



National Paediatric Diabetes Audit Core Dataset

(Revised dataset to be collected from 1st April 2017)



















<u>Introduction</u>

This document contains details of the core NPDA dataset to be collected from the 1st April 2017, and replaces the dataset in use since 2012/13. The dataset has been revised following publication of new guidance issued by the National Institute for Health and Care Excellence (NG18) in 2015. The majority of data items remain unchanged but there are a number of new items and some items have been amended in light of the new guidance. Some of the new items also cover Best Practice Tariff (BPT) requirements. Although the Best Practice Tariff does not apply to Welsh Paediatric Diabetes Units (PDUs), its requirements are considered to represent good practice in Wales and form part of Quality Assurance standards. This new dataset contains fewer items than were previously collected, as some aspects of care will be audited separately in more detail as part of additional 'spotlight audits' over the next few years.

The dataset is split into four sections:

- Patient information
- Routine measurements
- Annual review/diagnosis
- In-patient entry

Permitted values are provided for every data item listed, along with a justification/reference for inclusion of the item within the dataset and guidance notes in some cases. The data item names will correspond with the column headers within the CSV template for submitting data to the audit from 2017.

If you have any queries about the dataset please do not hesitate to contact the NPDA.

Tel: 020 7092 6157

Email: npda@rcpch.ac.uk

	Data item name	Permitted Values	Notes	Justification / Standard
1	NHS Number	10 digit numeric		This is a unique identifier and necessary to collect for linkage analysis with other databases such as Hospital Episode Statistics (HES) for England and the Patient Episode Database for Wales (PEDW).
2	Date of Birth	Format: DD/MM/YYYY		Full D.O.B. is required to calculate an accurate decimal age for each patient. This allows interpretation of data collected on height, weight, calculated BMI and BP since these are age and gender specific. This also allows casemix adjustment.
3	Postcode of current address	The patient's full postcode	Enter the postcode in upper case and with a space in the correct place i.e. 'E13 ORJ'.	This allows analysis of the effect of deprivation on outcome measures and analysis of population statistics.
4	Gender	1 = Male 2 = Female 3 = Not specified 99 = Unknown	'Not Specified' means indeterminate, i.e. the patient is unable to be classified as either male or female. 'Unknown' means that the sex of the patient has not been recorded.	To allow analysis of the effect of gender on outcomes and for interpretation of height, weight, calculated BMI and BP collected data. This also allows case-mix adjustment.





	Data item name	Permitted Values	Notes	Justification / Standard
5	Ethnic Category	A = White - British B = White - Irish C = White - Any other White background D = Mixed - White and Black Caribbean E = Mixed - White and Black African F = Mixed - White and Asian G = Mixed - Any other Mixed Background H = Asian - Indian J = Asian - Pakistani K = Asian - Bangladeshi L = Asian - Any other Asian background M = Black - Caribbean N = Black - African P = Black - Any other Black background R = Chinese S = Other - Any other ethnic group Z = Not stated 99 = Not Known	Ethnicity should be self-reported by the family. The Information Standards Board for Health and Social Care Dataset Change Notice (DSCN) 11/2008 states: "the national code of 'Z- not stated' means that the person had been asked and had declined, either refusing to provide this information, or a genuine inability to choose, and should only be used in this circumstance and not to represent an unknown ethnicity. 'Not Known' should be used where the patient had not been asked or the patient was not in a condition to be asked, e.g. unconscious. If the ethnic category is 'Not Known' use code 99. In some hospitals this information is collected at registration and recorded on your Patient Management System (PMS). Therefore, this data should be available to you.	Necessary to examine the influence of ethnic origin on outcomes. Also allows for case-mix adjustment.







