

# Data Provision Notice

## Diabetes Transition and Young Adult Care Pilots – Evaluation

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## Background

The Health and Social Care Act 2012 (the Act) gives [NHS England](#) statutory powers, under section 259(1)(a), to require data from health or social care bodies, or organisations that provide publicly funded health or adult social care in England, where it has been directed to establish an information system by the Secretary of State for Health and Social Care.

The data, as specified by NHS England in this published Data Provision Notice, is required to support a direction from the Secretary of State for Health and Social Care to NHS England. Therefore, organisations that are in scope of the notice are legally required, under section 259(5) of the Act, to provide the data in the form and manner specified below.

## Purpose

National NHS England funding has been made available for 15 NHS trust pilot sites to implement a model of enhanced care for young adult diabetes services.

The pilots will reach approximately 4,000 patients aged between 16-25 years with diabetes over a 2-year implementation period. The expected benefits include improved health outcomes and improved patient engagement with specialist services.

This data collection is required to support the evaluation of the pilots in a timely manner and will help underpin future national policy and wider improvements in young adult diabetes care. It will enable the primary evaluation questions to be answered which are:

*What impact has national investment to implement a model specification for diabetes young adult care in different settings had on:*

- i) diabetes service engagement and*
- ii) diabetes clinical outcomes*

*and within this an economic analysis and the following sub questions:*

- 1. To what extent have pilot sites implemented the model specification for diabetes young adult care?*
- 2. Has investment in the pilot sites improved patient engagement with the site's services?*
- 3. Has investment in the pilot sites improved HbA1c control?*
- 4. Has investment in the pilot sites improved care process completion in sites?*
- 5. What impact has investment had on the type 2 diabetes population? (BMI is a key outcome for this group)*
- 6. Has investment in the pilot sites improved diabetes self-management ability?*
- 7. Has investment in the pilot sites reduced diabetes related admissions?*

NHS England will compare the pilot sites to a like group comparator, this will be a randomised group of individuals from the national diabetes audit collection (NDA) who share similar characteristics to the treatment group, to assess the impact of the pilot intervention.

The national programme cannot use existing NDA data to conduct the evaluation of the pilots as the specialist diabetes services NDA data is only reported annually. Awaiting the national collection would mean data on the impact of the pilot implementation period would not be available until February 2026, whereas this evaluation is needed before then to support systems with making the case for continued investment after the national funding ends in March 2025.

Interim and final analytical reports, containing fully anonymised data, will be shared with pilot sites, our qualitative evaluation partner Ipsos and national governance groups (such as the national CYA Diabetes Oversight Group, Diabetes Programme Directors Group, Diabetes Programme Board and the CYP Transformation Programme Board).

## Benefits

Actioning the results of the evaluation to improve care for patients as they transition from paediatric to adult care has the potential for societal and economic benefits, both from improved outcomes for people with diabetes as well as reductions in future demands on local health care services.

## Legal basis for collection, analysis, publication and dissemination

### Collection and analysis

NHS England has been directed by the Secretary of State for Health and Social Care under section 254 of the Health and Social Care Act 2012; to establish and operate a system for the collection and analysis of the information specified for this service. The direction and accompanying requirements specification are published on the NHS England website:

This information is required by NHS England under section 259(1)(a) of the Health and Social Care Act 2012.

In line with section 259(5) of the Act, all organisations in scope, in England, must comply with the requirement and provide information to NHS England in the form, manner and period specified in this Data Provision Notice.

This Notice is issued in accordance with the procedure published as part of an NHS England duty under section 259(8).

The National Data Opt-Out will not apply to the submission of data to NHS England for this collection as the Data Provision Notice is a legal requirement with which the participating organisations must comply. Where NHS England disseminates data, the National Data Opt-Out will be applied in accordance with the national data opt-out policy:

<https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document>

### Publication

Under section 260(1) of the Health and Social Care Act 2012, NHS England must publish all information it obtains by complying with a direction under section 254 or a request under section 255 of the Act unless the information falls within section 260(2).

NHS England will publish the evaluation outputs in the form of summary reports and bespoke reporting tailored to different audiences (including commissioning bodies, people with diabetes and clinicians).

The level of granularity for reporting is agreed with stakeholders and in line with NHS England disclosure policy, e.g. individual pilot sites and all pilot sites combined as an intervention group. The raw data will not be published. Interim and final analytical reports will contain fully anonymous data.

All reports produced are made available in the public domain, at named provider level, excluding any information that might make individual patients identifiable.-NHS England in

consultation with the Secretary of State for Health and Social Care considers it is in the public interest to publish information at named provider level.

## Dissemination

NHS England may use its discretionary powers under section 261 of the Health and Social Care Act 2012 to disseminate any information collected or obtained as a result of these Directions via the Data Access Request Service (DARS) where there is a suitable legal basis.

## Transparency

NHS England has issued a Transparency Notice for this data collection as required under Article 14 of the UK General Data Protection Regulation (UK GDPR).

Data providers in scope of this Data Provision Notice are required under Article 13 of the UK GDPR to provide their own transparency information to their patients (data subjects) and can link to the NHS England Transparency Notice to provide additional information.

The details of any data disseminations made by NHS England from this collection will be regularly published in the [Data Uses Register](#) which is available on the NHS England website.

