

National Paediatric Diabetes Audit

Notes on Data Analysis for Audit Year 2016-17

**Document produced by the NPDA for all participating Paediatric
Diabetes Units in England and Wales**

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Introduction

This document has been prepared to aid understanding of the analysis and preparation of NPDA data. The data received by the NPDA from each submitting Paediatric Diabetes Unit (PDU) is analysed under the same rules. This makes the NPDA a powerful tool for benchmarking local and national PDUs. It is inevitable that there will be small differences in NPDA calculations compared to unit level data analysed locally as the same rules may not be applied to data cleaning and analysis.

Inclusion criteria for the audit

For a patient to be included in the analysis, they must:

- have a valid NHS number
- have a valid and consistent date of birth
- be allocated to a registered PDU, and
- be below the age of 25 on the first day of the audit year.

Records are also excluded if the visit date is missing, invalid or outside of the audit cycle, i.e. the period 1 April 2016 to 31 March 2017.

Pseudonimisation

Before analysis, all duplicate rows of data are removed and all patient identifiable information is pseudonymised. This process involves:

- converting NHS numbers to a pseudo-code,
- converting postcodes to lower super output areas (LSOA)
- converting date of birth to the number of whole weeks since a specified date (known only to the NDPA analysis team), and
- converting date of death to the number of whole weeks since a specified date (known only by the NDPA analysis team).

Demographic data

The table below summarises the rules applied to demographic data.

Variable	Rules applied
Date of birth	Where more than one date of birth was recorded for an individual, the most common was applied across all records. Records without a valid or consistent date of birth were recoded as 'missing'.
Sex	Where an individual was recorded as both male and female, the most common was applied. If the inconsistency could not be resolved the gender was changed to 'unknown'.
Ethnicity	Where some records indicted the ethnic group of a patient as unspecified but another record for the same individual specified an ethnicity, this ethnicity was applied. Where an individual was recorded as having two or more ethnic groups the most common was applied across all records. If the inconsistency could not be resolved the ethnicity was considered 'missing'.
Diabetes Type	Where there were inconsistent diabetes types recorded for a patient, the more specific type of diabetes was used to replace the less specific types (e.g. Type 1 diabetes replaces not specified). If the inconsistency could not be resolved, the diabetes type was considered 'not specified'.
Diagnosis date	If more than diagnosis date was recorded, the earliest diagnosis date provided for each patient was used. If the diagnosis date was invalid or missing, the patient pseudo-key was used to check if a valid diagnosis date was recorded for the patient in the previous audit year. If no valid diagnosis date was found, diagnosis date was recorded as 'missing'.
PDU	If a patient received care from more than one PDU within the audit period, their data were attributed to the last PDU at which they received care.
LSOA	If a patient was recorded as living in more than one LSOA within the audit period, they were allocated to their last known LSOA within the audit year.
Deprivation quintile	Deprivation data was based on the Indices of Multiple Deprivation (IMD) for England and Wales, with a score calculated from the lower super output area.
GP practice code	If a patient attended more than one GP practice within the audit period, they were attributed to the last GP practice that they attended within the audit year.
Region and country	Patients were assigned to the region and country of the last PDU that they received care from, rather than their region or country of residence.
Clinical Commissioning Group	Patients were assigned to a clinical commissioning group according to their GP practice code, or the CCG associated with their postcode if GP code was unavailable.
Sustainability & transformation partnership	Patients were first assigned to a sustainability and transformation partnership (STP) according to their CCG.

Completion of health checks (care processes)

There are several healthcare checks recommended by NICE for children and young people with Type 1 diabetes (NG18, NICE 2015; NG19, NICE 2015) that should be performed at least once annually. The NPDA considers seven of these to be essential annual checks:

1. Glycated Haemoglobin A1c (HbA1c) (blood test for diabetes control)
2. Body Mass Index (BMI) (measure of cardiovascular risk)
3. Blood pressure (measure of cardiovascular risk)
4. Urinary albumin (urine test for kidney function)
5. Thyroid screen (blood test for hyper/hypothyroidism)
6. Eye screening (photographic test for eye risk)
7. Foot examination (foot examination for ulcer risk)

The healthcare checks for children and young people with Type 2 diabetes recommended in NG18 and NG19 (NICE, 2015) differ slightly from those for Type 1 diabetes. The NPDA includes cholesterol screening rather than thyroid screening.