	Data item name	Permitted Values	Notes	Justification / Standard
6	Diabetes Type	1 = Type 1 Insulin-Dependent Diabetes Mellitus 2 = Type 2 Non-Insulin Dependent Diabetes Mellitus 3 = Cystic Fibrosis Related Diabetes 4 = MODY (monogenic forms of diabetes) 5 = Other specified Diabetes Mellitus 6 = Unknown/unspecified	If you are unable to classify your patient into any of the categories 1-4: Use category 5 where there is a recognised cause of diabetes (e.g. post organ transplantation, steroid induced diabetes, post pancreatitis/pancreatectomy) or related to a syndrome (e.g. Prader Willi or Lawrence Moon Biedl Syndrome). Use code 6 when the patient has diabetes but the cause is unknown.	Important to know about the heterogeneity of diabetes in children and young people.
7	Date of Diabetes Diagnosis	Format: DD/MM/YYYY	If you are unable to classify your patient's diagnosis date as they were diagnosed elsewhere and exact date cannot be ascertained, insert the first day in the month of diagnosis and year. E.g. diagnosed in March 2014, enter 01/03/2014.	Will allow accurate analysis of age bands. Will allow data from newly diagnosed patients to be analysed independently. Accurate date of diagnosis is required to provide relationships of outcome with duration of diabetes, and permits case-mix adjustment.
8	Date of leaving service	Format: DD/MM/YYYY	Enter date if patient left the service during the audit year otherwise leave blank.	
9	Reason for leaving service	1 = Transitioned to adult diabetes service 2 = Moved out of area 3 = Other	Enter reason for leaving if patient has left your service during the audit year.	
10	Death Date	Format: DD/MM/YYYY	Mandatory if patient dies from any cause in audit year.	This is important information to collect to establish mortality rates in children and young people with diabetes.







	Data item name	Permitted Values	Notes	Justification / Standard
11	GP Practice Code	Format X99999, where X can be A-H, J-N, P	You can download GP Practice code data here: Once you have downloaded and opened this XLS file you will see that the GP Practice Codes are listed in Column A. You are able to search the Excel file by selecting Ctrl + F and can search for PCT Name, Senior Partner name, Address, Postcode etc. to look for the relevant GP Practice Code.	Necessary to produce an atlas of variation for outcomes for GP practices across England and Wales and for reporting at CCG level in England and Health Board level in Wales.
12	PDU Number	Format: 000 (3 digit numeric)	This is the number used on your NPDA registration form as in previous years (previously PZ XXX) and is on your NPDA log in. If you do not know your organisation code, please find it here on the NPDA website under 'PDU number'.	





ROUTINE MEASUREMENTS

	Data item name	Permitted Values	Notes	Justification / Standard
13	Visit Date	Format: DD/MM/YYYY	Defines a row of data by a visit date. N.B. the date of any care process or outcome measure within a row may not always be identical to the visit date.	
14	Patient Height (cm)	Format: 999.9 cm	At least one height/weight measurement should be recorded	NG18: 1.2.45 At each clinic visit for children and young people with type 1 diabetes measure height and weight
15	Patient Weight (kg)	Format: 999.9 kg	during the audit year. BMI will be calculated centrally. Combined observation date for height and weight. If only height or weight measured still enter date.	and plot on an appropriate growth chart. Check for normal growth and/or significant changes in weight because these may reflect changes in blood glucose control. [2004, amended 2015] NG18: 1.3.20 At each clinic visit for children and young people with type 2 diabetes: • measure height and weight and plot on an appropriate growth chart
16	Observation Date (Height and weight)	Format: DD/MM/YYYY		 calculate BMI. Check for normal growth and/or significant changes in weight because these may reflect changes in blood glucose control. [2004, amended 2015]
17	HbA1c Value	Format: 99.9	Collect and submit ALL the measurements with dates taken throughout the audit cycle. Use a new row for each with visit date for each measurement.	By providing ALL measurements of HbA1c a more powerful data analysis can be performed centrally. Allows means/median values for the year to be calculated. Data from first 3 months following diagnosis should be supplied but will be analysed independently as early measurements of HbA1c are not representative of overall diabetes control.
18	HbA1c result format	1 = mmol/mol 2 = Percentage (%)	Values in either mmol/mol or % will be accepted.	NG18: 1 1.2.71 Offer children and young people with type 1 diabetes measurement of their HbA1c level 4 times a year
19	Observation Date: HbA1c Value	Format: DD/MM/YYYY	Date performed (within the audit year) is mandatory if observation value provided is to be accepted.	(more frequent testing may be appropriate if there is concern about suboptimal blood glucose control). NG18: 1.3.28 Measure HbA1c levels every 3 months in children and young people with type 2 diabetes.







