems with depression, eating disorders and can experience adjustment difficulties in self managing their condition. Therefore the need for improved routine access to psychological and emotional support from healthcare professionals with an understanding of mental health and diabetes was suggested by stakeholders.

Psychological (emotional and behavioural needs) assessment by MDTs was recommended to enable timely intervention and to avoid serious co-morbidity from depression, eating disorders or drug taking in later life.

Type 1 diabetes requires routine self-management therefore a stakeholder suggested that paediatric diabetes healthcare professionals should be trained to be able to deliver mental health support themselves and should also be provided with guidance for diagnosing and managing the most common mental health problems in particular depression, anxiety and eating disorders. Conversely where expert psychological support is provided, those providing it should have specific experience of diabetes.

Stakeholders also highlighted the importance of psychological support in CYP with type 2 diabetes. Early intervention by mental health professionals, in particular clinical psychologists was supported in line with NICE Clinical Guideline NG18.

4.6.1 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 10 to help inform the Committee’s discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Psychological and social issues in CYP with type 1 and type 2 diabetes	**NICE NG18 Recommendations** Type 1- 1.2.94, 1.2.96, 1.2.97, 1.2.98 (KPI), 1.2.100, 1.2.104, 1.2.106 Type 2- 1.3.33, 1.3.36, 1.3.37, 1.3.39, 1.3.40, 1.3.41
Psychological and social issues in CYP with type 1 diabetes	**NICE NG18 Recommendations** 1.2.103 and 1.2.105

Psychological and social issues in CYP with type 2 diabetes	**NICE NG18 Recommendation** 1.3.42

*** Please note where possible this paper presents merged recommendations on CYP with type 1 and type 2 diabetes**

Psychological and social issues in CYP with type 1 and type 2 diabetes

NICE NG18 Recommendation 1.2.94 and 1.3.33

Diabetes teams should be aware that children and young people with type 1 [or type 2] diabetes have a greater risk of emotional and behavioural difficulties. **[2004, amended 2015]**

NICE NG18 Recommendation 1.2.96

Assess the emotional and psychological wellbeing of young people with type 1 diabetes who present with frequent episodes of diabetic ketoacidosis (DKA). **[2004, amended 2015]**

NICE NG18 Recommendation 1.2.97 and 1.3.36

Be aware that a lack of adequate psychosocial support has a negative effect on various outcomes, including blood glucose control in children and young people with type 1 diabetes, and that it can also reduce their self-esteem. **[2004, amended 2015]**

NICE NG18 Recommendation 1.2.98 (KPI) and 1.3.37

Offer children and young people with type 1 [or type 2] diabetes and their family members or carers (as appropriate) timely and ongoing access to mental health professionals with an understanding of diabetes because they may experience psychological problems (such as anxiety, depression, behavioural and conduct disorders and family conflict) or psychosocial difficulties that can impact on the management of diabetes and wellbeing. **[2004, amended 2015]**

NICE NG18 Recommendation 1.2.100 and 1.3.39

Diabetes teams should have appropriate access to mental health professionals to support them in psychological assessment and the delivery of psychosocial support. **[2004]**

NICE NG18 Recommendations 1.2.104 and 1.3.40

Offer screening for anxiety and depression to children and young people with type 1 [or type 2] diabetes who have persistently suboptimal blood glucose control. **[2004]**

NICE NG18 Recommendations 1.2.106 and 1.3.41

Refer children and young people with type 1 [or type 2] diabetes and suspected anxiety and/or depression promptly to child mental health professionals. **[2004]**

Type 1 diabetes

NICE NG18 Recommendation 1.2.103

Consider a programme of behavioural intervention therapy or behavioural techniques for children and young people with type 1 diabetes in whom there are concerns about psychological wellbeing in order to improve:

- health-related quality of life – for example, counselling or cognitive behavioural therapy (CBT), including CBT focused on quality of life
- adherence to diabetes treatment – for example, motivational interviewing or multisystemic therapy
- blood glucose control in children and young people with high HbA1c levels (HbA1c above 69 mmol/mol [8.5%]) – for example, multisystemic therapy. **[new 2015]**

NICE NG18 Recommendation 1.2.105

Diabetes teams should be aware that children and young people with type 1 diabetes may develop anxiety and/or depression, particularly when difficulties in self-management arise in young people and children who have had type 1 diabetes for a long time. **[2004]**

Type 2 diabetes

NICE NG18 Recommendation 1.3.42

Ensure that children and young people with type 2 diabetes and their family members or carers (as appropriate) have timely and ongoing access to mental health services when needed**. [new 2015]**

4.6.1 Current UK practice

Gosden et al (2010)[11] assessed UK provision of paediatric and adolescent diabetes services and examined service delivery changes since 2002. It was reported that in 2002 only 21% of clinics have a psychological professional integrated within the diabetes team.

The National Paediatric Diabetes Audit 2013[12] concluded that assessment for expert psychological review is undertaken in fewer than 50% of CYP with diabetes.

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[11] The fifth UK paediatric diabetes services survey: meeting guidelines and recommendations? – Gosden et al (2010)

[12] 2013-14 National Paediatric Diabetes Audit Royal College of Paediatrics and Child Health

4.7 Monitoring for complications and associated conditions of type 1 and type 2 diabetes

Summary of suggestions

Monitoring for complications and associated conditions of type 1 and type 1 diabetes

A stakeholder raised the importance of appropriate monitoring for complications of type 1 and type 2 diabetes as early identification can lead to improvement in diabetes control.

Diabetic retinopathy in CYP with type 1 and 2 diabetes

It was reported by a stakeholder that diabetic retinopathy can lead to visual disability if left untreated. Stakeholders supported annual diabetic retinopathy screening for young people aged 12 and above. This is in line with NICE Clinical Guideline NG18.

4.7.1 Selected recommendations from development source

Table 11 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 11 to help inform the Committee’s discussion.

Table 11 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Monitoring for complications and associated conditions of type 1	**NICE NG18 Recommendations** 1.2.110 and 1.2.114
Diabetic retinopathy in CYP with type 1 diabetes	**NICE NG18 Recommendation** 1.2.115
Diabetic retinopathy in CYP with type 2 diabetes	**NICE NG18 Recommendation** 1.3.52

Monitoring for complications and associated conditions of type 1 diabetes

NICE NG18 Recommendation 1.2.110

Offer children and young people with type 1 diabetes monitoring for:

- thyroid disease at diagnosis and annually thereafter until transfer to adult services

- diabetic retinopathy annually from 12 years
- moderately increased albuminuria (albumin:creatinine ratio [ACR] 3–30 mg/mmol; 'microalbuminuria') to detect diabetic kidney disease, annually from 12 years
- hypertension annually from 12 years. **[new 2015]**

NICE NG18 Recommendation 1.2.114

Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) the importance of annual monitoring from 12 years for diabetic retinopathy and diabetic kidney disease. **[new 2015]**

Diabetic retinopathy in children and young people with type 1 diabetes

NICE NG18 Recommendation 1.2.115

Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that:

- monitoring for diabetic retinopathy begins at 12 years (see recommendation 1.2.110) because diabetic retinopathy that needs treatment is extremely rare in children and young people under 12
- background retinopathy is often found through monitoring, and improving blood glucose control will reduce the risk of this progressing to significant diabetic retinopathy
- annual monitoring from 12 years is important because, if significant diabetic retinopathy is found, early treatment will improve the outcome. **[new 2015]**

Diabetic retinopathy in children and young people with type 2 diabetes

NICE NG18 Recommendation 1.3.52

Explain to children and young people with type 2 diabetes and their family members or carers (as appropriate) that:

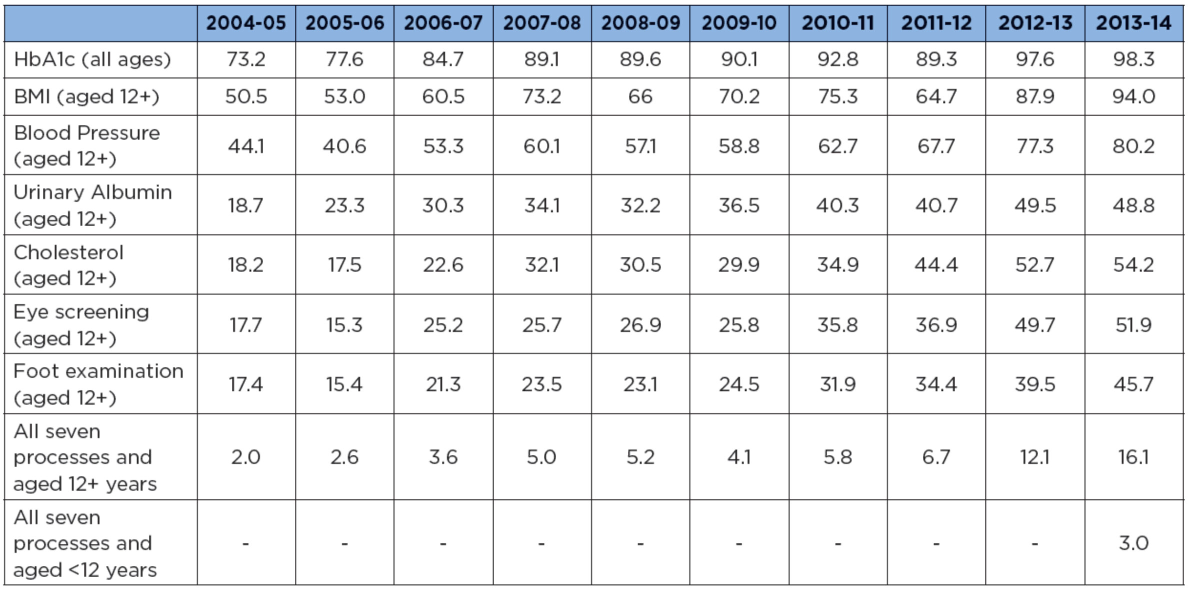
- background retinopathy is often found through monitoring (see recommendation 1.3.43), and improving blood glucose control will reduce the risk of this progressing to significant diabetic retinopathy
- annual monitoring from 12 years is important because, if significant diabetic retinopathy is found, early treatment will improve the outcome. **[new 2015]**

4.7.2 Current UK practice

Diabetic retinopathy in CYP with type 1 and type 2 diabetes

The National Paediatric Diabetes Audit (2013-14)[13] reported an uptake eye screening rate of 52% of eligible CYP with type 1 and type 2 diabetes. Please see Figure 2 below.