NG18 (NICE, 2015) and NG20 (NICE, 2015) also recommend screening for thyroid and coeliac disease at diagnosis.

Completion of health check data include children and young people with Type 1 or Type 2 diabetes who have received a complete year of care. A child or young person is categorised as completing a full year of care if they:

- were diagnosed before 1 April in the audit year (if no valid diagnosis date is recorded, these records are excluded as it is not possible to determine if the diagnosis date is before the audit year)
- did not transition during the audit year, and
- did not die during the audit year.

The following tables summarise the criteria that are used to establish whether a health check was completed and the age at which each health check should commence.

Key health checks (care processes) - inclusion criteria

Health check	Specific health check criteria	Age	Reported for:
HbA1c	HbA1c value between 2 and 195 (including values recorded as a % or in mmol/mol) and observation date within the audit period	All ages	Type 1 and Type 2
Body mass index (BMI)	Height between 40 and 220, weight between 2 and 200 and observation date within the audit period Both measurements taken on the same day	All ages	Type 1 and Type 2
Thyroid	Thyroid function TSH value greater than 0 and observation date within the audit period	All ages	Type 1 only
Blood pressure	Systolic blood pressure between 50 and 200 and observation date within the audit period	Aged 12 or older*	Type 1 and Type 2
Eye screen	Retinal screening recorded as 'performed' and observation date within the audit period <i>OR</i> Retinal screening result recorded as 'normal' or 'abnormal' and observation date within the audit period	Aged 12 or older*	Type 1 and Type 2
Foot exam	Foot examination date within the audit period	Aged 12 or older*	Type 1 and Type 2
Urinary Albumin	Urinary albumin level recorded within the audit period	Aged 12 or older*	Type 1 and Type 2
Cholesterol	Total cholesterol level between 2-15 and observation date within the audit period	Aged 12 or older*	Type 1 and Type 2

*Aged 12 or older as of 1 April 2016

Screening at diagnosis - Inclusion criteria

Health check	Specific health check criteria	Age	Reported for:
Thyroid disease	Observation date within the audit period and within 90 days of diagnosis	All ages	Type 1
Coeliac disease	Observation date within the audit period and within 90 days of diagnosis	All ages	Type 1

Outcomes of care

HbA1c outcome

HbA1c is a marker of overall diabetes blood glucose management and provides a measure of long term risk of microvascular complications.

HbA1c outcomes are reported for children and young people with a valid HbA1c measurement, taken more than 90 days after diagnosis. Where a measurement has been provided for patients who transitioned to adult services or who moved regions or PDUs during the audit period, their data was included even though they may not have completed a whole year of care.

Small vessel (microvascular) outcomes

People with diabetes are at increased risk of microvascular disease including chronic kidney disease (nephropathy) and eye disease (retinopathy). Outcome data is shown for people aged 12 years and older where there is an indication that they have had eye screening or a valid albuminuria test.

Kidney disease

Increased risk of kidney disease is indicated by the presence of either micro- or macro-albuminuria. For albuminuria to be included in the analysis as an outcome measure, the measurement must be taken during the audit year and have an interpretation of the result e.g. normo-albuminuria, micro-albuminuria or macro-albuminuria. The local interpretation is necessary for inclusion as different methodologies are used in different areas of the country with different cut off ranges.

Eye disease

For retinopathy screening to be included as an outcome measure, the process must have been carried out within the audit year and a result needs to be recorded as normal or abnormal.

Macrovascular outcomes

People with diabetes are at an increased risk of cardiovascular disease secondary to macrovascular risk factors including high blood pressure, abnormal lipid levels, high body mass index and smoking.

Blood pressure

Blood pressure outcome measures include data on young people aged 12 years and older with a valid systolic or diastolic blood pressure (BP) measurement. Acceptable systolic BP values were between 20 and 200 and acceptable diastolic BP were between 15 and 150.

As blood pressure varies with age and sex, data is converted to age and sex specific centiles using survey data between 1995 and 1998 from the general population aged between 4 and 24 years old (Jackson et al., 2007). A blood pressure between the 91st and 98th centile is classed as 'high normal' and a blood pressure above the 98th centile is classed as 'high' (Jackson et al., 2007).