ROUTINE MEASUREMENTS

	Data item name	Permitted Values	Notes	Justification / Standard
20	Diabetes Treatment at time of HbA1c measurement	1 = One - three injections/day 2 = Four or more injections/day 3 = Insulin pump 4 = One - three injections/day plus other blood glucose lowering medication 5 = Four or more injections/day plus other blood glucose lowering medication 6 = Insulin pump therapy plus other blood glucose lowering medication 7 = Dietary management alone (no insulin or other diabetes related medication) 8 = Dietary management plus other blood glucose lowering medication (non Type-1 diabetes) 99 = Unknown	Enter the treatment at the time of the visit for all types of diabetes. Options 1-6 usually will relate to children and young people with Type 1 diabetes. Options 7-8 usually will relate to children and young people with non-Type 1 diabetes.	Important to get information that can relate intensification of insulin regimen to diabetes outcomes.
21	Was the patient using a real-time continuous glucose monitor (CGM) with alarms at this visit date?	1 = Yes 2 = No 99 = Unknown	Please do <u>not</u> enter 'Yes' if the patients is using flash glucose monitoring.	Collected for national monitoring of usage. NG18: 1.2.62 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).







	Data item name	Permitted Values	Notes	Justification / Standard
22	Systolic Blood Pressure	Format: 999 mm Hg	Mandatory for Blood Pressure care process completion. Enter Systolic BP and Diastolic BP (if collected) Please use the methodology from the Diagnosis, Evaluation, and Treatment of High Blood Pressure in Children and Adolescents Report	To assess cardiovascular risk. NG18: 1.2.110 Offer children and young people with type 1 diabetes monitoring for: hypertension annually from 12 years. NG18: 1.3.43 Offer children and young people with type 2 diabetes annual monitoring for: hypertension starting at diagnosis.
23	Diastolic Blood pressure	Format: 999 mm Hg	if performed.	
24	Observation Date (Blood Pressure)	Format: DD/MM/YYYY	Provide an observation date within the audit period. Date relates to both the systolic AND/OR diastolic pressure measurement.	
25	Foot Assessment/ Examination Date	Format: DD/MM/YYYY	Complete only if screen performed. Mandatory care process if 12 years or older.	NG19: 1.3.2 For young people with diabetes who are 12-17 years, the paediatric care team or the transitional care team should assess the young person's feet as part of their annual assessment, and provide information about foot care. If a diabetic foot problem is found or suspected, the paediatric care team or the transitional care team should refer the young person to an appropriate specialist.
26	Retinal Screening date	Format: DD/MM/YYYY	Complete only if screen performed. Mandatory care process if 12 years or older	NG18: 1.2.110 Offer children and young people with type 1 diabetes monitoring for: diabetic retinopathy annually from 12 years
27	Retinal Screening Result	1 = Normal 2 = Abnormal 99 = Unknown	Provide a result for retinal screening only if screen performed. Abnormal is defined as any level of retinopathy in either eye.	NG18: 1.3.43 Offer children and young people with type 2 diabetes annual monitoring for: • diabetic retinopathy from 12 years •







	Data item name	Permitted Values	Notes	Justification / Standard
28	Urinary Albumin Level	Format 9999.9	Mandatory for children with type 1	Albuminuria is a marker for future microvascular
29	Observation Date: Urinary Albumin Level	Format: DD/MM/YYYY	diabetes aged 12 years and above and optional before 12 years.	complications and early mortality but is rare during pre- puberty. Its presence requires intensification of both monitoring and diabetes therapy which can result in lower
30	Albuminuria Stage	1 = Normoalbuminuria 2 = Microalbuminuria 3 = Macroalbuminuria 99 = Unknown	Mandatory for children with type 2 diabetes from diagnosis. Provide and observation date if a value provided. Submit your interpretation of the urinary albumin level based on your local laboratory reference ranges. Mandatory if level submitted.	albuminuria levels and reduced risk of future complications. NG18: 1.2.110 Offer children and young people with type 1 diabetes monitoring for moderately increased albuminuria (albumin:creatinine ratio [ACR] 3-30 mg/mmol; 'microalbuminuria') to detect diabetic kidney disease, annually from 12 years . NG18: 1.3.43 Offer children and young people with type 2 diabetes annual monitoring for moderately increased albuminuria (albumin:creatinine ratio [ACR] 3-30 mg/mmol; 'microalbuminuria') to detect diabetic kidney disease, starting at diagnosis. Necessary to determine national prevalence of albuminuria.
31	Total Cholesterol Level (mmol/l)	Format 99.9 mmol/l	Mandatory only for children with type 2 diabetes annually from	NG18: 1.3.43 Offer children and young people with type 2 diabetes annual monitoring for dyslipidaemia starting at
32	Observation Date: Total Cholesterol level	Format: DD/MM/YYYY	diagnosis. Entry for patient with type 1 s is optional and will not be included as an essential care process but will be reported as an outcome measure. Report if performed. Observation date mandatory if value provided.	diagnosis.