Figure 2: Percentage of children and young people recorded as receiving care processes by year of audit



	2004-05	2005-06	2006-07	2007-08	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14
HbA1c (all ages)	73.2	77.6	84.7	89.1	89.6	90.1	92.8	89.3	97.6	98.3
BMI (aged 12+)	50.5	53.0	60.5	73.2	66	70.2	75.3	64.7	87.9	94.0
Blood Pressure (aged 12+)	44.1	40.6	53.3	60.1	57.1	58.8	62.7	67.7	77.3	80.2
Urinary Albumin (aged 12+)	18.7	23.3	30.3	34.1	32.2	36.5	40.3	40.7	49.5	48.8
Cholesterol (aged 12+)	18.2	17.5	22.6	32.1	30.5	29.9	34.9	44.4	52.7	54.2
Eye screening (aged 12+)	17.7	15.3	25.2	25.7	26.9	25.8	35.8	36.9	49.7	51.9
Foot examination (aged 12+)	17.4	15.4	21.3	23.5	23.1	24.5	31.9	34.4	39.5	45.7
All seven processes and aged 12+ years	2.0	2.6	3.6	5.0	5.2	4.1	5.8	6.7	12.1	16.1
All seven processes and aged <12 years	-	-	-	-	-	-	-	-	-	3.0

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[13] 2013-14 National Paediatric Diabetes Audit Royal College of Paediatrics and Child Health

4.8 Diabetic ketoacidosis (DKA)

Summary of suggestions

A stakeholder reported that DKA is the principle mortality cause and long term morbidity in newly diagnosed, in particular in pre-school age children. A stakeholder highlighted studies which demonstrate that 1 in 5 children in England and Wales still present in this way. It was suggested that wider awareness in the community, education system and primary care is needed.

A stakeholder noted that DKA incidence reflects the effectiveness of diabetes teams in supporting families to manage illness as well as young people struggling to manage their care.

4.8.1 Selected recommendations from development source

Table 12 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 12 to help inform the Committee’s discussion.

Table 12 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Recognition, referral and diagnosis	**NICE NG18 Recommendation** 1.4.7

NICE NG18 Recommendation 1.4.7

If DKA is suspected or confirmed in a child or young person, explain to them and to their family members or carers (as appropriate) that DKA is a serious matter that needs urgent hospital assessment. **[new 2015]**

4.8.2 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

4.1 Service provision

Summary of suggestions

Service provision

NICE Clinical Guideline NG18 (2015) states that all children and young people with diabetes over 12 years of age should receive the following seven key care processes - HbA1c monitoring, height and weight, blood pressure, urinary albumin, cholesterol, eye screening and foot examination.

A stakeholder suggested that paediatric diabetes units (PDUs) should implement guidance on blood ketone monitoring and offer CYP and their carers access to 24hour telephone advice.

4.1.1 Selected recommendations from development source

Table 13 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 13 to help inform the Committee’s discussion.

Table 13 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Service provision	NICE NG18 Recommendations 1.5.1-1.5.4

Service provision

NICE NG18 Recommendation 1.5.1

Offer children and young people with diabetes an ongoing integrated package of care provided by a multidisciplinary paediatric diabetes team. To optimise the effectiveness of care and reduce the risk of complications, the diabetes team should include members with appropriate training in clinical, educational, dietetic, lifestyle, mental health and foot care aspects of diabetes for children and young people. **[2004, amended 2015]**

NICE NG18 Recommendation 1.5.2

Offer children and young people with diabetes and their family members or carers (as appropriate) 24-hour access to advice from their diabetes team. **[2004, amended 2015]**

NICE NG18 Recommendation 1.5.3

Involve children and young people with diabetes and their family members or carers (as appropriate) in making decisions about the package of care provided by their diabetes team. **[2004, amended 2015]**

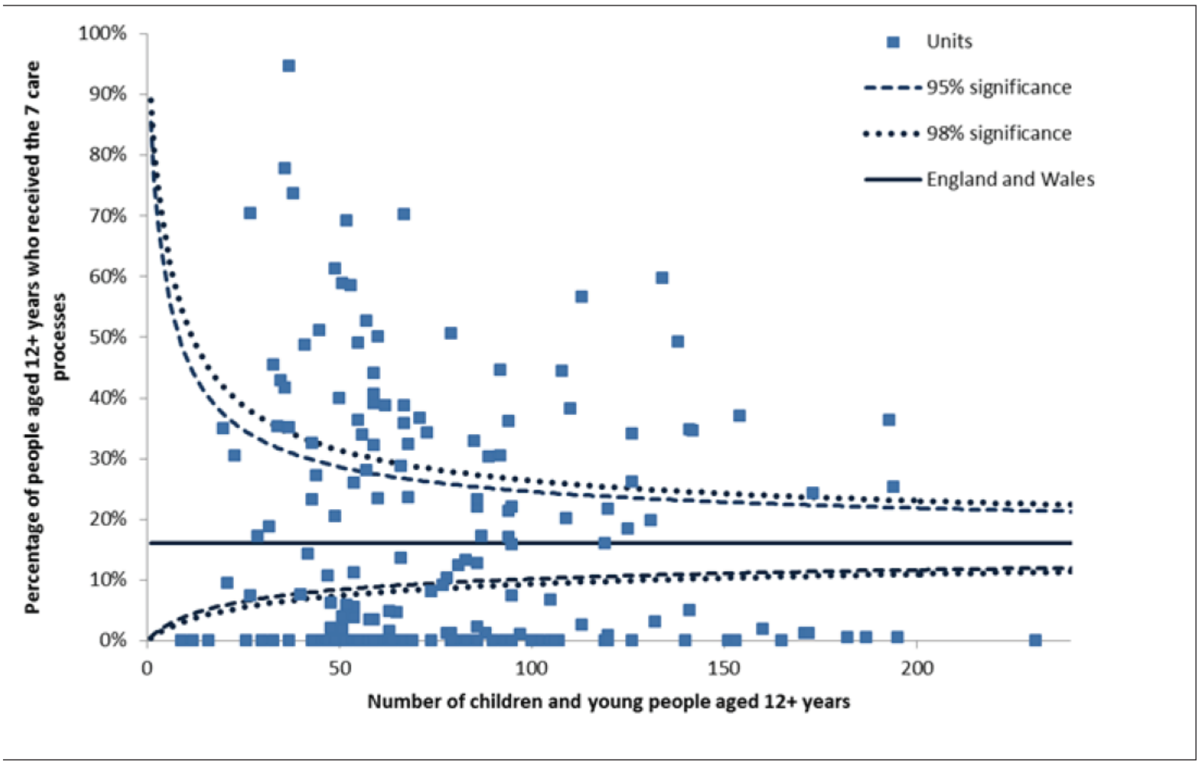
NICE NG18 Recommendation 1.5.4

At diagnosis, offer children and young people with diabetes home-based or inpatient management according to clinical need, family circumstances and wishes. Explain that home-based care with support from the local paediatric diabetes team (including 24-hour telephone access) is safe and as effective as inpatient initial management. **[2004, amended 2015]**

4.1.1 Current UK practice

The 2013-14 National Paediatric Diabetes Audit[14] concluded that the overall completion rate of all recommended seven care processes remains low with 16%. Despite this showing steady improvement from 12% in 2012-13 significant variation was reported in the completion rate across regional networks and Paediatric Diabetes Units. This ranged from 0% to 95%. Please see Figure 3 below.

Figure 3: Percentage of people aged 12 years and older who had all seven care processes by unit (2013-14)



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[14] 2013-14 National Paediatric Diabetes Audit Royal College of Paediatrics and Child Health

4.2 Transition from paediatric to adult care

Summary of suggestions

Transition from paediatric to adult care

A stakeholder highlighted that young people should have access to a smooth and effective transition process between the child and adult diabetes services which they receive. This includes adult specialist and primary care services. This transitional process should, therefore, be a well-coordinated multidisciplinary one which actively includes and involves both adult and paediatric teams of healthcare professionals. It should be age-appropriate and tailored to each individual child's needs and circumstances. Adequate evaluation of the young person's needs should happen when the young person possesses sufficient understanding and ability about self-management in order to optimise their ability to use adult diabetes services.

4.2.1 Selected recommendations from development source

Table 14 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 14 to help inform the Committee's discussion.

Table 14 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Transition from paediatric to adult care	**NICE NG18 Recommendations** 1.5.9- 1.5.13

Transition from paediatric to adult care

<u>NICE NG18 Recommendation 1.5.9</u>

Allow sufficient time for young people with diabetes to familiarise themselves with the practicalities of the transition from paediatric to adult services because this improves clinic attendance. **[2004, amended 2015]**

<u>NICE NG18 Recommendation 1.5.10</u>

Agree specific local protocols for transferring young people with diabetes from paediatric to adult services. **[2004, amended 2015]**

NICE NG18 Recommendation 1.5.11

Base the decision about the age of transfer to the adult service on the young person's physical development and emotional maturity, and local circumstances. **[2004, amended 2015]**

NICE NG18 Recommendation 1.5.12

Ensure that transition from the paediatric service occurs at a time of relative stability in the young person's health and is coordinated with other life transitions. **[2004, amended 2015]**

NICE NG18 Recommendation 1.5.13

Explain to young people with type 1 diabetes who are preparing for transition to adult services that some aspects of diabetes care will change at transition. **[2004, amended 2015]**

4.2.1 Current UK practice

The 2013-14 National Paediatric Diabetes Audit[15] concluded that approximately 25% of admissions for DKA are aged between 16 and 25.

