

Data Provision Notice

National Pregnancy in Diabetes Audit

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Background

The Health and Social Care Act 2012 (the Act) gives the Health and Social Care Information Centre now known as [NHS Digital](#) and hereafter referred to by this name, statutory powers, under section 259(1), to require data from health or social care bodies, or organisations who provide health or adult social care in England, where it has been directed to establish an information system by the Department of Health (DH) (on behalf of the Secretary of State) or NHS England.

The data, as specified by NHS Digital in this published Data Provision Notice, is required to support a direction from NHS England to NHS Digital. 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 of the collection

NHS England has directed NHS Digital to establish and operate a system for the collection and analysis of the National Diabetes Audit (NDA) including the National Pregnancy in Diabetes (NPID) Audit.

The NPID Audit is part of the NDA Diabetes Audit programme. The NDA is managed under contract by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England and the Welsh Government. The NDA is delivered by NHS Digital working with Diabetes UK.

The NPID audit provides a picture of the care provided to women with diabetes before and during pregnancy and the resulting outcomes for women and babies.

The NPID audit looks at:

- how well women with diabetes are prepared for pregnancy
- whether the treatment and care given to women reduced the risk of certain complications during pregnancy
- whether treatment and care minimised the risk of the baby developing abnormally, or dying before or shortly after birth

The findings from the NPID audit are made available to every maternity unit with a joint diabetes and maternity service that has taken part. Hospital managers and staff are asked to look at areas where their care is below standard and to develop plans to improve these services. The full audit findings are also made publicly available on the [NHS Digital Website](#).

Benefits of the collection

The NPID audit collects information and produces reports to highlight where pregnancy care is good and meets national guidelines as well as providing information to support services in making improvements.

The findings of the NPID audit support services in raising the standards for care for women with diabetes from pre-conception through to the end of pregnancy. The National Institute for Health and Care Excellence (NICE) produces the guidelines for diabetes in pregnancy. The NPID audit measures whether the care given meets these guidelines. The main aim is to check that women with diabetes have treatment and care before and during pregnancy that minimises the risk of health complications for the woman, her foetus, and her new-born baby(ies).

Legal basis for the collection, analysis, publication and dissemination

NHS Digital has been directed by NHS England 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 the National Diabetes Audit in the Technical Output Specification or any subsequent amended version of the specification, as approved by the Board. The direction was accepted by the NHS Digital Board on 28 March 2017; the signed copy is published on the [gov.uk website](#).

The Technical Output Specification is available on the NDA website [here](#).

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

In line with section 259(5) of the Act, all specialist diabetes services within NHS trusts in England must comply with the requirement and provide information to NHS Digital 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 NHS Digital's duty under section 259(8).

Persons consulted

Following receipt of a direction to establish a system to collect National Pregnancy in Diabetes Audit data, NHS Digital has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following persons:

- NHS England
- Healthcare Quality Improvement Partnership (HQIP)
- Joint General Practice Information Technology Committee (JGPITC)
- National Advisory Group on Clinical Audit and Enquiries (NAGCAE)

- Welsh Government
- National Clinical Directors
- Representatives from NICE
- Clinicians
- Healthcare professionals
- Patient body representatives
- People with diabetes
- Research community
- The Data Coordination Board (DCB)

Scope of the collection

Under section 259(1) of the Health and Social Care Act 2012, this Notice is served in accordance with the procedure published as part of the NHS Digital duty under section 259(8) of the Act for all maternity units with a joint diabetes and maternity service within NHS Trust in England.

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

Form of the collection

The following patient identifiable information is included in the collection:

- NHS Number
- Date of birth
- Postcode

Full details of the data to be collected can be found in the NPID audit: list of information collected form under the “User documents” section of the NPID website [here](#).

Manner of the collection

Data is collected from each secondary care maternity unit with a joint diabetes and maternity service within NHS trusts using the NPID online data collection tool. The NPID audit is a continuous collection with data collected and submitted throughout the year.

Users must register for the online data collection tool and gain Caldicott Guardian approval.

Guidance on how to register is available under the “How to participate” section of the NPID website [here](#).

The Participant Information Leaflet can be found under “User documents” on the NPID webpage [here](#).

The required information can be collected using the NPID data collection form found under “User documents” on the NPID webpage [here](#).

Period of the collection

The NPID audit is a continuous collection and data can be submitted throughout the year.

A cut of the data is taken on an annual basis with results fed back to participating units and published on a regular basis.

Annual data (based on pregnancies with a recorded outcome between 1 January and 31 December) should be entered into the online tool for the audit by February each year (dates to be confirmed on the [NPID website](#)).

Subsequent collections will take place each year within the same period with specific details available [here](#).

Burden of the collection

Steps taken by NHS Digital to minimise the burden of collection

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 Digital has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This assessment is carried out by the Data Standards and Assurance Service (DSAS) which carries out a Detailed Burden Assessment (DBA) and reports findings and recommendations, as part of the overarching Data Coordination Board (DCB) process. The DSAS oversees the development, assurance and acceptance of information standards, data collections and data extractions for the health and social care system in England.

Detailed burden assessment findings

The below recommendations were drawn from the detailed burden assessment report.

For the collection owner:

1. Investigate if it would be useful to users to see NPID data regarding the different insulin delivery types (injection vs pumps) in type 1 diabetes and newer medication use in type 2 diabetes.
2. Explore options to obtain results from the retinal screening data as an automated extraction.

Assessed costs

The associated burden of the data collection is:

Burden on providers	£168k	Based upon, 172 Acute Foundation Trust.
Set up costs for the data collection	£84.5k	Includes NHS Digital and supplier costs, representing a maximum estimate.
Other costs of the data collection	£87.5k	The cost to analyse and publish the data.
Total costs	£340k	Overall, total costs of the collection.

Help us to identify inappropriate collections

NHS Digital's Challenging Burden Service (CBS) offers a Collection Referral Service which is a simple and confidential way to allow data providers to refer data collections they feel would benefit from further scrutiny.

For more details and information on how to refer a collection, please visit:
<https://digital.nhs.uk/services/the-challenging-burden-service>

Help us to improve this product

We are continually looking at ways to improve the products that we provide to our customers. By taking a few minutes to complete the following questions you will help us to improve future DPNs.

To complete the short survey, please visit:

<https://nhs-digital.citizenspace.com/rocr/ef5cf941>

For further information

www.digital.nhs.uk

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