Cholesterol

Data were reported for all young people aged 12 years and older with a total cholesterol level of between 2 and 15 mmol/l that was taken within the audit year.

Total cholesterol levels are no longer a mandatory requirement for children and young people with Type 1 diabetes following NICE guidance NG18 (2015), however results are still presented where data has been submitted.

Body Mass Index

BMI outcome data was included for all children and young people with a valid BMI measurement (i.e. height and weight within the specified range and taken on the same day within the audit period).

To allow direct comparisons across different ages and genders, BMI scores require standardisation whereby BMI scores are converted to z scores using the UK 1990 reference (Pan & Cole, 2012) and weight categories are defined as:

- Underweight: below the 5th centile
- Healthy weight: between the 2nd and 85th centile
- Overweight: between the 85th and 95th centile
- Obese: above the 95th centile

Smoking

Data were included for young people aged 12 and over with a recorded smoking result in the audit period classified as 'current smoker'.

Other outcome measures

Psychological outcomes

Psychological assessment and access to psychology services should be available to all children and young people and their families with diabetes. Outcome measures were reported for all children and young people recorded as having a psychological assessment within the audit period.

Hospital admissions

Diabetes related hospital admission rates were calculated using data from PDUs that submitted admission data to the 2016/17 audit. Data relates to children and young people with Type 1 diabetes who were admitted at least once during the audit period. Data are reported for those with Type 1 diabetes only due to small number of admissions for children and young people with other types of diabetes.

Summary of outcome measures

The table below provides a summary of the outcome measures reported in 2016/17.

Outcome measure	Summary of measure	Reported for:
Unadjusted mean and median HbA1c (mmol/mol)	Where more than one unique HbA1c was recorded for an individual, the median value for the year was calculated and used to calculate the overall mean and median HbA1c.	Type 1 and Type 2
HbA1c target levels	The following HbA1c target levels were included: <ul style="list-style-type: none">• Percentage \leq 48 mmol/mol• Percentage \leq 53 mmol/mol• Percentage $<$ 58 mmol/mol• Percentage \geq 69 mmol/mol• Percentage $>$ 75 mmol/mol• Percentage $>$ 80 mmol/mol	Type 1 only
Adjusted mean HbA1c	A multivariate regression model was used to estimate the effect of age, sex, ethnicity, duration of diabetes, and deprivation on mean HbA1c. The output of the model was then used to estimate the predicted, patient level HbA1c. At unit level, the adjusted mean HbA1c is equal to the sum of the patient level results divided by the sum of the expected HbA1c, multiplied by the population mean.	Type 1 only

Outcome measure	Summary of measure	Reported for:
Adjusted HbA1c target levels	<p>A logistic regression model was used to estimate the effect of age, sex, ethnicity, duration of diabetes, and deprivation on the likelihood of achieving a HbA1c result below 58 mmol/mol (or above 80 mmol/mol). The output of the model was then used to calculate the predicted probability of an individual having a HbA1c value below 58 mmol/mol (or above 80 mmol/mol).</p> <p>At unit level, the adjusted percentage with a HbA1c value below 58 mmol/mol (or above 80 mmol/mol) is equal to the sum of the observed number of patients with a HbA1c value below 58 mmol/mol (or above 80 mmol/mol) divided by the sum of the predicted probabilities, multiplied by the overall percentage of patients with a HbA1c value below 58 mmol/mol (or above 80 mmol/mol).</p>	Type 1 only
Albuminuria	<p>Percentage of young people (aged 12 or older with Type 1 diabetes or all ages with Type 2 diabetes) with albuminuria (either micro- or macro-albuminuria)</p> <p>Missing refers to those with a valid recorded albuminuria level within the audit period but no interpretation of the albuminuria result.</p>	Type 1 and Type 2
Eye disease	<p>Percentage of young people aged 12 or older with an abnormal eye screening result</p> <p>Missing refers to those who had an eye screening result recorded as unknown or those who received a retinal screening but no result was recorded.</p>	Type 1 and Type 2
Blood pressure	<p>Percentage of young people (aged 12 or older with Type 1 diabetes or all ages with Type 2 diabetes) with a recorded blood pressure classified as 'high normal' or 'high'</p>	Type 1 and Type 2
Cholesterol	<p>Percentage of young people (aged 12 or older with Type 1 diabetes or all ages with Type 2 diabetes) with a total cholesterol level exceeding cholesterol targets (≥ 4 mmol/l or ≥ 5 mmol/l) *</p> <p>*Prior to the 2016/17 audit, the percentage of young people with a total cholesterol below the cholesterol targets were reported</p>	Type 1 and Type 2
BMI	<p>Percentage of children and young people within BMI categories:</p> <ul style="list-style-type: none"> • Underweight • Healthy weight • Overweight • Obese 	Type 1 and Type 2