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[15] 2013-14 National Paediatric Diabetes Audit Royal College of Paediatrics and Child Health

4.3 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 3 December 2015.

Peer-led education programmes for young people with type 1 diabetes

A stakeholder highlighted the need for peer-led education programmes to be led by the young person. This is a research recommendation in Clinical Guideline NG18.

Peer review of services

A stakeholder highlighted peer review as being important for benchmarking with the Best Practice Tariff being implemented in 2012. Sharing best practice through regional and national networks could reduce variation in practice and clinical outcomes which consequently would lead to healthcare quality improvement.

Effective relationships between child or young person and healthcare professional team

A stakeholder highlighted the need for effective relationships between CYP and all members of their healthcare professional team. These relationships could maintain and improve self-care from the point of diagnosis

Virtual clinics

A stakeholder highlighted the use of virtual clinics to supplement annual hospital appointments. This use of information technology was reported as more convenient and practical for CYP as school time is lost due to hospital appointment attendance.

Testing for Fatty Acids and Vitamin D

A stakeholder highlighted the importance of this testing by GPs.

Treatment other than insulin or metformin in type 2 diabetes

A stakeholder highlighted that alternative treatments to insulin and metformin should be considered as some young people may be treated with other agents.

School compliance to new legal obligations to CYP with type 1 diabetes

In line with the Children and Families Act 2014, a stakeholder noted there are a set of new legal school obligations to provide support to children with type 1 diabetes. This includes establishing an education, health and care plan for each child with type 1 diabetes and having a medical conditions policy at each school. These legal obligations are crucial in ensuring that children and their parents are empowered to manage the condition with access to appropriate help at an early stage.

Recording of delayed diagnosis of type 1 diabetes

A stakeholder highlighted that all delayed diagnoses of type 1 diabetes should be recorded as children are still being offered inappropriate primary care investigations which delays effective treatment and can lead to the complication of DKA in many cases.

Appendix 1: Key priorities for implementation (NG18)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

Education and information for children and young people with type 1 diabetes

Take particular care when communicating with and providing information to children and young people with type 1 diabetes if they and/or their family members or carers (as appropriate) have, for example, physical and sensory disabilities, or difficulties speaking or reading English. **[2004] [recommendation 1.2.9]**

Insulin therapy for children and young people with type 1 diabetes

Offer children and young people with type 1 diabetes multiple daily injection basal–bolus insulin regimens from diagnosis. If a multiple daily injection regimen is not appropriate for a child or young person with type 1 diabetes, consider continuous subcutaneous insulin infusion (CSII or insulin pump) therapy as recommended in continuous subcutaneous insulin infusion for the treatment of diabetes mellitus[16] . **[new 2015] [recommendation 1.2.19]**

Dietary management for children and young people with type 1 diabetes

Offer level 3 carbohydrate-counting education from diagnosis to children and young people with type 1 diabetes who are using a multiple daily insulin injection regimen or continuous subcutaneous insulin infusion (CSII or insulin pump) therapy, and to their family members or carers (as appropriate), and repeat the offer at intervals thereafter. **[new 2015] [recommendation 1.2.37]**

Blood glucose and HbA1c targets and monitoring for children and young people with type 1 diabetes

Advise children and young people with type 1 diabetes and their family members or carers (as appropriate) to routinely perform at least 5 capillary blood glucose tests per day. **[new 2015] [recommendation 1.2.58]**

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

- frequent severe hypoglycaemia or

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[16] Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus NICE technology appraisal guidance [TA151] (2008)

- impaired awareness of hypoglycaemia associated with adverse consequences (for example, seizures or anxiety) or
- inability to recognise, or communicate about, symptoms of hypoglycaemia (for example, because of cognitive or neurological disabilities). **[new 2015] [recommendation 1.2.62]**

Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that an HbA1c target level of 48 mmol/mol (6.5%) or lower is ideal to minimise the risk of long-term complications. **[new 2015] [recommendation 1.2.67]**

Hyperglycaemia, blood ketone monitoring and intercurrent illness in children and young people with type 1 diabetes

Offer children and young people with type 1 diabetes blood ketone testing strips and a meter, and advise them and their family members or carers (as appropriate) to test for ketonaemia if they are ill or have hyperglycaemia. **[new 2015] [recommendation 1.2.74]**

Psychological and social issues in children and young people with type 1 diabetes

Offer children and young people with type 1 diabetes and their family members or carers (as appropriate) timely and ongoing access to mental health professionals with an understanding of diabetes because they may experience psychological problems (such as anxiety, depression, behavioural and conduct disorders and family conflict) or psychosocial difficulties that can impact on the management of diabetes and wellbeing. **[2004, amended 2015] [recommendation 1.2.98]**

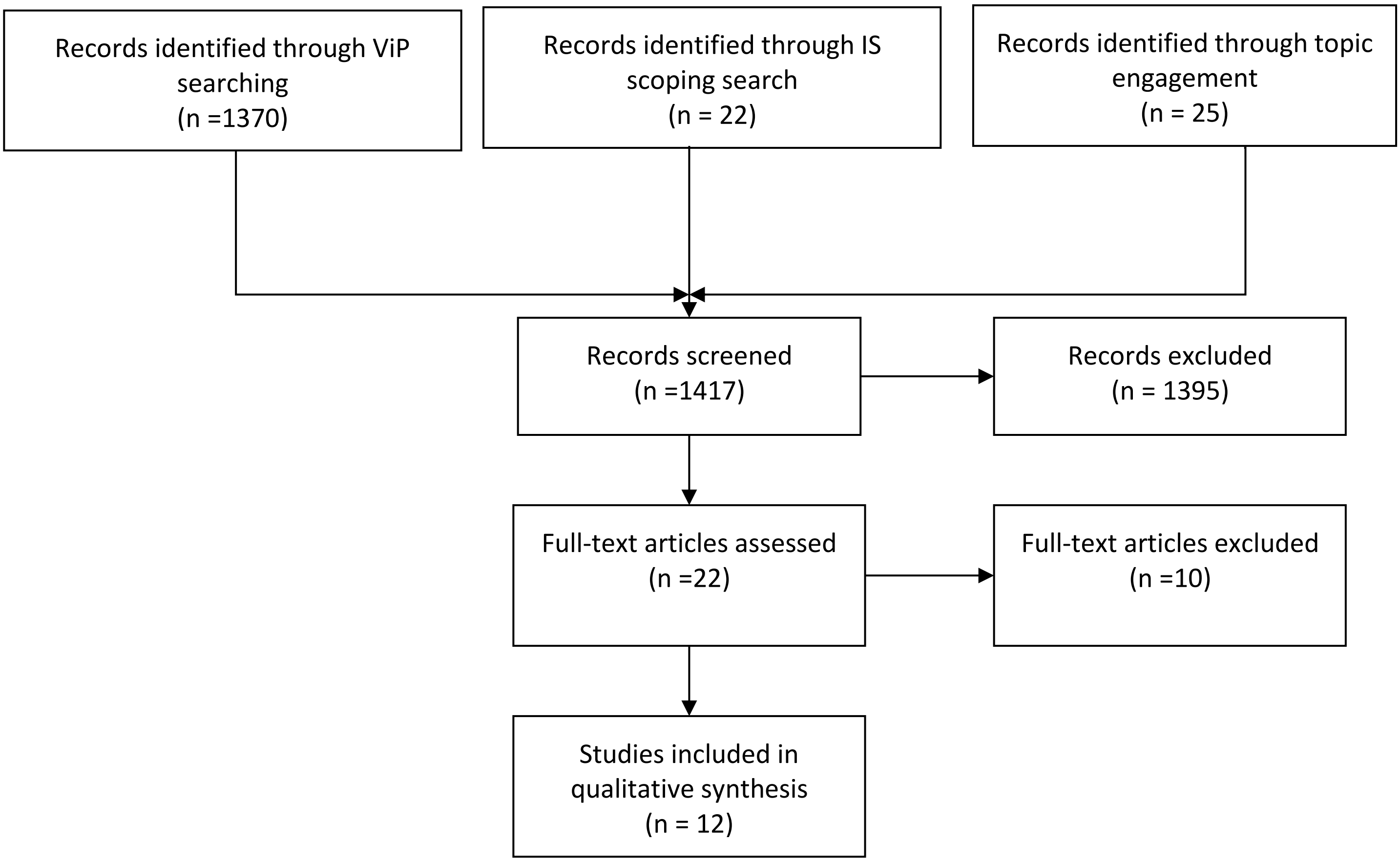
Diabetic kidney disease in children and young people with type 2 diabetes

Explain to children and young people with type 2 diabetes and their family members or carers (as appropriate) that:

- using the first urine sample of the day ('early morning urine') to screen for moderately increased albuminuria (ACR 3–30 mg/mmol; 'microalbuminuria') is important, as this reduces the risk of false positive results
- if moderately increased albuminuria is detected, improving blood glucose control will reduce the risk of this progressing to significant diabetic kidney disease

- annual monitoring (see recommendation 1.3.43) is important because, if diabetic kidney disease is found, early treatment will improve the outcome. **[new 2015] [recommendation 1.3.54]**

Appendix 2: Review flowchart



Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Diagnosis					
01	SCM1		Refer from Primary care on the same day	Reduction of DKA on diagnosis Earlier admission to an appropriate service Improved communication between primary and secondary care	Italy and/or Spain did a nationwide primary care information plug for the basic signs and symptoms of undiagnosed or poorly controlled diabetes in CYP and the number of serious DKA admissions reduced dramatically.
02	Association of Children's Diabetes Clinicians	Early diagnosis of T1DM amongst healthcare professionals and primary care 1. All CCG must ensure they have Referral guidelines for Primary Care Staff that is in line with current NICE guideline	25-40% of newly diagnosed children present in DKA . Many of these have had several contacts with health care professionals Effective use of technology and digital strategies in improving clinical outcomes and patient satisfaction.-this practice was recognised as emergent published in BMJ quality reports http://qir.bmj.com/content/4/1/u209396.w3846.abstract	The increasing number of CYP with diabetes poses a major challenge for the NHS and there is increasing reports of delayed diagnosis of diabetes resulting in diabetic ketoacidosis (DKA) presentations (Lokulo-Sodipe K, 2014).	(Ali K et al 2013) showed that 30 per cent of newly diagnosed children have had at least one related medical visit prior to diagnosis, suggesting the condition is being missed by doctors Sundaram PC et al 2009 showed that common reasons for delay in diagnosis, and therefore delay in starting insulin therapy, include attempts to confirm the diagnosis in Primary care (e.g. requesting fasting blood

