National Pregnancy in Diabetes Audit

Data Quality Statement

Published 10th October 2019
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Introduction

The National Pregnancy in Diabetes (NPID) audit is a continuous data collection that measures the quality of care and outcomes for women with pre-gestational diabetes who become pregnant and aims to support quality improvement.

All joint antenatal diabetes services in England and Wales are eligible to collect and submit audit data from consenting women. The audit has also received data from the Isle of Man.

The NPID audit measures against national standards set out in the NICE (National Institute for Health and Clinical Excellence) guideline NG3 (https://www.nice.org.uk/guidance/ng3), previously NICE Clinical Guideline CG63.

The audit seeks to address three key questions:

- Were women adequately prepared for pregnancy?
- Were appropriate steps taken during pregnancy to minimise adverse outcomes to the mother?
- Did any adverse outcomes occur?

The fifth national report on pregnancies ending in 2018 was published on 10th October 2019, together with service level data aggregated for pregnancies ending in 2016, 2017 and 2018.

The audit is part of the National Diabetes Audit (NDA) programme, and is managed by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

The NDA is delivered by NHS Digital in partnership with Diabetes UK and is supported by Public Health England (PHE).

Relevance

The NPID audit monitors the quality of care for women with diabetes who become pregnant against national standards. (NICE CG63 superseded by NG3 in February 2015 and NICE Quality Standard for Diabetes 6.)

The NICE guideline was developed in response to the Confidential Enquiry into Maternal and Child Health (CEMACH) survey of diabetes and pregnancy in 2002-03, which identified severe deficiencies in the provision of care before and during pregnancy for women with diabetes in England and Wales and poor outcomes against international standards.

The audit results will be relevant to women with diabetes who are pregnant or may become pregnant and to all those involved in planning and delivering care to women with diabetes, such as:

- Diabetes and maternity services
- Primary care teams

1 www.nice.org.uk/guidance/QS6
2 www.hqip.org.uk/national-programmes/a-z-of-clinical-outcome-review-programmes/cmace-reports
• Specialist diabetes services
• Family planning services
• Clinical Commissioning Groups (CCGs) and Local Health Boards (LHBs)
• Public Health programmes
• Patient education programmes
• Diabetes and maternity networks
• Diabetes support groups and charities.

The audit published data for the first time at service level in the 2015 report. Service level data is available alongside the publication. Antenatal diabetes services will be able to use their data to identify areas of care to target with quality improvement work.

Coverage

It is difficult to assess accurately the level of participation in the audit, as a definitive list of antenatal diabetes services is not available.

The 2019 National Maternity and Perinatal Audit (NMPA) Organisational Survey\(^3\) listed 164 maternity services in England and Wales with a multidisciplinary diabetes team. 152 (93 per cent) of these maternity services submitted 2018 data to the NPID audit. In addition, NPID received submissions from 19 services which we were unable to reconcile with the services on the NMPA list.

In England the data is collected under direction by NHS England, it is assumed that all women who are eligible for the audit, from all eligible sites, are entered. However this cannot be verified as this information is not collected anywhere else, therefore case ascertainment cannot be calculated accurately. In Wales and the Isle of Man the antenatal diabetes team need to obtain explicit consent from each woman for the collection and submission of her data. No record is kept of how many women did not consent, so similarly to England it is not possible to calculate case ascertainment.

Data has been published at the following geographic levels:

• National report – England and Wales 2018 data.

Accuracy and Reliability

To minimise the burden of data collection and submission, the audit data is partly collected from antenatal diabetes services and partly obtained by linking the directly collected data to:

\(^3\) [http://www.maternityaudit.org.uk/Audit/Charting/Organisational](http://www.maternityaudit.org.uk/Audit/Charting/Organisational)
- National Diabetes Audit (NDA) data
- Hospital Episode Statistics (HES) data
- Patient Episode Database for Wales (PEDW) data
- Maternity Services Dataset (MSDS)

**Directly entered data**

All data collected by the NPID audit should already be stored in clinical records; no additional data should need to be collected.

The majority of the data collected by the NPID audit is entered into a custom-built secure online database by staff at antenatal diabetes services. As there is no facility to upload a pre-populated data file, data entry is manual which introduces a risk of data entry error. Several validation methods are used to mitigate this risk (see Validation section below).