Outcome measure	Summary of measure	Reported for:
	Missing refers to records that had a BMI recorded but the result was missing or recorded incorrectly	
Smoking	Percentage of young people aged 12 years and older recorded as 'current smoker'	Type 1 and Type 2
Psychological support	<p>Outcome of assessment for need of Child and Adolescent Mental Health Services/psychological support:</p> <ul style="list-style-type: none"> Percentage recorded as referred and seen Percentage recorded as referred but no evidence of being seen Percentage recorded as no referral required <p>Missing refers to those who were recorded as being in need of psychological assessment but there was no indication that a referral was made</p>	Type 1 and Type 2
Hospital admissions	<p>Percentage of children and young people (excl. those who were admitted due to diabetic ketoacidosis (DKA) at diagnosis) admitted at least once in the audit year for:</p> <ul style="list-style-type: none"> DKA not at diagnosis - defined as a DKA related admission that did not take place between 10 days before or 10 days after the diagnosis date. Hypoglycaemia Ketosis without acidosis Other admission 	Type 1
Hospital admissions - DKA at diagnosis	<ul style="list-style-type: none"> Percentage of newly diagnosed patients that had a DKA related admission. DKA at diagnosis was defined as a DKA related admission that took place between 10 days before or 10 days after the diagnosis date. 	Type 1

Differences between health check denominators and outcome denominators

The patient cohorts included in the reporting of health checks and outcome measures are not the same. The main, but not the only, difference is that key health check data include only individuals who have completed a full year of care. The difference is best illustrated using the example below.

PDU X submits valid data on 150 children and young people with Type 1 diabetes. Of the 150, 126 were not diagnosed during the audit year, did not die and did not transition during the audit year i.e. 126 children and young people completed a full year of care. Therefore, the denominator for the HbA1c, BMI and thyroid health checks would be 126. In addition, 80 out of the 126 were aged 12 or older at the beginning of the audit period, therefore, the denominator for the remaining health checks (blood pressure, eye disease, foot exam, and urinary albumin) would be 80. If 124 of the 126 children and young people with a complete year of care have a valid HbA1c health check recorded, then the completion rate for this health check would be 98.4% (124/126). Similarly, if 50 of those with a complete year of care aged 12 and above are recorded as receiving a urinary albumin health check within the audit period, then the completion rate for this measure would be 62.5% (50/80).

For an outcome measure, an individual is not required to have completed a full year of care and therefore outcome data may be drawn from the totality of valid data submitted for the 150 children and young people. Some measures are calculated for all ages while others are calculated for those aged 12 or older only and as shown above, some outcome measures have additional inclusion criteria.

For HbA1c outcome measures, an individual is not required to have completed a full year of care and only HbA1c values taken after 90 days of diagnosis are used to calculate HbA1c outcome measures. Therefore, the denominator may increase or decrease depending on the number of children and young people who completed a full year of care and/or depending on the number of newly diagnosed children and young people with a HbA1c measurement taken only within 90 days of diagnosis.

For albuminuria, we know there are at least 50 patients with a result but there may be others where there is a result but did not complete a year of care due to transition, moving away or diagnosis within the audit year, these would be included in the denominator of the outcome measure. If there are 10 additional patients with valid results, the denominator for this outcome measure is therefore 60 (10 + 50). For albuminuria, an interpretation of the result is also required for it to be considered as an outcome measure. Although there may be 60 patients with a submitted value, only 30 of them have an interpretation submitted e.g. normoalbuminuria, microalbuminuria or macroalbuminuria. Potentially the denominator for the outcome measure could be greater than that used for the health check if there have been a lot of new patients or patients leaving the service where a health check has been performed as it would be included in the outcome measures.