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
03					glucose) or instances where a CYP is referred to outpatients rather than same day referral. 1. Ali K, Harnden A, Edge JA. Type 1 diabetes in children. BMJ. 2011; 342: d294 [PMID: 21325386 DOI: 10. 1136/bmj. d294]. 2. Sundaram PC, Day E, Kirk JM . Delayed diagnosis in type 1 diabetes mellitus. Arch Dis Child 2009;94:151–2.
Education and information for CYP with type 1 and 2 diabetes					
03	Association of Children's Diabetes Clinicians	Improvement in structured education for diabetes management in CYP	Patient education and self management- the national paediatric diabetes audit and Dquins reports for all units shows significant variations in units providing structure education		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
04	JDRF	Education for people with type 1 diabetes	Diabetes education is recommended within NICE guidance. Education should be ongoing; and open to family members as well as people with type 1. The National Diabetes Audit notes that structured education 'is a key foundation of effective self-care but presently seems to be assigned low priority'.	Diabetes education is a vital part of giving people the right tools to manage their condition. However, the National Diabetes Audit found that just 2.4 per cent of people with type 1 in England and Wales have been offered the chance to participate in any form of structured education provision. This is despite clear NICE guidance stating that structured education should be 'made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on a formal, regular assessment of need'.	The National Diabetes Audit is the largest annual clinical audit in the world, integrating data from both primary and secondary care sources, making it the most comprehensive audit of its kind. The All Party Parliamentary Group for Diabetes undertook a yearlong investigation into the barriers to diabetes education: "Taking Control: supporting people to self-manage their diabetes"
05	Diabetes UK	Support for self-management, including access to self-management tools and quality-assured structured education	Structured education programmes play a vital role in developing the ability of children and young people to manage their own condition and ultimately therefore to prevent the risk of long-term complications. These must thus be supported and expanded. There must additionally be improved communication to children with	Currently only 45% of children and young people with diabetes are receiving some form of structured education steadily on an annual basis. Moreover, there is considerable variation across England – varying from only 11% in the South West to 62% in the North West. Both the significant variation and the overall average level of structured education need to increase.	The figures referred to in relation to structured education can be found in the National Paediatric Diabetes Audit Report 2013-2014, which is available online at http://www.rcpch.ac.uk/system/files/protected/page/Revised%20Sept%202

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			diabetes and their parents of all the available treatments and tools for self-management, including the newest ones, so that they can receive those that are most appropriate for them. These might include, for example, multiple daily injections, the most appropriate type of insulin, insulin pumps and continuous blood glucose monitoring.		014%20NPDA%20Report%201%20FINAL.pdf.
06	Royal College of Paediatrics and Child Health	Support for structured education and self-management tools	Structured education programmes play a vital role in developing the ability of children and young people to manage their own condition and ultimately therefore to prevent the risk of long-term complications. These must thus be supported and expanded. There must also be improved communication to children with diabetes and their parents regarding all the available treatments and tools for self-management, so that they can receive those that are most appropriate for them. These might include, for example, multiple daily injections, the most appropriate type of insulin, insulin pumps and continuous blood glucose monitoring.	Below half of children and young people with diabetes are receiving some form of structured education on an annual basis. There is considerable variation across England – varying from only 11% in the South West to 62% in the North West. Both the significant variation and the overall average level of structured education need to increase.	National Paediatric Diabetes Audit Report 2011-12 http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-paediatric-diabetes-audit-n-0

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
07	SCM5	Education and information	Education and information for children and young people with diabetes	Find out what works with CYP to help self-management, and to deliver this to them. This is notoriously poor in practice.	
Insulin therapy for children and young people with type 1 diabetes					
08	SCM1		Insulin therapy options and access to pumps is clearer and should be more accessible for CYP	Technology will lead the way to a closed loop for diabetes treatment in the future so we should be advocating for increasing technology with our CYP, Parents and diabetes MDT's.	Improving diabetes technologies are dashing ahead and it would be silly for teams to be left behind in the global market. Also our HbA1c targets are not being met with current therapy options, but pump therapy improves outcomes for most CYP.
09	Medtronic Limited	Insulin pump therapy (continuous subcutaneous insulin Infusion, CSII) for children and young people with type 1 diabetes	Insulin pump therapy has been widely demonstrated to facilitate significant reduction in HbA1c levels in people with type 1 diabetes. This therapy is included as a Key Priority Implementation within the NICE Guideline on Diabetes for Children and Young People, and therefore should be prioritised within the Quality Standard as a key area of for quality improvement.	There is robust clinical evidence on insulin pump therapy in type 1 diabetes, and this is deemed to be a cost-effective use of NHS resources (NICE TAG 151). Despite this, the uptake of insulin pump therapy in the UK has yet to reach projected targets from the NICE TA 151 (2008). The most recent Insulin Pump Audit report (2013) recorded 1,812 paediatric patients on insulin pump therapy across the UK, which is substantially below the suggested 50% of the prevalent type 1 diabetes paediatric population that NICE has suggested may benefit from this therapy (NICE TA151).	The Together for Health – A Diabetes Delivery Plan (Welsh Assembly – up to 2016) states that *"Priority #1: Children and Young People – Ensure children and young people with diabetes have the best possible start in life and are given the opportunity to fulfil their potential."* *Actions. Local Health Boards will:*

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				Further, the NICE TA151 for continuous subcutaneous insulin infusion has been endorsed in Wales, Scotland and Northern Ireland, however, access to insulin pump therapy in these regions is still very limited despite Government diabetes delivery plans prioritising this technology.	*<u>Ensure provision of an insulin pump service in line with NICE guidance"</u>* The Diabetes Improvement Plan (The Scottish Government, Nov 2014) sets out the following priorities which include a focus on insulin pump therapy: Priority #2: Type 1 Diabetes. To improve the care and outcomes of all people living with type 1 diabetes. "..only 22% of individuals with type 1 diabetes have optimal glycaemic control, defined as an HbA1c <58 mmol/mol…. We therefore need focussed activity to improve glycaemic control for all ages, aiming to support NHS Boards to increase the number of people with

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					HbA1c <58 mmol/mol and reducing the number of people with HbA1c>75 mmol/mol." Action: Improve glycaemic control: • Develop and implement strategies that promote good glycaemic control. • Implement a national improvement programme to increase the proportion of people with type 1 diabetes with optimal glycaemic control, including timely and appropriate access to insulin pumps.
10	JDRF	Access to insulin pumps	Insulin pumps have proven benefits in the management of type 1 diabetes but access is patchy across the UK. NICE Technology Appraisal 151 (2008) sets out criteria for recommending insulin pumps, and their utility in under 12s is particularly highlighted.	Insulin pumps have proven benefits in the management of type 1 diabetes but the United Kingdom Insulin Pump Audit showed that currently only seven per cent of people with type 1 have access to an insulin pump. This compares to over 15 per cent of people with type 1 in Germany and Norway and over 40 per cent in the USA. The Scottish Government has a target of 25% of young people with type 1 to be using insulin pump therapy.	See NICE Technology Appraisal 151 (2008) for guidelines. The uptake and barriers to uptake of insulin pumps in the UK is summarised in the Insulin Pump Audit.
	Royal College of	Equal access to all forms of therapy for diabetes	Diabetes care needs to be individualised to suit the needs of every child to	This will reduce the risk of long-term complications and lead to improved life expectancy.	NICE guidance NG18 pump therapy

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
11	Paediatrics and Child Health	including insulin pumps and continuous glucose monitoring.	achieve optimal control and improve life expectancy.		
12	SCM5		Insulin therapy for children and young people with type 1 diabetes	Getting more CYP on insulin pumps when they qualify under the TA.	
Dietary management for children and young people with type 1 and 2 diabetes					
13	SCM1		Carb counting from diagnosis should be the norm and include lower glycaemic information. In the Ke should aim to lower the glycaemic index routinely in everyone, not just those with diabetes to improve obesity levels and help folk to understand some of the healthier choices to improve overall health and wellbeing	Probably more trained dietitians in all CYP clinics	Look at adult DAFNE, Kick Off in Sheffield and Bertie in young adults
14	Association of Children's Diabetes Clinicians	Improvements in dietary management of diabetes in CYP	Dietary management o T1 and T2 diabetes in children The practice of level 3 carbohydrate counting from diagnosis was recommended in NICE 2015 . However, the practice remains highly variable amongst units		. It was recognised as emergent within the 2015 Diabetes QiC http://www.qualityincare.org/awards/diabetes/qic_diabetes_results/qic_diabetes_2015_results/best_dietary_management_initiative
15	SCM4	Dietary management for children and young people with type 1 diabetes – group education programme provision	Currently there is a national structured group diabetes education programmes for adults with type 1 diabetes (DAFNE) but nothing available for children. Education programmes tend to be	In house education programmes may be of variable quality, content etc. Standardising these programmes would ensure everyone is getting the same high standard of care and education provision. Also group education can be very beneficial for learning,	NICE guidance – Diabetes (type 1 and type 2) in children and young people: diagnosis and management:

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			developed and delivered in-house on an individual basis.	understanding and peer-support.	1.2.33-1.2.46 Dietary management for children and young people with type 1 diabetes. 2.1 Research recommendations: peer-led education programmes for YP with type 1 diabetes.
16	SCM4	Dietary management for children and young people with type 2 diabetes – group education programme provision	Currently there are structured group diabetes education programmes for adults with type 2 diabetes (DESMOND, X-pert) but nothing available for children.	Weight management interventions available for children but nothing specific for children/YP with type 2 diabetes. Education needed in relation to weight loss, diet and physical activity in the specific context of type 2 diabetes. Again group education sessions can be very beneficial for learning, understanding and peer support.	NICE guidance - Diabetes (type 1 and type 2) in children and young people: diagnosis and management: 1.3.1 Offer continuing programme of education from diagnosis 1.3.14-18 Advise about benefits of physical activity and weight loss, offer dietetic support to optimise body weight and blood glucose control….
17	SCM5		Dietary management for children and young people with type 1 diabetes	Ensure all CYP have full carbohydrate training from diagnosis.	
Blood glucose and HbA1c targets and monitoring for children and young people with type 1 diabetes					
	Medtronic	Ongoing real-time	Real-time continuous glucose	Severe hypoglycaemic episodes in paediatric type 1	The National Paediatric

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18	Limited	continuous glucose monitoring for children and young people with type 1 diabetes	monitoring (CGM) for children and young people with type 1 diabetes is recommended in the NICE Guideline as a Key Priority Implementation for the following patient groups: 1.frequent severe hypoglycaemia, or 2.impaired awareness of hypoglycaemia associated with adverse consequences (for example, seizures or anxiety), or 3.inability to recognise, or communicate about, symptoms of hypoglycaemia. This is an important consideration for this NICE Quality Standard because hypoglycaemia is the limiting factor in the management of diabetes, and a key concern when aiming to achieve the desired levels of glycaemic control in type 1 diabetes patients (Cryer PE. Hypoglycemia is the limiting factor in the management of diabetes. Diabetes Metab Res Rev 1999 Jan 1;15(1):42-6.). Use of CGM has been shown to improve glycaemic control in this population, with significant reductions observed in time spent in hypoglycaemia in	patients have a significant impact on both patient and parent/carer quality of life, and on healthcare resources. Hypoglycaemic episodes and subsequent hospital admissions can be avoided with the use of CGM, particularly when used in conjunction with insulin pump therapy (NICE Diagnostic Assessment Programme provisional recommendations on sensor augmented pump therapy: https://www.nice.org.uk/guidance/indevelopment/gid-dt22). Access to this technology should be therefore be highlighted as a key area for quality improvement. It is also important that the occurrence of severe hypoglycaemic episodes in children and young people is reduced as much as possible in order to avoid poor control of HbA1c due to fear of hypoglycaemia. A strong recommendation from the latest National Paediatric Diabetes Audit states that “There should be a clear emphasis on improving blood glucose control. Achieving this will reduce the future risk and progression of complications of diabetes”. Improving uptake of CGM in carefully selected paediatric patients could help to both avoid severe hypoglycaemia and the fear associated with this complication, helping with both short- and long-term glucose control.	Diabetes Audit identified 6,210 hospital admissions out of 25,199 children and young people under the age of 25 with diabetes in 2011-12. Specifically, the audit found that: • Approximately half of all hospital admissions in children with diabetes are related to acute complications including DKA and hypoglycaemia. • Nearly 1 in 10 admissions to hospital of children and young people with diabetes is as a result of a hypoglycaemic episode. Further, experts from Universities across Wales recently published hospitalisation data in children (<15 years) with type 1 diabetes (Sayers A, et al. 2015. BMJ Open;5:e005644. doi:10.1136/bmjopen-

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			paediatric type 1 patients (JDRF Continuous Glucose Monitoring Study Group. Diabetes Care 2009; Battelino, T. et al. Diabetes Care 2011, Apr 34 (4): 795 – 800).		2014-005644). The authors reported that children with type 1 diabetes were almost 5 times more likely to need hospital care than non-diabetic children, and academic group stated that money should be spent on improving ongoing care, with diagnosed cases rising 3-4% a year. In addition to the high rate of hospital admissions for DKA and hypoglycaemic episodes in this patient population, the National Paediatric Diabetes Audit also found that just 18.5% of type 1 paediatric patients were achieving an HbA1c target of <7.5% in England, and only 20.3% were achieving this target across Wales. It is clear that there is a

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19					key area for quality improvement that can be addressed by the use of CGM and insulin pump therapy in selected patient groups.
19	SCM2	Reduction in the proportion of individuals with elevated HbA1c (>75 mmol/mol)	We know that the risks of developing the long term complications of diabetes increase exponentially with increasing HbA1c levels. Reducing the relative and absolute numbers with elevated HbA1c will result in the greatest improvement in long term prospects. and to avoid >70 mmol/mol	The DCCT1 and EDIC2 studies showed unequivocally the link between HbA1c values and the risk of developing and progressing long term complications. The UK compares very poorly internationally with over 1/3 of children <15 years and over half of young people 15-24 years with HbA1c values >75 mmol/mol	Numerous DCCT and EDIC publications. 1. New England Journal of Medicine, 329(14),September 30, 1993. 2. New England Journal of Medicine 353(25), December 22, 2005. 3. JA McKnight, SH Wild, MJE Lamb et al, Diabet Med. 2015 Aug;32(8):1036-50
20	SCM2	Increase in the proportion of individuals with HbA1c <48 mmol/mol	Having an HbA1c of <48mmol/mol will significantly reduce the risk of developing long term diabetes complications. The latest NICE guideline NG15 has recommended a target HbA1c of 48 mmol/mol or less	It is recognised that shared targets (between Multi-disciplinary team members and patients) are very influential on metabolic outcomes. By having a lower HbA1c target the overall HbA1c level in a clinic population will fall including a reduction in the absolute numbers with high HbA1c values.	Swift PGF, Skinner TC, de Beaufort CE et al, for the Hvidovre Study Group on Childhood Diabetes. Pediatr Diabetes 2010: 11: 271–278. Clements SA, Anger MD, Bishop FK et al. Int J Pediatr Endocrinol 2013: 17. doi:10.1186/1687-

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					9856-2013-17
21	SCM3	Measurement of the extent to which children and young people (CYP) with diabetes achieve an HbA1c level of 48 mmol/mol (6.5%) or lower.	HbA1c is the most important measurable outcome in children and young people (CYP) with diabetes. NICE guidance now recommends that the ideal HbA1c target is 48 mmol/mol (6.5%) or below. Currently there is no way that the achievement of this target can be measured. If this can be added to the National Paediatric Diabetes Audit as an audit measure, it can be compared between centres looking after CYP with diabetes.	HbA1c levels are very variable across England and Wales (Royal College of Paediatrics and Child Health (2015) National Paediatric Diabetes Audit Report 2013-14 Part 1: Care Processes and Outcomes). Units have received funding from the Best Practice Tariff to improve care of CYP with diabetes, and the outcomes should therefore be improving.	2013-14 NPDA data (see excel spreadsheet at http://www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/national-paediatric-diabetes-au-1 - National Paediatric Diabetes Audit Report 2013-2014
22	SCM3	Appropriate screening for complications in Type 1 and Type 2 diabetes.	NICE recommendations stipulate that certain screening should be undertaken in Type 1 diabetes and also in Type 2 diabetes. Screening for complications is important as early identification can lead to treatment r secondary prevention (improvement in diabetes control).	Screening percentage is variable amongst units (see NPDA report 2013 -14, RCPCH). Screening in Type 2 is recommended for certain aspects from diagnosis, and this is not reported separately in the NPDA.	http://www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/national-paediatric-diabetes-au-1 - National Paediatric Diabetes Audit Report 2013-2014
23	JDRF	Access to Advanced Glucose	The technology for checking glucose levels is advancing rapidly, but the NHS has been slow to recognise this. New meters that give continuous readings (Continuous Glucose Monitors, CGMs),	The NHS has also been slow in its reimbursement of advanced glucose monitors, including Continuous Glucose Monitors (such as those by Abbott, Dexcomm and Medtronic) and Flash Glucose Monitors (such as Abbott's Freestyle Libre).	A literature review (2012) covered multiple studies of real time CGMs. They all identified that regular CGM use was associated

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		Meters	graphs and trend arrows make it much easier to achieve target blood glucose levels and thus reduce the chance of complications. Recent NICE guidance widens the criteria for recommending or considering CGMs but without concerted initiatives to increase uptake, NHS-funded CGM use in the UK looks likely to remain low.		with a decrease in HbA1c of between 0.5% to 1.0%, a significant improvement for people with type 1. Since this literature review CGMs have become smaller and more user friendly, negating some of the problems highlighted in the literature review.
24	SCM4	Availability of Continuous Glucose Monitoring (CGM) provision	Long-term CGM can be very useful to help individuals monitor their blood glucose levels and improve their glycaemic control.	Currently cost is an important factor limiting availability of CGM. Not all centres/services routinely use CGM. Variability in who is offered CGM - everyone should have equal opportunity to utilise this technology.	NICE guidance - Diabetes (type 1 and type 2) in children and young people: diagnosis and management: 1.2.62-64 Blood glucose monitoring. Offering CGM monitoring
25	Royal College of Paediatrics and Child Health	To achieve the best level of diabetes control by targeting blood glucose levels and keeping glycated haemoglobin (HBA1c) within NICE targets.	There are ~26,500 children and young people in England and Wales with diabetes (95% Type 1 diabetes) receiving care from 177 Paediatric Diabetes Units (PDUs). Diabetes is a chronic lifetime disease and carries considerable risk of complications and decreased life	Adverse outcomes are related to overall diabetes control. Improved diabetes control reduces this risk as demonstrated in the DCCT trial. The National Paediatric Diabetes Audit reports on HbA1c outcomes in children and young people with diabetes and hence acts as the measuring tool for any improvement in quality of care.	DCCT Trial: The Diabetes Control and Complications Trial Research Group. (1993). "The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-