The majority of the data fields are mandatory items, which means completeness is generally high, although a ‘Don’t Know’ response is available for many questions.

Until 2015, data from hospitals in the North East of England was collected by the Northern Diabetes in Pregnancy (NorDIP) survey and securely transferred to NHS Digital. This means that mandatory data values may be missing in data from the North East of England but also means that the data had been validated and had much fewer integrity issues than data supplied directly to the NPID audit by other participating services.

**Linked data**

Linkage to the National Diabetes Audit core dataset is conducted to enrich the NPID dataset with information on ethnicity and deprivation, and also to provide additional details on diabetes type where this is missing in NPID.

Ethnicity and Lower Super Output Area (LSOA) of residence were obtained for 98 per cent of women in the NPID audit by linking to the most recent NDA data for the women (see the Methodology paper available at https://digital.nhs.uk/data-and-information/publications/statistical/national-pregnancy-in-diabetes-audit/national-pregnancy-in-diabetes-annual-report-2018 for fuller details of the linkage process).

Year of diabetes diagnosis was obtained for 95 per cent of women in the NPID audit by linking to the earliest diagnosis year recorded in any year of NDA data.

Diabetes type was added to the NPID audit collection for direct data entry from 1 Jan 2015. For 2014 records where diabetes type was not retrospectively entered directly to the NPID audit record, and for subsequent records where the diabetes type remained unknown in NPID, this has been obtained (where possible) by linking to NDA data.

Where it has not been possible to obtain these data items via linkage this may be because:

- The woman’s GP practice did not participate in the NDA or-
- The woman registered a Type 1 opt-out so that her data was not included in the GP practice’s NDA submission or-
- The woman was diagnosed with diabetes after 31 March 2018 or-
These data items were left blank in the NDA submission

Following the NDA linkage almost all records (more than 99.5%) had a known diabetes type. Onset of labour and mode of delivery were obtained for 89 per cent of 2016 and 87 percent of 2017 pregnancies reported by services in England by linking to the relevant financial years of HES, allowing for up to 7 days difference in pregnancy end date between the NPID audit data and the HES episode data.

The relative timing of the NPID audit dates and HES release dates means that it is not yet possible to link the 2018 NPID audit data.

However, onset of labour was missing or coded as ‘not known’ for 16 per cent of linked pregnancies and the delivery method was missing or coded as ‘not known’ for 10 per cent of linked pregnancies.

Although 82 per cent of 2016 and 91 percent of 2017 pregnancies could be linked to a hospital episode record in the PEDW data, onset of labour was missing or coded as ‘not known’ for 12 per cent of linked pregnancies and the delivery method was missing or coded as ‘not known’ for 12 per cent of linked pregnancies.

**Validity**

The data entry system validates certain data items such as height, weight and HbA\textsubscript{1c} values at the point of data entry, so that records can only be submitted where values are within the valid range.

For questions with categorical response options (e.g. Pregnancy Outcome), users must choose a response option from a drop down list so only valid data values can be entered.

**Integrity**

As the audit records several dates in each pregnancy, date entry errors may make a record internally inconsistent. For example, the first contact with the antenatal diabetes team may be recorded as after the pregnancy end date or the first HbA\textsubscript{1c} measurement may be recorded at a date before the woman was pregnant.

The number of such errors has been reduced by:

- Providing an annual data quality report back to the submitting antenatal diabetes service for them to review and correct the errors identified
- Introducing validation within the data entry system that cross-checks the dates entered at the point of data entry and flags errors which must be resolved before the record can be submitted (as of 1 Jan 2015)
- Making available reports within the online system that flag certain unlikely combinations to those entering the data so these can be checked prior to submission deadlines
- Allowing each service to download its own raw data from the data entry system for review
• Providing management reports for each submitting organisation through the Clinical Audit Platform. These reports reproduce some of the measures used in the NPID report so that the impact of missing data on calculated measures can be seen.

Some other issues that have been identified as the dataset accumulates over time are:

• Second pregnancies for the same woman being entered incorrectly i.e. as twins with different pregnancy end dates, rather than two separate pregnancies

• Inconsistent diabetes type information for different pregnancies for the same woman

There are also a small number of medically implausible combinations of values present in the data, such as women recorded as having Type 1 diabetes not on insulin. As it is not possible to correct these, they have been left in the data and flagged as a data quality issue where used in the report.