## Persons consulted

To deliver this pilot collection under the National Diabetes Audit Directions 2017, NHS England has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following persons:

- The Department of Health and Social Care, as the directing organisation
- NHS England's Clinical leads, as advisors
- NHS Diabetes Programme directors, as users of the information
- NHS England's Information Governance team
- Pilot site clinicians, as providers of the information
- NHS Arden and Greater East Midlands Commissioning Support Unit (AGEM CSU), as processors of the information
- Young people with diabetes, as persons from whom the data is about
- The Data Alliance Partnership Board (DAPB) - established in November 2020 as part of a system-wide information and technology governance model. The DAPB acts with delegated authority from the Secretary of State as the main governance route through which all data collections and standards requirements are agreed and priorities assigned.

## Scope of the collection

Under section 259(1)(a) of the Health and Social Care Act 2012, this Notice is served in accordance with the procedure published as part of the NHS England duty under section 259(8) on the following persons:

- Barts Health NHS Trust
- Dorset Country Hospital and University Hospitals Dorset NHS Foundation Trust
- East Suffolk and North Essex Foundation Trust

- Kings Health Partners (Guy's and St Thomas', King's College Hospital and South London and Maudsley NHS Foundation Trusts)
- Liverpool University Hospital NHS Foundation Trust and Alder Hey Children's NHS Foundation Trust
- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Norfolk & Norwich University Hospital NHS Foundation Trust
- Oxford University Hospitals
- Sheffield Teaching Hospitals NHS Trust
- Sherwood Forest Hospitals NHS Foundation Trust
- Southampton General Hospital
- Southport and Ormskirk NHS Trust
- Stockport NHS Foundation Trust
- Torbay and South Devon NHS Foundation Trust
- University Hospital of Derby and Burton NHS Foundation Trust

Under section 259(5) of the Health and Social Care Act 2012 the organisations specified above must comply with the Form, Manner and Period requirements below.

## Form of the collection

The data metrics within this collection relate to patients with diabetes on the caseloads of the 15 NHS trust pilot sites (i.e. patients known to services) aged between 16-25 years.

NHS Trusts will source the data from their patient administration systems collected as part of the direct care of the patient.

The personal and special categories of data to be collected are detailed below:

- NHS number
- Age
- Sex
- Indices of Multiple Deprivation (IMD) quintile
- Ethnicity
- Type of diabetes (type 1, type 2, other)
- Attendance at clinic(s) and level of frequency of contacts with the young adult diabetes service
- Whether HbA1c, blood pressure and/or BMI were measured and whether they received annual mental health screening.
- HbA1c levels and BMI
- Whether they received structured education at diagnosis
- Whether they were using diabetes treatment technology

The dataset specification for this collection will be made available on the data landing platform ([Data Landing Portal \(ncrs.nhs.uk\)](https://ncrs.nhs.uk)).

## Manner of the collection

Providers will submit the agreed dataset specification, on a 6 monthly basis, via the national data landing portal (DLP) platform.

The data will then be loaded and processed by AGEM CSU, who will perform data validation checks for data quality purposes, pseudonymise the NHS Numbers and conduct derivations of a key fields such as changing full date of birth to age.

The data will then be made available for onward analysis by NHS England within the National Commissioning Data Repository (NCDR) and the Unified Data Access Layer (UDAL). Access will be limited to the diabetes analytical team who will be directly involved in the analysis of the data for evaluation of the pilot sites. The data will be linked to the National Diabetes Audit (NDA) and the Secondary Uses Services (SUS) datasets, using a common pseudo key, to compare the pilot sites to a like group comparator in order to assess the impact of the pilot interventions.

## Period of the collection

- Collection start date: January 2024
- First submission date: January 2024
- Subsequent submission dates: June 2024, December 2024, June 2025
- Publication dates: September 2025, September 2026
- Collection end date (state if ongoing): 31 March 2026

## Data quality

Quality and accuracy of data will rely on what is supplied by pilot sites (NHS trusts), as they are the initial data controllers.

Data quality checks will be applied by the AGEM CSU Data Services for Commissioners Regional Office (DSCRO) team receiving the data from sites to the quarterly submissions from pilot sites. Data quality reports will be shared with projects to allow them to check and resubmit their data if required. The high-level checks will include:

- Check dataset matches specification (i.e. right number and names of fields)
- Data formats match specification (e.g. dates are formatted DD/MM/YYYY)
- Any coded values match list of expected values (e.g. ethnicity codes)
- Identify any missing values in mandatory fields

# Burden of the collection

## Steps taken by NHS England to minimise the burden of collection

NHS England has a statutory duty under section 253(2)(a) of the Act to seek to minimise the burden it imposes on others. In seeking to meet these obligations in relation to this collection, NHS England has:

- By agreeing to be pilot sites the 15 NHS trusts signed up to sharing data with national team and our evaluation partners for the purposes of evaluation.
- We are only requesting the minimal number of metrics required to support the evaluation, for example sourcing existing data on hospital admissions from other data sources (e.g. SUS) rather than requesting information from pilot sites
- The draft record level submission template has been tested with two sites who thought that it would be feasible.

In addition, in support of its obligation under 265(3) of the Act, NHS England has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This process is carried out by the Data Standards Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching Data Alliance Partnership Board (DAPB) approval process. The DAPB, acting under authority of the Secretary of State, oversees the assurance, approval and publication of information standards and data collections for the health and social care system in England.

## Assessed costs

The associated burden of the data collection is:

Burden on providers	£9,126	Year 1 costs (including set up costs) Sites have allocated, on average 2 days a week Band 3 (AfC) resource to support the data submissions
Burden on providers	£9,126	Year 2 and ongoing annual costs Sites have allocated, on average 2 days a week Band 3 (AfC) resource to support the data submissions