

Data Provision Notice

National Paediatric Diabetes Audit

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Change control

This is a revision of this Data Provision Notice both to support the extension of scope of the collection and to reflect the legal and organisational changes which came into effect on 1 February 2023.

The last version of this Data Provision Notice was issued by NHS England on 11 March 2022 in pursuant to a direction under section 254 of the Health and Social Care Act 2012 from NHS England.

On 1 February 2023, the statutory functions of NHS Digital transferred to NHS England under the [Health and Social Care Information Centre \(Transfer of Functions, Abolition and Transitional Provisions\) Regulations 2023](#) (Transfer Regulations). Under these Transfer Regulations, all directions from either the Secretary of State for Health and Social Care or NHS England to NHS Digital are now treated as directions from the Secretary of State for Health and Social Care to NHS England.

Consequently, the legal basis for this Notice is still the direction identified below, with its status now deemed to be a direction from the Secretary of State for Health and Social Care to NHS England under section 254 of the Health and Social Care Act 2012.

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. Under section 259(1)(b) of the Act, NHS England may request information from any person that holds information that NHS England considers is necessary or expedient for it to have to fulfil a section 255 request.

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 and a request from Digital Health and Care Wales to NHS England. Therefore, organisations that are in scope of section 259(1)(a) are legally required, and organisations in scope of section 259(1)(b) are requested, under section 259(5) of the Act, to provide the data in the form and manner specified below.

Purpose

The National Paediatric Diabetes Audit (NPDA) is managed by the Royal College of Paediatrics and Child Health (RCPCH) on behalf of the Healthcare Quality Improvement Partnership (HQIP) and NHS England.

NPDA data relates to any child or young person receiving care from a paediatric diabetes service in England and Wales up to the age of 25. NHS England links NPDA data to National Diabetes Audit adult data to evaluate the care of patients who transition from children to adult diabetes services.

The aggregated findings of this evaluation will be published by NHS England. Following a review of the initial Adolescent and Young Adult (AYA) Audit by the audit team and NHS

England, it was agreed to design a future report looking at type 2 care for young people (under the age of 40). This report will focus on care processes and treatment targets, as set out in the AYA Audit, as well as demographic information relating to where these patients are being seen and how many are being diagnosed with type 2 diabetes.

From 2024, a subset of NPDA data for England relating to hybrid closed loop (HCL) technologies will be collected quarterly and linked to the NDA Core data set to measure uptake, equitable access and effectiveness of HCL devices as part of NHS England's [Hybrid closed loop technologies: 5-year implementation strategy](#). This strategy was developed following the publication of the National Institute for Health and Care Excellence (NICE) technical appraisal guidance, [TA943](#). Results from the linkage will also be used to support healthcare improvement work directly with hospital services and Integrated Care Boards (ICBs) via NHS England's [Getting It Right First Time programme](#). Data relating to HCL technologies will not be collected for Wales.

HQIP and NHS England are joint controllers for the NPDA data. HQIP acts as commissioner, on behalf of NHS England, for both the NPDA and the NDA programme.

NHS England has a statutory obligation to keep collections under review on an ongoing basis. As such a review date must be set at which point NHS England will review the continuing need for this collection.

Benefits

The collection will allow the publication of results pertaining to the care of young patients with diabetes as they move from paediatric to adult services and provide further information relating to young adults with type 2 diabetes around demographics and achieving care processes and treatment targets. The reports will be published at service level and allow those services to understand their performance and target improvements where they need to be made. Linking NPDA data for England to the NDA Core data will help to measure uptake, equitable access and effectiveness of HCL devices.

Legal basis for collection, analysis, publication and dissemination

Collection and analysis

England

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.

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. However, a local opt-out mechanism is in place which enables patients and their carers to ask their paediatric diabetes team not to submit their data to the RCPCH for inclusion in the NPDA.

Where NHS England disseminates data, the National Data Opt-Out will be applied in accordance with the [national data opt-out policy](#).

Wales

NHS England has been requested by Digital Health Care Wales (DHCW) under section 255 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. A copy of the [request](#), which sets out the legal basis under which DHCW has made this request, is published on the NHS England website.

The National Data Opt-Out does not apply to healthcare provided in Wales.

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

In line with section 259(5) of the Act, all organisations in scope, 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).

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).

Dissemination

NHS England will use its discretionary powers under section 261 of the Health and Social Care Act 2012 to disseminate any information collected or obtained under a section 254 Direction or section 255 Request.

All dissemination will follow established NHS England governance processes through the Data Access Request Service (DARS) including advice from the Advisory Group for Data (AGD) in accordance with the statutory guidance published by the Secretary of State for Health and Social Care under Section 274A of the Health and Social Care Act 2012.

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

NHS England has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following persons:

- Department of Health and Social Care, as the directing organisation
- Digital Health and Care Wales, as the requesting organisation
- Healthcare Quality Improvement Partnership (HQIP)
- The British Medical Association General Practitioners Committee - Sub IT Committee
- National Advisory Group on Clinical Audit and Enquiries (NAGCAE) (no longer in existence)
- Welsh Government
- National Clinical Directors
- National Institute for Health and Care Excellence (NICE)
- Clinicians
- Healthcare professionals
- Patient body representatives
- People with diabetes
- Research community
- 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)(b) 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:

- Healthcare Quality Improvement Partnership (HQIP) and their processor the RCPCH.

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

Form of the collection

The [data set for the collection](#) has been published on the RCPCH website.

Full details of the data to be collected by NHS England can be found on the [National](#)

[Paediatric Diabetes Audit Data Provision Notice webpage.](#)

The following patient identifiable information is included in the collection

- NHS Number
- Date of birth
- Postcode
- Sex
- Ethnicity
- Date of death

Manner of the collection

The initial data set and subsequent updates will be transferred to NHS England via Secure Electronic File Transfer (SEFT). Once collected, the data will be stored within NHS England analytical processing environments in line with the National Diabetes Audit Directions 2017 and the National Diabetes Audit for NHS Wales Request 2021.

Period of the collection

The NPDA data for England and Wales will be collected annually in autumn for the previous audit year's data and quarterly for Hybrid Closed Loop (HCL) purposes (England only).

Data quality

The NPDA data is checked and validated by the RCPCH prior to it being sent to NHS England.

Burden of the collection

Steps taken by NHS England to minimise the burden of collection

In discharging its statutory duty to seek to minimise the burden it imposes on others, NHS England is:

Linking data from NPDA that NHS Trusts provide to the RCPCH with the NDA, rather than asking NHS Trusts to also provide the NPDA data to NHS England. This will result in there being no burden for NHS Trusts. There will be minimal burden for the RCPCH to prepare a file of data and submit to NHS England via SEFT

In seeking to minimise the burden it imposes on others, in line with sections 253(2)(a) and 265(3) of the Health and Social Care Act 2012, NHS England has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

The provision of data to NHS England under this Notice does not have to be assessed for burden, as burden only applies to the initial submission by care providers to the Royal College of Paediatrics and Child Health. This process is carried out by the Data Standards

Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching 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.