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			expectancy. It remains the most common cause of end stage renal failure requiring dialysis and/or renal transplant, sight threatening retinopathy, and lower limb amputation. Risk of these complications is related to diabetes control reflected as HbA1c. In particular, there is a need to reduce the numbers of children and young people who currently have levels of blood glucose (HbA1c) which are unacceptable There are nine annual checks designed to monitor and improve the health of people with diabetes, which were proposed by NICE in its Quality and Outcomes Framework (QOF) indicator menu in 2014. The seven care processes refers to the provision of these nine yearly checks, with the exception of the serum creatinine measurement and the record of smoking status. The importance of these processes is that not only do they enable healthcare professionals to monitor and manage the care of	Despite the fact that the percentage of young people (aged between 12 and 24) who are receiving each of these seven care processes nearly doubled from 6.7% in 2011-12 to 12.1% by 2012-13, the overall completion rate remains significantly short of that for adults with Type 1 diabetes. Indeed, completion rates for eye, feet, kidney and cholesterol testing are still below 50%.	dependent diabetes mellitus". N Engl J Med. 329 (14): 977–86. EDIC trial (follow up from DCCT): New England Journal of Medicine, 353(25), December 22, 2005. National Paediatric Diabetes Audit Report 2011-12 http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-paediatric-diabetes-audit-n-0

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			children with diabetes, but they also help to reduce the risk of complications associated with diabetes.		
26	SCM5		Blood glucose monitoring	Ensure CYP have access to continuous glucose monitoring.	
27	SCM5		Blood glucose monitoring	Provide CYP with sufficient support to ensure that achieve their individual target.	
Hyperglycaemia, blood ketone monitoring and intercurrent illness in children and young people with type 1 diabetes					
28	SCM1		Access to blood ketone monitoring systems and advice on how and when to use them	Reduction in DKA admissions in existing CYP with diabetes, better self-care management, Reduction in cost of treating severe DKA	NICE 2015 looked at cost effectiveness for using blood ketone testing instead of urine ketone testing, and found it to be cost effective. Promoting self care in CYP is paramount to self-cares in young adult life
29	SCM3		Blood ketone monitoring during intercurrent illness or when insulin has been discontinued in a pump or through missed injections, is the best way to tell whether a child or young person is developing ketoacidosis. The use of ketone monitors has been shown to prevent hospitalisation during	Many centres do not provide blood ketone monitors to their patients, and rely on urine ketone testing. Not only do CYP not like doing urine tests (Laffell et al), the levels are delayed and unreliable. GPs are reluctant to provide testing strips as they go out of date more quickly than blood glucose strips, but they are very valuable in monitoring illness and providing information for diabetes HCPs to provide advice on	http://www.glucomen.co.uk/wp-content/themes/glucomen/assets/pdfs/sick_day_management_laffel_2005.pdf

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			illness. NICE has recommended that blood ketone monitors are provided as they are cost-effective.	insulin dosing.	
30	Association of Children's Diabetes Clinicians	1.Blood Ketone monitoring in times of illness and hyperglycaemia to prevent DKA 2.Ensure all children and young people with diabetes are taught how to test for bllod ketones, interpret the result ant take preventative action to prevent DKA 3.All GP's to ensure that all CYP are prescribed regular blood ketone test strips 4.All Paediatric diabetes units to have in place guidelines for managing illness that includes blood ketone monitoring 5.All Paediatric diabetes units to offer CYP and their carers access to 24hour telephone advise	Studies have confirmed that blood ketone testing is superior to urine for preventing as well as managing diabetic ketoacidosis. Patients are also less likely to test their urine for ketones than blood. A study comparing blood and urine ketone testing showed that blood ketone testing can actually lead to reduced hospital admissions	UK has a high rate of admissions for DKA. This has a negative impact on CYP as well as cost implications for the NHS	1. Klocker AA, Phelan H, Twigg SM, Craig ME. Blood beta-hydroxybutyrate vs. urine acetoacetate testing for the prevention and management of ketoacidosis in Type 1 diabetes: a systematic review. Diabetic medicine : a journal of the British Diabetic Association 2013;30:818-24. 2. Laffel LM, Wentzell K, Loughlin C, Tovar A, Moltz K, Brink S. Sick day management using blood 3-hydroxybutyrate (3-OHB) compared with urine ketone monitoring reduces hospital visits in young people with T1DM: a randomized clinical trial. Diabetic medicine : a journal of the British

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					Diabetic Association 2006;23:278-84.
Psychological and social issues in CYP with type 1 and 2 diabetes					
31	SCM1		Improved access to psychology and mental health professionals.	We need to focus on improving self-esteem in our CYP who struggle with the demands of living with diabetes, type 1 and type 2. Access should be rountine rather than wait until problems occur.	The Teens Project work looked at emotional well-being and different ages and found that the oldest group, 18-25yr olds struggle the most, then the 12-18 yr olds and the younger ones, 12-17 yrs didn’t struggle in the same way as parents or carers supported them much more. Parental and family expectations are unrealistic for many self-care needs and CYP often expect too much of themselves in times of high anxiety – exams, going to Uni, etc…
32	SCM3	Timely and ongoing access to mental health professionals for both Type 1 and Type 2 diabetes.	It is well known that CYP with diabetes are more likely to have problems with depression, eating disorders, as well as difficulties with adjustment to a chronic disease. Early intervention by mental health professionals, particularly clinics psychologists is very important and has	In the latest workforce survey of centres looking after CYP with diabetes, only 22% had easy access to mental health professionals, and this had not changed over the past 15 years. Access to psychological support and waiting times are not collected routinely as far as I am aware, except in	Arch Dis Child. 2010 Oct;95(10):837-40. doi: 10.1136/adc.2009.176925. Epub 2010 Jul 6. **The fifth UK paediatric diabetes services survey:**

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			been recommended by NICE.	workforce surveys which have been done approximately every 5 years since 1994.	**meeting guidelines and recommendations?** **Gosden C1, Edge JA, Holt RI, James J, Turner B, Winocour P, Walton C, Nagi D, Williams R, Matyka K.** **http://www.ncbi.nlm.nih.gov/pubmed/20605860**
33	Diabetes UK	Access to psychological and emotional support from appropriately trained healthcare professional with an understanding of mental health and diabetes	In general, people with diabetes are twice as likely to suffer from depression as the general population, and overall, 41% of people with diabetes report suffering from “poor psychological wellbeing”. This is a problem which applies also to children and young people with diabetes. Having Type 1 diabetes (which 96% of children and young people have) requires a routine of self-management which can be challenging and result in poor mental health experiences for many. Children, young people and their families can experience significant emotional turbulence and problems both at diagnosis of diabetes and in terms of the management required to	There continue to be significant disparities in the quality and provision of psychological support and care for children and young people with diabetes. The quality of the data itself is poor, with data missing for 45% of children and young people on the use of Child and Adolescent Mental Health Services (CAMHS), but with the proportion of those with missing data varying between 18% in the South Central region to 70% in the North East. It appears that quality data is therefore required in order to provide further analysis on the adequacy of psychological and emotional support for children and young people. The National Paediatric Diabetes Audit reports that less than 50% of children with diabetes are recorded as having an expert psychological assessment enabling access to psychological support where required.	The figures referred to in relation to CAMHS can be found in the National Paediatric Diabetes Audit Report 2013-2014, which is available online at http://www.rcpch.ac.uk/system/files/protected/page/Revised%20Sept%202014%20NPDA%20Report%201%20FINAL.pdf.

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			keep blood glucose levels within range. Psychological assessment by multidisciplinary teams of their emotional and behavioural needs is recommended to enable timely intervention and to avoid co-morbidity from depression, eating disorders or drug taking. Emotional problems can significantly curtail a family and child's ability to manage on a day to day basis and thus their ability to prevent the development of serious comorbidities later in life. Consequently, paediatric diabetes healthcare professionals should be trained to be able to deliver mental health support themselves, and they should be provided with guidelines for diagnosing and managing the most common mental health problems (namely depression, anxiety and eating disorders). Conversely, where expert psychological support is provided, those providing it should have specific experience of diabetes.		
34	Royal College of Paediatrics and Child Health	Psychological and emotional support	People with diabetes are twice as likely to suffer from depression compared to the general population. This is a problem also applying to children and	There are significant disparities in the quality and provision of psychological support and care for children and young people with diabetes. The quality of the data itself is poor, with data missing for 45% of children and	National Paediatric Diabetes Audit Report 2011-12 http://www.rcpch.ac.uk/i

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			young people with diabetes. Given that having Type 1 diabetes means there should be a routine of self-management. Unfortunately, poor mental health curtails a person's ability to do self-manage and prevent the development of serious comorbidities later in life. Therefore, paediatric diabetes healthcare professionals should be trained to deliver mental health support. They should also be provided with guidelines for diagnosing and managing the most common mental health problems (i.e. depression, anxiety and eating disorders). Conversely, where expert psychological support is provided, those providing it should have specific experience of diabetes.	young people on the use of Child and Adolescent Mental Health Services (CAMHS), but with the proportion of those with missing data varying between 18% in the South Central region to 70% in the North East. It appears that data quality and data completeness is therefore required in order to provide further analysis on the adequacy of psychological and emotional support for children and young people.	mproving-child-health/quality-improvement-and-clinical-audit/national-paediatric-diabetes-audit-n-0
35	SCM5		Psychological and social issues in children and young people with type 1 diabetes	Ensure CYP have sufficient and appropriate access to psychological support	
Monitoring for complications and associated conditions of type 1 and type 2 diabetes					
36	Institute of Child Health	Percentage of eligible children provided annual screening for diabetic eye disease	1. Diabetic retinopathy and maculopathy can lead to visual disability if left untreated 2. Retinal changes act as a marker of microvascular disease in diabetic	Although the percentage of children and young people with diabetes who receive annual eye screening is thought to have increased over the past few years, the latest National Paediatric Diabetes Audit reported that nevertheless 48% of eligible children did not undergo	Please see Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE

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			children / young people, and are a visual aid in communicating the microvascular consequences of poor glycaemic control to affected young people and their families. Current NICE guidance is that all young people over the age of 12 years with diabetes should receive an annual screening for diabetic eye disease.	eye screening during the audit period. Moreover, there is evidence of significant regional heterogeneity across the different services with the proportion recorded as having an eye screening exam during the audit period ranging from 3.1% to 97.4%	guideline NG18, which recommends annual monitoring from 12 years for diabetic retinopathy. Please see Royal College of Paediatrics and Child Health (2015) National Paediatric Diabetes Audit Report 2013-14 Part 1: Care Processes and Outcomes, which reports the completion rate for individual care processes (51.9% for eye screening). http://www.rcpch.ac.uk/system/files/protected/page/Revised%20Sept%202014%20NPDA%20Report%201%20FINAL.pdf Individual unit level aggregated data, excluding small numbers - Care processes and outcomes
	The Royal College of Ophthalmologist	Percentage of eligible children provided annual	3. Diabetic retinopathy and maculopathy can lead to visual disability if left untreated	Although the percentage of children and young people with diabetes who receive annual eye screening is thought to have increased over the past few years, the	Please see Diabetes (type 1 and type 2) in children and young people:

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37	s	screening for diabetic eye disease	4. Retinal changes act as a marker of microvascular disease in diabetic children / young people, and are a visual aid in communicating the microvascular consequences of poor glycaemic control to affected young people and their families. Current NICE guidance is that all young people over the age of 12 years with diabetes should receive an annual screening for diabetic eye disease.	latest National Paediatric Diabetes Audit reported that nevertheless 48% of eligible children did not undergo eye screening during the audit period. Moreover, there is evidence of significant regional heterogeneity across the different services with the proportion recorded as having an eye screening exam during the audit period ranging from 3.1% to 97.4%	diagnosis and management (2015) NICE guideline NG18, which recommends annual monitoring from 12 years for diabetic retinopathy. Please see Royal College of Paediatrics and Child Health (2015) National Paediatric Diabetes Audit Report 2013-14 Part 1: Care Processes and Outcomes, which reports the completion rate for individual care processes (51.9% for eye screening). http://www.rcpch.ac.uk/system/files/protected/page/Revised%20Sept%202014%20NPDA%20Report%201%20FINAL.pdf Individual unit level aggregated data, excluding small numbers - Care processes and outcomes (XLSX, 190KB)
Diabetic ketoacidosis (DKA)					
		Reduction in rate of Diabetic	Diabetic ketoacidosis (DKA) is still the	DKA at diagnosis is theoretically preventable(1) but the	(1) M Vanelli, G Chiari, L

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38	SCM2	ketoacidosis in newly diagnosed cases of diabetes	principle cause of mortality and long term morbidity in the newly diagnosed, particularly in pre-school age children	most recently available data (2) suggests that 1 in 5 children in England and Wales still present in this way. Wider awareness in the community, education system and primary care are needed.	Ghizzoni, G et al. Diabetes Care January 1999 22:1 7-9 (2) National Paediatric Diabetes Audit Report 2011-12: Part 2 February 2014
39	SCM2	Reduction in rate of Diabetic Ketoacidosis in established cases of diabetes	DKA is also the main cause of mortality in established cases of diabetes.	The incidence reflects the effectiveness of diabetes teams in supporting families to manage illness as well as young people struggling to manage their care. There is a wide variation in DKA rates across England and Wales suggesting there is much room for improvement.	National Paediatric Diabetes Audit Report 2011-12: Part 2 February 2014
40	Royal College of Paediatrics and Child Health	Reduction in Diabetic Ketoacidosis rates at diagnosis and Reduction of DKA admission rates post diagnosis	DKA at diagnosis still accounts for ~20% of newly presenting children with Type 1 diabetes. DKA is a life threatening event and also requires prolonged hospital admission and intensive therapy. DKA admissions pose a burden on families and hospitals, and are potentially life-threatening.	DKA at diagnosis is not necessary if symptoms and signs are recognised early. Public and healthcare awareness campaigns should lead to a reduction in DKA at diagnosis rates by early awareness of symptoms and early referral for treatment. The DKA rate in England and Wales in children with established diabetes is too high occuring in ~6% of individuals.	https://www.diabetes.org.uk/the4TS David M. Maahs,1 Julia M. Hermann,2 Naomi Holman,3 Nicole C. Foster,4 Thomas M. Kapellen,5 Jeremy Allgrove,6 Desmond A. Schatz,7 Sabine E. Hofer,8 Fiona Campbell,9 Claudia Steigleder-Schweiger,10 Roy W. Beck,4 Justin T. Warner,11 and Reinhard W. Holl,

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Service provision					
41	Diabetes UK	1) Provision of each of the seven care processes and the reduction in the numbers of children and young people with high HbA1c levels	There are nine annual checks designed to monitor and improve the health of people with diabetes, which were proposed by NICE in its Quality and Outcomes Framework (QOF) indicator menu in 2014. The seven care processes are the key health care essential checks that children and young people should have access to as the basis to inform care decisions, interventions and goals. In particular, there is a need to put in the support and care to reduce the numbers of children and young people who currently have levels of blood glucose (HbA1c) which are outside of range. The importance of these processes is that they enable healthcare professionals to monitor diabetes management and to inform the basis of care planning discussions to identify personal priorities and support needs to improve clinical outcomes, to help to reduce the risk of complications associated with diabetes.	Despite the fact that the percentage of young people (aged between 12 and 24) who are receiving each of these seven care processes nearly doubled from 6.7% in 2011-12 to 12.1% by 2012-13, the overall completion rate remains significantly short of that for adults with Type 1 diabetes. Indeed, completion rates for eye, feet, kidney and cholesterol testing are still below 50%. In relation to blood glucose, currently more than 25% of children and young people have blood glucose levels out of target range, and only 12% receive all of their recommended health checks. It is crucial that this changes.	Please see State of the Nation: Challenges for 2015 and beyond, https://www.diabetes.org.uk/Documents/About%20Us/What%20we%20say/State%20of%20the%20nation%202014.pdf at pages 28-29. This provides greater breakdown of the figures to which have been referred. Please see also the National Paediatric Diabetes Audit Report 2012-13, which provides further information in relation to blood glucose levels, at http://www.rcpch.ac.uk/system/files/protected/page/NPDA%202012-13%20Core%20Report%202nd%20FINAL%20v%203.3.pdf.

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			Improving the care of children and young people and support for families requires attention to be placed on ensuring that paediatric teams have the required competencies and diabetes knowledge to provide high quality and person centred care.		
42	Diabetes UK	Patient and parent involvement in the care process through care planning	It is important that the child and their parents are actively involved in making decisions about their priorities and needs and that they are able to provide meaningful input into their own care. This means being able to work with their healthcare team to create and agree a plan for how their condition will be treated, as well as being able to talk through it and ask questions they may have. Greater empowerment of the individual and their parent or carer to take ownership of managing their condition embeds a greater long-term capacity of the individual to self-manage during their lifetime.	The 2009 *Diabetes UK Children's members survey* showed that as many as 20% of young people felt that they rarely, if at all, discussed their goals for diabetes care at their check-ups. This demonstrates that there is a significant distance to go in improving the cultural and relational aspects of the healthcare system. Incorporating this issue into the quality standard would be a step in the right direction.	Please see Diabetes UK (2009), *A survey of the views and experiences of children and young people who are Diabetes UK Members: Access to and Quality of Care,* for more background into the cultural aspects to which have been referred.
43	Royal College of Paediatrics and Child Health	Patient and parent involvement in the care process	It is important that the child and their parent are actively involved in making decisions about the care received and that are able to see the importance of good management of diabetes. This involves working with their healthcare	Young people can feel that they rarely discuss their goals for diabetes care at their clinic appointments. Improvement is needed to change the cultural aspects of the healthcare system. Incorporating this issue into the quality standard would be a positive step to take.	Diabetes UK (2009), *A survey of the views and experiences of children and young people who are Diabetes UK Members: Access to and*

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			team to create a treatment plan and to ask questions they may have. Greater empowerment and ownership of the individual and their parent in the management of their condition. This will embed into a greater long-term capacity of the individual to self-manage during their lifetime.		*Quality of Care,* for more background into the cultural aspects to which have been referred.
Transition from paediatric to adult care					
44	Diabetes UK	Effective transition from child to adult diabetes services	It is imperative that all young people have access to a smooth and effective transition process between the child and adult diabetes services which they receive. This includes adult specialist and primary care services. This transition process should, therefore, be a well-coordinated multidisciplinary one which actively includes and involves both adult and paediatric teams of healthcare professionals. Moreover, it ought to be age-appropriate and centred around each individual child's needs and circumstances. This means ensuring, in particular through adequate evaluation of the young person's needs, wishes and	The transition process between child and adult diabetes services is an especially sensitive period during the lifetime of a person with diabetes. Diabetes control often deteriorates during adolescence, and furthermore, this age group is the one in which life-long health behaviours are strongly developed. Ensuring an effective transition process is thus a crucial element in the whole life-long process of embedding effective self-management. It is important to note, moreover, that around 25% of admissions for diabetic ketoacidosis are aged between 16 and 25. It is thus especially important that this issue be addressed through an improved transition process.	Please see the National Paediatric Diabetes Audit Report 2011-12, which provides further information in relation to the issue of diabetic ketoacidosis, at http://www.rcpch.ac.uk/system/files/protected/page/NPDA%202011-12%20compreport.v5%20FINAL.pdf.