Outliers

Unit results are described within the report as being higher, similar to or lower than the national average based on whether they fall within or outside of 2 standard deviations from the mean. Negative outlier results are considered to represent an 'alert' if they fall outside of two standard deviations or an 'alarm' if they fall outside of three standard deviations, as per DoH definitions. These cut-offs are visible within the funnel plots within the unit summaries.

In 2016/17, a PDU was defined as an outlier based on their performance on 2 metrics:

- Adjusted mean HbA1c
- Overall health check completion rate

Adjusted Hba1c

Given the variations in HbA1c associated with different demographic and social characteristics, it is appropriate to adjust HbA1c figures to take account of the characteristics of their patients or case-mix to allow for equitable benchmarking of individual PDU performance. The case-mix adjustments applied to the 2016/17 data considers the effect of age, sex, ethnicity, duration of diabetes and deprivation on mean HbA1c and the likelihood of having a HbA1c lower than the treatment target of 58 mmol/mol or higher than the upper limit of 80 mmol/mol. A summary of the output of the regression models used to construct the case-mix adjusted measures can be found on the NPDA website.

Prior to 2016/17, units were defined as outliers if they were outside of 3 standard deviations of the mean on any one of the three adjusted HbA1c outcome measures (adjusted mean HbA1c, adjusted percentages with HbA1c <58 or > 80mmol/mol. This year, a unit was classified as an outlier only if had an adjusted HbA1c mean outside of 3 standard deviations of the mean.

Health check completion rate

Prior to 2016/17, units were defined as outliers based on the percentage of children and young people who completed all seven health checks. This year, health check outlier status was calculated using an overall health check completion rate.

The health check completion rate is calculated by dividing the total number of health checks completed in each unit by the total expected number of health checks (which is equal to the number of young people with Type 1 diabetes aged 12 or older who completed a full year of

care, multiplied by seven; seven is the number of key NICE recommended health checks each patient should receive).

For example, say if in PDU X, there are 80 young people with Type 1 diabetes aged 12 or older who completed a full year of care and of those 20 received all seven health checks, 30 received six health checks and the remaining 30 received five health checks.

The percentage of children and young people who completed all seven health checks would equal 25% (20/80) whereas the unit's overall health check completion rate would equal 89.3% (see calculation of health check completion rate below).

$$\begin{aligned} \text{Health check completion rate} &= \frac{(20 \times 7) + (30 \times 6) + (30 \times 5) + (0 \times 4) + (0 \times 3) + (0 \times 2) + (0 \times 1)}{80 \times 7} \\ &= \frac{140 + 180 + 150 + 0 + 0 + 0 + 0}{560} \\ &= \frac{470}{560} \\ &= 83.9\% \end{aligned}$$

Additional measures included in the report

Treatment regimen

The NPDA collects information on treatment regimens used by all children and young people included within the audit. Data is collected to observe trends in usage of different regimens and to examine outcomes related to the different treatments. Where an individual patient's treatment regimen changes within the audit year, the latest regimen is used within breakdowns of treatment regimens used at unit/regional/national level.

'Structured patient education' for self-management

Structured education is important to support children and young people with diabetes and their families to understand the optimal management of their treatment regimen, blood glucose monitoring, the effects of diet, physical activity and illness, and how to detect and manage hypoglycaemia, hyperglycaemia and ketosis.

Structured education is counted as having been delivered if it is recorded as 'being delivered' within the audit period, irrespective of whether or not the child or young person completed a full year of care.

Thyroid and coeliac disease

Data were reported for children or young people with Type 1 diabetes only. A child or young person was counted as having thyroid disease if they were recorded as being treated for thyroid disease and counted as having coeliac disease if they were following a gluten-free diet.

References

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Welsh Government. Welsh index of multiple deprivation 2014. 2015.

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Further information

For further information on the audit or to view NPDA data, please visit:

- The NPDA webpage on the RCPCH website - <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/national-paediatrics-diabetes-audit>
- [NPDA results online](http://npda-results.rcpch.ac.uk/) - <http://npda-results.rcpch.ac.uk/>
- [Data.gov.uk](http://data.gov.uk)

Alternatively, feel free to contact the NPDA team at npda@rcpch.ac.uk or 020 7092 6157.