	Data item name	Permitted Values	Notes	Justification / Standard
33	Observation Date: Thyroid Function	Date: (format DD/MM/YYYY)	This measure is for all children with type 1 diabetes annually. Mandatory to provide an observation date if performed.	Monitoring for complications and associated conditions of type 1 diabetes NG18: 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 (NG18).
34	At time of, or following measurement of thyroid function, was the patient prescribed any thyroid treatment?	1 = No thyroid therapy 2 = Thyroxine for hypothyroidism 3 = Antithyroid medication for hyperthyroidism 99 = Unknown	Mandatory if thyroid testing performed,	Thyroid treatment allows prevalence of thyroid autoimmunity associated with Type 1 diabetes to be calculated.
35	Observation Date: Coeliac Disease Screening Has the patient been recommended a Gluten-free diet?	Format: DD/MM/YYYY 1 = Yes 2 = No 99 = Unknown	Date of coeliac disease screening only to be completed if patient was diagnosed within audit year. Process complete if date is within 90 days of diagnosis for patient with Type 1 diabetes. Provide dietary status for all patients: A 'yes' response will be interpreted as the patient having a diagnosis of coeliac disease. Dietary status should be reported for every patient within each audit year to allow prevalence of coeliac disease to be calculated.	NG 20: 1.1.1 Offer serological testing for coeliac disease to people with: Type 1 diabetes, at diagnosis.







	Data item name	Permitted Values	Notes	Justification / Standard
37	Observation Date - Psychological Screening Assessment	Format: DD/MM/YYYY	The absence of a date will be taken to indicate assessment for need of psychological support outside of MDT clinics has not taken place.	Regular assessment of a broad range of psychological and behavioural problems in children and adults with type 1 diabetes is recommended. SIGN Guideline 16: In children this should include eating disorders, behavioural, emotional and family functioning problems (Management of diabetes, p5). NG18: 1.2.94. Diabetes teams should be aware that children and young people with type 1 diabetes have a greater risk of emotional and behavioural difficulties.
38	Was the patient assessed as requiring additional psychological/CAMHS support outside of MDT clinics?	1 = Yes 2 = No 99 = Unknown	Applicable if patient was assessed to require ongoing psychological/CAMHS support.	NG18: 1.2.95 Offer children and young people with type 1 diabetes and their family members or carers (as appropriate) emotional support after diagnosis, which should be tailored to their emotional, social, cultural and age-dependent needs. [2004] NG18: 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] NG18: 1.2.97 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] NG18: 1.2.98 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]







	NG18: 1.3.37 Offer children and young people with 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]



	Data item name	Permitted Values	Notes	Justification / Standard
39	Does the patient smoke?	1 = Non-smoker 2 = Current smoker 99 = Unknown	Enter smoking status of the patient.	Smoking plays a significant contribution to micro and macrovascular disease development. Important to ascertain prevalence of smoking amongst the diabetic population.
40	Date of offer of referral to smoking cessation service (if patient is a current smoker)	Format: DD/MM/YYYY	Leave blank if not made.	NG18: 1.2.14 Offer smoking cessation programmes to children and young people with type 1 diabetes who smoke. See also the NICE guidelines on brief interventions and referral for smoking cessation, smoking cessation services, harm reduction approaches to smoking, and smoking cessation in secondary care. [2004, amended 2015] NG18: 1.3.10 Offer smoking cessation programmes to children and young people with type 2 diabetes who smoke. See also the NICE guidelines on brief interventions and referral for smoking cessation, smoking cessation services, harm reduction approaches to smoking, and smoking cessation in secondary care. [2004, amended 2015]
41	Date Level 3 carbohydrate counting education received	Format: DD/MM/YYYY	Level 3 carbohydrate counting is defined as carbohydrate counting with adjustment of insulin dosage according to an insulin:carbohydrate ratio. Enter date when provided. To be reported for patients diagnosed with type 1 diabetes during the audit year. If no date entered during the audit year then an assumption of incomplete care process will be made.	NG18: 1.2.37 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. Will be reported for patients diagnosed within audit year.