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			abilities, that it does not occur until the young person possesses sufficient understanding and ability about self-management in order to optimise their ability to use adult diabetes services. The adverse consequences of moving to adult services without a proper transitionary process risks young people disengaging from these services, thus leading ultimately to both poor self-management of diabetes and possible long-term comorbidities.		
45	Royal College of Paediatrics and Child Health	Effective transition from child to adult diabetes services	All young people should have access to a smooth and effective transition process between the child and adult services for their diabetes This transition process should be a well-coordinated multidisciplinary, involving both adult and paediatric teams of healthcare professionals. It needs to be age-appropriate and centred around the individual young person. This should not occur too young, but can start when the young person possesses sufficient clinical understanding about how to manage their condition in order to optimise their ability to use adult diabetes services.	The transition process between child and adult diabetes services is an especially sensitive period during the lifetime of a person with diabetes. Diabetes control often deteriorates during adolescence, and furthermore, this age group is the one in which life-long health behaviours are strongly developed. Ensuring an effective transition process is thus a crucial element in the whole life-long process of embedding effective self-management. It is important to note, moreover, that around 25% of admissions for diabetic ketoacidosis are aged between 16 and 25. It is thus especially important that this issue be addressed through an improved transition process.	National Paediatric Diabetes Audit Report 2011-12 http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-paediatric-diabetes-audit-n-0

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			The adverse consequences of an inability to carry out such a transition process include the risk that the young person will disengage from these services, thus leading ultimately to both poor self-management of diabetes and possible long-term comorbidities.		
46	Institute of Health and Human Development, University of East London		Transition from children to adult services should be a gradual transition rather than being a one-off event, as well as providing a patient personal plan.	In place, should be a gradual transition process supported by a personalised plan. The whole transition process should begin slowly from the age of 16/17. This should ensure that change is not as sudden as it currently is. Especially because during the 16-19 age range there's a lot of big changes going on in a young person's life. The young person should be able to meet all clinicians before their adult appointment. A recommended number of three joint meetings involving both teams should be offered. Young person should also be given options as to when they begin transition. From the age of around 14 young people should start the pre-transition plan and should be made aware of what transitioning is and they should slowly be provided with necessary information to promote independence. Such as starting private appointments. A checklist should be offered to ensure that young person is maintaining good health before they are ready to transition.	Newham CCG Commissioning Intention Letter drafted October 2015 and CLAHRC North Thames Youth Diabetes Project evaluation report (in preparation).
Additional areas					

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47	HQT Diagnostics	General Practitioners should test for Fatty Acids and supplement to achieve: • **Omega-3 Index: >8%** • **Omega-6/3 Ratio: <3:1** Re-test after 3 months to confirm Fatty Acid levels and other standard tests for Diabetes	This is being used widely in Germany by clients of HQT Diagnostics to ***treat*** both Type1 and Type2 Diabetes	Omega-3 Poly Unsaturated Fatty Acids (PUFA) are involved in glucose level control and insulin sensitivity	More at: www.expertomega3.com/omega-3-study.asp?id=2 http://www.omegametrix.eu/wasistomega3index.html?lang=EN http://www.omegaquant.com/omega-3-index/ www.hqt-diagnostics.com www.sanomega.de http://greenvits.eu/pages/omega-3
48	HQT Diagnostics	General Practitioners should test and supplement 25(OH)D to between 100-150 nmol/L for all Diabetes patients and review blood tests after 3 months GPs should also test levels of Magnesium and Calcium	Vitamin D - with co-factors such as Calcium and Magnesium – appears to both prevent and treat Diabetes	Vitamin D is a significant factor in insulin sensitivity	More at: www.vitamindwiki.com/Overview+Diabetes+and+vitamin+D http://greenvits.eu/pages/vitamin-d
49	SCM3		Treatment other than insulin or metformin in Type 2 diabetes should be considered. This is not recommended by NICE because there is a lack of evidence, but some young people may be treated with other agents. This	Delayed diagnosis of diabetes is more likely to lead to hospitalisation for DKA, with extra costs to the NHS and to families and patients, with the risk of death. The incidence of delayed diagnosis should be recorded and relayed to General Practices.	http://adc.bmj.com/content/early/2014/01/06/archdischild-2013-304818

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			should be recorded and evidence used to inform further recommendations. Secondly the incidence of delayed diagnosis of Type 1 diabetes should be recorded. Children are still being offered inappropriate investigations such as fasting blood glucose levels, oral glucose tolerance tests by primary care, which just delays effective treatment, resulting in DKA in many cases.		
50	Diabetes UK	2) Compliance by schools of new legal duties	Pursuant to the Children and Families Act 2014, there are a set of new legal obligations on schools to provide support to children with Type 1 diabetes. This includes establishing an education, health and care plan for each child with diabetes and having a medical conditions policy at each school. These legal obligations are crucial in ensuring that children and their parents are empowered to manage the condition and access the necessary help at an early stage. The Children and Families Act 2014 was only given Royal Assent in March 2014 and is therefore a new development. Local authorities, together with the Department for Education, need to ensure that all schools are aware of	In order to ensure that these legal obligations work effectively and consistently, it is important that the awareness of them is promoted and their enforcement is made possible. Given the direct causal proximity between these legal obligations and the quality of care which individual children are able to receive, it is a key area for quality improvement.	

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			these new legal obligations and that they understand what they mean in practice. OFSTED inspections should, moreover, check school's compliance of them.		
51	Royal College of Paediatrics and Child Health	Reduction of variability in outcomes for children with diabetes by sharing of good practice through regional and national networks.	The NPDA recognises large variation in clinical outcomes for children with diabetes across England and Wales. This is unacceptable and needs close collaboration between centres of care to improve outcomes.	Outcomes are related to on-going risk of complications and reduced life expectancy.	National Paediatric Diabetes Audit Report 2011-12 http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-paediatric-diabetes-audit-n-0
52	Royal College of Paediatrics and Child Health	Peer review of services	This is important for benchmarking and sharing best practice, leading to effective quality improvement	This will lead to the reduction of variability by sharing of good practice through regional and national networks.	
53	Institute of Health and Human Development, University of East London		Young patients with diabetes need to experience good relationships with all members of their health care team in order to maintain and improved self-care. The three key focuses are on private appointments or slots, clinicians learning from DNS on how to broker a youth-centred dialogue - which addresses the whole person - and patients having on-going invitations to talk with a psychologist and not just at	Young patients with diabetes can experience delays in developing self-care skills due to not being encouraged to attend appointments on their own and betiding and testing self-advocacy skills. Clinicians should initiate these marked step towards independence by providing a slot for one-to-one discussion in patient's appointments. The patient must feel confident that doctors will maintain confidentiality – where appropriate. Also, a private appointment with psychologist should be offered at key phase in the patient's treatment and offered more than once around	Newham CCG Commissioning Intention Letter drafted October 2015 and CLAHRC North Thames Youth Diabetes Project evaluation report (in preparation).

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			the point of diagnoses.	the time of diagnoses.	
54	Institute of Health and Human Development, University of East London		Virtual clinics are recommended to supplement annual hospital appointments. Periodic hospital appointments can be made quicker (able to ask questions whenever), or avoided all together by the use of ICT, which is more convenient and practical for patients.	Valuable school time is being lost each year due to attending hospital appointments. Appointments are generally hospital based and the date and time is out of the control of patients. The time spent waiting is often disproportionate to the time spent with the clinician. Skype and other social media platforms can be used to effectively carry out virtual clinics. It is not recommended that Skype appointments replace annual appointments. The negative side to virtual clinics maybe less personal contact with the health care team and no or slow wifi connection for some patients.	Newham CCG Commissioning Intention Letter drafted October 2015 and CLAHRC North Thames Youth Diabetes Project evaluation report (in preparation).
55	Institute of Health and Human Development, University of East London		Peer educator. This is a user led support network to provide support, education and model good self-care.	Peer educators would help to decrease isolation and stigma among young people with debates and promote good self-care. Peer educators should be brokered through the health care team who would connect patients who are going through the same course of treatment and/or at different stages in managing their condition. Additionally, peer educators would work to deliver public education campaigns to help tackle the social stigma around diabetes.	Newham CCG Commissioning Intention Letter drafted October 2015 and CLAHRC North Thames Youth Diabetes Project evaluation report (in preparation).
56	SCM1		Fear of hypos in CYP is a major barrier to improving HbA1c and trying to reach new BG targets pre and post meals.	This is the bit of NICE that others get cross about in diabetes teams. My worry is that if we don't expect higher standards of ourselves as healthcare professionals and our CYP, then there is little drive to improve glucose control and try to limit long term effects of diabetes. It is not too late to change practice and be more positive about setting higher targets to achieve.	Look at Julie Edge's Oxford data where the paeds team there hold very high standards and set goals right from day 1 rather than setting lower targets that HCP feel the family and child can

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					achieve. You then have to move the goal posts when targets become stricter and this makes new goals harder to achieve. Folk with diabetes are doomed to fail if they don't believe their team is behind them to aim higher.
57	SCM 1		Think about having somebody who actually works in a school – both primary and secondary to join the group as CYP spend most of their days in school. These people would bring a new perspective to our discussions.		
58	SCM3	Offering Multiple Daily Injection regimens from diagnosis together with level 3 carbohydrate counting (defined as defined as carbohydrate counting with adjustment of insulin dosage according to an insulin:carbohydrate ratio)	This is the insulin regimen which provides the most physiological replacement of insulin and therefore should result in the most optimal control of blood glucose levels. Children starting on a multiple daily insulin regimen need their families to learn how to count carbohydrate in order to match the insulin dose with food, to keep blood glucose levels as normal as possible.	Many centres do not offer this insulin regimen from diagnosis. Twice and three-times daily insulin regimens are not likely to result in optimal blood glucose levels. The regimen offered at diagnosis is not currently reported anywhere. If insulin doses are provided by the diabetes health professionals, and there is no link to food consumed, then blood glucose levels will not be stable or optimal. This again is very variable in services, with some teaching it to all patients as soon as the child is	The NPDA should be able to work out from the insulin regimen data, and the diagnosis date, which regimen is provided from diagnosis. But carbohydrate counting is not currently a collected data item.

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			Although these are two separate recommendations from NICE, they need to be considered together as a quality standard.	diagnosed, and others delaying because of perceived difficulties, or lack of trained dietitians. Unfortunately the data on carbohydrate counting would not be easy to collect except as an add-on to the national diabetes audit, or other survey of units. It should be added as a measure to Peer Review if this is going to continue.	
59	NHS England	An obvious first comment - 7 of the 10 source documents relate to risk of Type 2 diabetes and the associated lifestyle issues.	In fact 95% of children and young people up to age 18 have Type 1 diabetes, not Type 2 diabetes.		