

National Paediatric Diabetes Audit

Notes on Data Analysis

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

020 7092 6157

npda@rcpch.ac.uk

Introduction

This document has been prepared to aid understanding of the analysis and preparation of NPDA data.

The data received from each submitting Paediatric Diabetes Unit (PDU) is analysed under the same rules; this makes NPDA data a powerful tool that can be used to undertake local, regional and national benchmarking. 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 (or admission date) is missing, invalid or outside of the audit cycle, i.e. the period 1 April 2019 to 31 March 2020.

Pseudonymisation

Before analysis, 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.

Table 1: 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 'not stated' or 'not known', but another record for the same individual specified an ethnicity, this ethnicity was applied. For the remaining patients whose ethnicity was recorded as 'not stated' or 'not known', the patient pseudo-key was used to check if a valid ethnicity was recorded for the patient in the previous audit year; if a valid ethnic code was recorded, it was used instead. 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 one 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 was 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.

Variable	Rules applied
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 and transformation partnerships	Patients were first assigned to a sustainability and transformation partnership (STP) according to their CCG.

Completion of health checks (care processes)

Completion of essential health checks

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.

Completion of health check data include children and young people with Type 1 or Type 2 diabetes who completed a full year of care. A child or young person is categorised as not completing a full year of care if they:

- were diagnosed after 1 April in the audit year or had no valid diagnosis date recorded, and
- transitioned or died during the audit year or left a PDU and did not end up receiving care at a different PDU at a later date within the audit period.

A summary of the criteria that are used to establish whether each health check was completed is shown in Table 2. The NPDA also collects data on additional health checks; the criteria that are used to establish whether additional health checks were completed are summarised in Table 3.

Table 2: Key health checks (care processes) - inclusion criteria

Data item	Criteria for inclusion
HbA1c	HbA1c value between 2 and 195 (including values recorded as a % or in mmol/mol) and observation date within the audit period.
Body mass index (BMI)	Height (cm) between 40 and 220, weight (kg) between 2 and 200 and observation date within the audit period.
Thyroid	Thyroid function observation date within the audit period. Type 1 only.
Cholesterol	Total cholesterol level between 2-15 and observation date within the audit period. Type 2 only.
Blood pressure	Systolic blood pressure between 50 and 200, observation date within the audit period and patient aged 12 and above at the beginning of the audit period.
Eye screen	Retinal screening observation date within the audit period and patient aged 12 and above at the beginning of the audit period.
Foot exam	Foot examination date within the audit period and patient aged 12 and above at the beginning of the audit period.
Urinary Albumin	Urinary albumin level recorded within the audit period and patient aged 12 and above at the beginning of the audit period.

Table 3: Additional health checks (care processes) - inclusion criteria

Data item	Criteria for inclusion
Psychological assessment	Psychological screening observation date within the audit period. <i>OR</i> Patient assessed as requiring additional psychological/CAMHS support outside of MDT clinic within the audit period.
Smoking status	Smoking status known within the audit period and patient aged 12 and above at the beginning of the audit period.
Offered dietetic appointment	Patient offered an additional appointment with a paediatric dietitian within the audit period.
Attended dietetic appointment	Additional dietetic appointment took place within the audit year.
Offered flu vaccine	Influenza immunisation offered within the audit period.
Received sick day advice	Advice ('sick-day rules') about managing diabetes during intercurrent illness or episodes of hyperglycaemia provided within the audit period.
Blood ketone testing equipment	Patient was using (or trained to use) blood ketone testing equipment within the audit period.

Care at diagnosis - Inclusion criteria

NG18 (NICE, 2015) and NG20 (NICE, 2015) recommend that children and young people with Type 1 diabetes receive screening for thyroid and coeliac disease at diagnosis. NG18 (NICE, 2015) also recommends offering level 3 carbohydrate-counting education to children and young people with Type 1 diabetes from diagnosis.

Table 4: Care at diagnosis - inclusion criteria

Data item	Criteria for inclusion
Thyroid disease	Observation date within the audit period and within 90 days of diagnosis.
Coeliac disease	Observation date within the audit period and within 90 days of diagnosis.
Carbohydrate counting	Observation date within the audit period and within 14 days of diagnosis

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 period 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 period 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 period.

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.

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 2th centile
- Healthy weight: between the 2nd and 85th centile

- Overweight: between the 85th and 95th centile
- Obese: above the 95th centile

Smoking

Data were reported for young people aged 12 and over with a recorded smoking result in the audit period classified as 'current smoker', and the proportion of 'current' smokers who were referred to smoking cessation services within the audit period.