	Data item name	Permitted Values	Notes	Justification / Standard
42	Was the patient offered an additional appointment with a paediatric dietitian?	1 = Yes 2 = No 3= Not known	The additional appointment could be 1:1 or a group session.	BPT indicator: Each patient should be offered at least one additional appointment per year with a paediatric dietitian (outside of the MDT clinic) with training in diabetes (or equivalent appropriate experience).
43	Date of additional appointment with dietitian	Format: DD/MM/YYYY	Leave blank if appointment not attended.	
44	Was the patient using (or trained to use) blood ketone testing equipment at time of visit?	1 = Yes 2 = No 99 = Unknown	Type 1 diabetes only	NG18: 1.2.74 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.
45	Date that Influenza immunisation was recommended	Format: DD/MM/YYYY	If no date entered during the audit year then an assumption of incomplete care process will be made.	NG18: 1.2.16 Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that the Department of Health's Green Book recommends annual immunisation against influenza for children and young people with diabetes over the age of 6months. [2004] NG18: 1.3.12 Explain to children and young people with type 2 diabetes and their family members or carers (as appropriate) that the Department of Health's Green Book recommends annual immunisation against influenza for children and young people with diabetes. [2004, amended 2015]







	Data item name	Permitted Values	Notes	Justification / Standard
46	Date of provision of advice ('sick-day rules') about managing diabetes during intercurrent illness or episodes of hyperglycaemia	Format: DD/MM/YYYY	Applies to patients with type 1 and type 2 diabetes. If no date entered during the audit year then an assumption of incomplete care process will be made.	NG18: 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 inter-current illness or episodes of hyperglycaemia, including: • monitoring blood glucose • monitoring and interpreting blood ketones (betahydroxybutyrate) • 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. NG18: 1.3.1 Offer children and young people with type 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: • HbA1c monitoring and targets • the effects of inter-current illness on blood glucose control • the aims of metformin therapy and possible adverse effects • the complications of type 2 diabetes and how to prevent them .





IN-PATIENT ENTRY

	Data item name	Permitted Values	Notes	Justification / Standard
47	Date of Admission	Format: DD/MM/YYYY	Please enter every hospital admission the patient has had (day case or longer) on separate rows. These should include admissions for stabilisation of diabetes (at diagnosis and/or in established patients), DKA (new and/or established patients), ketosis without acidosis, hypoglycaemia, surgical procedures or other causes.	
48	Date of Discharge	Format: DD/MM/YYYY		For calculating number of bed days.
49	Reason for admission	1 = Stabilisation of Diabetes 2 = DKA 3 = Ketosis without Acidosis 4 = Hypoglycaemia 5 = Surgical Procedures 6 = Other causes		Important to know why a child is admitted to hospital for reasons of having diabetes but not related to DKA or hypoglycaemia. Also to record incidence of DKA and hypoglycaemia complications. With Best Practice Tariff it is envisaged that this type of admission will decrease and this is of interest to commissioners.
50	Only complete if DKA selected in previous question: During this DKA admission did the patient receive any of the following therapies?	 1 = Hypertonic saline 2 = Mannitol 3 = Bicarbonate infusion 4 = None of the above 	Mandatory only if 'DKA' selected as Reason for admission.	
51	Only complete if OTHER selected: Reason for admission (free text)		Mandatory only if 'Other causes' selected as Reason for admission.	





REFERENCES

- 1. Best Practice Tariff Criteria, Randell (2012)
- 2. NG18: Diabetes (type 1 and type 2) in children and young people: diagnosis and management. NICE (2015)
- 3. NG19: Diabetic foot problems: prevention and management. NICE (2015)
- 4. NG20: Coeliac disease: recognition, assessment and management. NICE (2015)
- 5. Sign Guideline 116: Management of Diabetes (2010)