

NPDA Core Dataset – Frequently Asked Questions (FAQs)

Last updated: April 2026

This FAQ document supports the revised NPDA Core Dataset to be collected from 1st April 2026. It addresses common queries raised by units and provides clarification on how specific data items should be recorded.

For full dataset definitions and guidance, please refer to the Core Dataset document.

If you any queries or questions that aren't included in the FAQ, please contact npda@rcpch.ac.uk

| General Questions | |
|--|--|
| Questions | Answers |
| 1. What are the main changes in the 2026 dataset? | <p>The 2026 dataset includes a number of new data items and refinements to existing ones. Most notably:</p> <ul style="list-style-type: none"> • New fields relating to neurodevelopmental conditions (ADHD/ASD) and learning disabilities • Additional detail on treatment modalities and technologies • New items relating to immunotherapy and blood gas tests during admission • Some restructuring of 'treatment', 'monitoring', and 'admissions' fields <p>Any new items are highlighted in pink, and modified items in yellow, in the 2026 core dataset document</p> |
| 2. Can data from virtual or remote appointments be included? | <p>Yes. Where guidance allows, data collected via video or telephone appointments can be submitted, provided the relevant process or check has been completed and documented appropriately.</p> |

Neurodevelopmental Conditions & Learning Disabilities

| | |
|---|--|
| <p>3. Why don't we include those with suspected but undiagnosed learning disabilities, ADHD, or ASD? Data items 6 and 7.</p> | <p>Only conditions formally diagnosed by a qualified healthcare professional should be recorded. This ensures consistency and reliability across submissions.</p> <p>Suspected or unconfirmed conditions should not be included, including children and young people under investigation or on waiting lists, unless they have a confirmed diagnosis.</p> |
| <p>4. Does the term "learning disabilities" include conditions such as dyslexia? Data item 7</p> | <p>No. Learning disabilities refer to diagnosed conditions such as intellectual disability or global developmental delay. Learning difficulties alone, such as dyslexia, would not be included unless part of a broader diagnosis.</p> <p>DHSC (2001) definition of learning disabilities: <i>"a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood."</i></p> |
| <p>5. What should we do if we are unsure of the exact date of diagnosis? Data item 9</p> | <p>Use the best available estimate. If the exact date is unknown, apply a consistent local approach (e.g. first of the month if only month/year known).</p> |

Treatment and Monitoring

| | |
|---|---|
| <p>6. How should treatment be recorded if a patient is on multiple therapies (e.g. insulin, GLP-1 agonists, SGLT2 inhibitors)? Data item 21 and 22</p> | <p>Record the treatment that best reflects the patient's current clinical management. This may include insulin regimen (including hybrid closed loop) and/or non-insulin therapies. Where multiple treatments are used, select the option that best represents the primary treatment approach. E.g. for a patient with Type 1 Diabetes on a hybrid closed loop system and metformin choose option 5 in Q21 and option 2 in Q22.</p> |
| <p>7. What does "other non-insulin blood glucose lowering medication" refer to? Data item 22</p> | <p>This refers primarily to treatments used in Type 2 diabetes, such as metformin, GLP-1 agonists, and SGLT2 inhibitors. Select the option that best reflects the patient's treatment at the time of the visit.</p> |

| | |
|---|--|
| <p>8. What counts as “lifestyle and dietary modification” being recommended? Data item 23</p> | <p>This includes advice or support on diet, physical activity, or weight management intended to treat diabetes.</p> <p>It primarily refers to Type 2 and other non-type 1 forms of diabetes. However, where there has been ‘lifestyle and dietary modification’ over and above the dietary advice provided and delivered to those with Type 1 in the form of carbohydrate counting, it should be entered in Q23.</p> <p>It does not need to be delivered by a dietitian and is separate from structured dietetic input recorded elsewhere.</p> |
| <p>9. What counts as continuous glucose monitoring (CGM)? Data item 24</p> | <p>This includes both real-time CGM (rtCGM) and flash CGM. Record whether CGM was in use at the time of the visit.</p> |
| <p>10. What if a child has received immunotherapy during a double-blind trial? Data item 26 and 27</p> | <p>If it is not known whether the patient received the active drug or placebo, select ‘99 = Not Known’. This can be updated at a later date once the trial has been unblinded. The NPDA will use the most recent submitted value.</p> |
| <p>11. Which patients should have immunotherapy recorded? Data item 26 and 27</p> | <p>This applies to newly diagnosed patients with Type 1 diabetes who have received immunotherapy intended to delay the onset or progression of diabetes, either before or after diagnosis of stage 3 Type 1 diabetes.</p> |

| <h2 style="text-align: center; color: #0070C0;">Annual Review – Health Checks/Psychology/Dietetics</h2> | |
|--|---|
| <p>12. What counts as a psychological assessment? Data item 47</p> | <p>A formal assessment for the ‘need of additional psychological support’ conducted by a member of the paediatric diabetes MDT. This can be completed in person or remotely.</p> |
| <p>13. Which roles are included under the term “mental health professional”? Data item 49</p> | <p>This includes members of the diabetes MDT whose role is primarily to provide psychological care to patients. This includes, but is not limited to, clinical psychologists, counselling psychologists, CBT therapists, psychotherapists, and family therapists.</p> <p>It does not include school counsellors or educational psychologists.</p> |

Admissions

| | |
|--|--|
| <p>14. Can an admission or observation date be before the date of diagnosis? Data item 53</p> | <p>This depends on the item.</p> <p>An admission may begin before diagnosis is confirmed. Health checks should be completed after the diagnosis of diabetes.</p> <p>The diagnosis date should reflect when diabetes was clinically diagnosed.</p> |
| <p>15. What admissions should be recorded? Data item 53 – 59</p> | <p>All diabetes-related admissions should be recorded, including diagnosis, DKA, hypoglycaemia, ketosis, and other related causes. The options are provided in the notes section of the dataset.</p> <p>Each admission should be entered separately.</p> |

Submission & Data Quality

| | |
|---|--|
| <p>16. What should we do if data is missing or incomplete?</p> | <p>Submit as much data as possible to reflect the care provided by your service. Missing data can often be updated in later quarters. Use “Unknown” where appropriate.</p> |
| <p>17. What if a health check cannot be completed? E.g. because the patient refused or is physically unable to have the health check completed.</p> | <p>If a patient does not receive a health check, the data item should be left blank. Patients and circumstances vary, and not all children and young people will be able or willing to complete every care process.</p> <p>For NPDA purposes, a blank entry is interpreted as the examination having not taken place, regardless of the reason (e.g. patient refusal, non-attendance, or other circumstances). This is acceptable and does not need to be recorded separately.</p> <p>This should not disadvantage you in the NPDA. We understand that there will be circumstances where checks cannot be completed. While 100% represents the maximum possible score, achieving 100% may not always reflect optimal or realistic care. NPDA metrics are designed so that higher percentages generally indicate better care, but it is</p> |

| | |
|---|--|
| | recognised that exceptions and patient-specific factors will exist. |
| 18. Who should we contact if we are unsure how to complete a field? | Please contact the NPDA team at: npda@rcpch.ac.uk or by calling 020 7092 6137. |