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. Outcomes of children and young people with diabetes were reported for those who had a known outcome of the assessment recorded within the audit period.

Hospital admissions

Diabetes related hospital admission rates were calculated using data from the 155 out of 166 PDUs that submitted admission data to the audit. 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.

Table 5: Outcome measures reported

Outcome measure	Summary of measure
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.
HbA1c target levels	The following HbA1c target levels were included: <ul style="list-style-type: none"> • Percentage with an HbA1c \leq 48 mmol/mol • Percentage with an HbA1c \leq 53 mmol/mol • Percentage with an HbA1c $<$ 58 mmol/mol • Percentage with an HbA1c \geq 69 mmol/mol • Percentage with an HbA1c $>$ 75 mmol/mol • Percentage with an HbA1c $>$ 80 mmol/mol
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.
Adjusted HbA1c target levels	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). 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).
Albuminuria	Percentage of young people (aged 12 and above with Type 1 diabetes or all ages with Type 2 diabetes) with albuminuria (either micro- or macro-albuminuria). <i>Missing and unknown results were not reported.</i>
Eye disease	Percentage of young people aged 12 and above with an abnormal eye screening result. <i>Missing and unknown results were not reported.</i>
Blood pressure	Percentage of young people (aged 12 and above with Type 1 diabetes or all ages with Type 2 diabetes) with a recorded blood pressure classified as 'high normal' or 'high'.

Outcome measure	Summary of measure
Cholesterol	Percentage of young people (aged 12 and above 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). Prior to the 2016/17 audit, the percentage of young people with a total cholesterol below the cholesterol targets were reported
BMI	<p>Percentage of children and young people within BMI categories:</p> <ul style="list-style-type: none"> • Underweight: below the 2nd centile • Healthy weight: between the 2nd and 85th centile • Overweight: between the 85th and 95th centile • Obese: above the 95th centile <p><i>Missing and unknown results were not reported.</i></p>
Psychological support	<p>Percentage of children and young people recorded as requiring additional psychological/CAMHS support within the audit period.</p> <p><i>Missing and unknown results were not reported.</i></p>
Hospital admissions	<p>Percentage of children and young people with Type 1 diabetes who were admitted at least once with a diabetes-related admission, not associated with diagnosis, within the audit period. An admission that did not take place between 10 days before or 10 days after the diagnosis date was counted as an admission not associated with diagnosis.</p>
Hospital admissions - DKA at diagnosis	<p>Percentage of newly diagnosed patients that had a DKA related admission that took place between 10 days before or 10 days after the diagnosis date.</p>

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, did not die or did not transition during the audit period 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. 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).

If 80 out of the 126 are aged 12 and above at the beginning of the audit period, the denominator for the remaining health checks (blood pressure, eye disease, foot exam, and urinary albumin) would be 80. For example, 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 and above 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, if more than 50 young people received screening and did not complete a year of care due to transition, moving away or being diagnosed within the audit period, then the denominator for the outcome measure could be greater than 50. For example, if there are ten additional patients with a valid result, the denominator would be 60 (10 + 50). In addition, an interpretation of the result is also required for albuminuria to be considered as an outcome

measure. Although there may be 60 patients with a submitted value, if only 30 of them have an interpretation submitted e.g. normo-albuminuria, microalbuminuria or macroalbuminuria, the denominator will fall to 30. The denominator for the outcome measure could also be greater than that used for the health check if the PDU had a lot of new patients or patients left the service where a health check had been performed.

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 Department of Health definitions. These cut-offs are visible within the funnel plots within the unit summaries.

A PDU is defined as an outlier based on their performance on two 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 adjustment 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.

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 and above 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 and above 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 25.0% (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 period, the latest regimen is used within breakdowns of treatment regimens used at unit/regional/national level.

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

Department for Communities and Local Government. English indices of deprivation 2015. 2015. <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015>

Jackson LV, Thalange NK & Cole TJ (2007) Blood pressure centiles for Great Britain. *Arch Dis Child* **92**: 298–303

Pan H, Cole TJ. (2012) LMS growth, a Microsoft Excel add-in to access growth references based on the LMS method (version 2.77). Harlow Healthcare, South Shields. Available at: <http://www.healthforallchildren.com/shop-base/shop/software/lmsgrowth>

Welsh Government. Welsh index of multiple deprivation 2014. 2015. <https://gov.wales/statistics-and-research/welsh-index-multiple-deprivation/?lang=en>

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.