Data cleaning

Following the data quality review period, a final dataset was extracted.

Where outstanding errors remained, the data was cleaned by NHS Digital.

Where possible the majority of the data from each record was used and only the invalid dates removed. For date errors, pregnancy end date was assumed correct and dates inconsistent with this were set to missing.

A small number of errors that were flagged on the data quality reports remained uncorrected and could not be resolved by cleaning rules, such as:

• All other data completed but ‘Alive at 28 days’ left blank

• Fundamental errors such as same outcome data recorded against two different pregnancies

Just over 200 records with such unresolved errors were excluded from the final cleaned dataset for 2014-2018. Just over one third of these records were excluded because the ‘Alive at 28 days’ field had been left blank.

Allocation of records

Different antenatal diabetes services may be involved in a woman’s care during a pregnancy, for example if the woman moves house or needs to be transferred to a more specialist service.

For 2014 data, NPID audit data was linked only to the service submitting the data, which may have provided care throughout the pregnancy, only for the beginning, or only for the end.

From 2015, the NPID audit has recorded ‘Booking Hospital’ and ‘Delivery Hospital’ for each pregnancy.
**Timeliness**

This publication includes pregnancies ending on or before 31 December 2018. The submission deadline for this data was 15th February 2019, with data quality amendments permitted up to 31st March 2019.

The time lag to publication is 9 months from the end of the audit period and 6 months after the end of the data quality amendment period.

Due to the relative timing of the NPID audit cycle and HES and PEDW data releases, onset of labour and mode of delivery data in this publication covers 2017 and 2018 NPID audit data linked to 2015/2016, 2016/2017 and 2017/2018 HES and PEDW years.

**Accessibility**

The report is published as a PDF document and as a PowerPoint presentation so that data users can take the charts and tables directly into their own presentations. Tables and charts used in the report are also provided in Excel format. A summary sheet highlighting the key findings and recommendations is also available.

Service level reports are in Excel format and local data users can either print their own report, or copy charts and tables into their own documents.


**Comparability**

**Over time**

The same data items have been collected over the 6 years of the audit to date with improvements made to data quality through minor collection changes and the addition of validation rules as explained in the validity section of this document.

The number of women recorded in the NPID audit and the number of services submitting data has increased each year since 2013:

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of women</th>
<th>Number of services</th>
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<tbody>
<tr>
<td>2013</td>
<td>1,697</td>
<td>128</td>
</tr>
<tr>
<td>2014</td>
<td>2,537</td>
<td>150</td>
</tr>
<tr>
<td>2015</td>
<td>3,036</td>
<td>155</td>
</tr>
<tr>
<td>2016</td>
<td>3,297</td>
<td>172</td>
</tr>
<tr>
<td>2017</td>
<td>3,840</td>
<td>166</td>
</tr>
<tr>
<td>2018</td>
<td>4,390</td>
<td>164</td>
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The increase in the number of women being recorded in the audit is likely to be due partly to more complete annual data submitted by units as the audit has become more established, and partly due to an increase in Type 2 diabetes amongst women of child bearing age. Differences in audit results over time may be due to changes in participation and data submission rather than changes in service delivery.

Other sources

Other than the NPID audit, the last national survey of pregnancy in women with pre-existing diabetes was the CEMACH survey in 2002-2003. There have been some regional pregnancy in diabetes surveys since then but no up to date national information is available outside the NPID audit. Comparisons with the CEMACH survey, particularly where data for all diabetes types was reported together, may show differences which are in part due to the increase in the proportion of women with Type 2 diabetes in the NPID audit compared to CEMACH.

Assessment of User Needs and Perceptions

The NPID Audit is supported by an advisory group including patient representatives, Diabetes UK, clinicians, researchers and analysts. The advisory group provides input to the design of the analysis and the report as well as the direction and development of the audit. The advisory group sought feedback in summer 2015 regarding the process of participating in the audit and the way the data was reported from services participating in the NPID audit. The most common request was for service level data to be produced. Due to the small numbers of pregnancies in women with diabetes, accumulated data over 3 years was needed to be able to publish data at service level. Service level reports were published for the first time alongside the 2015 report, and have been repeated in subsequent publications, including a larger set of data items.

Your feedback on this publication is welcome and may be sent to Enquiries@nhsdigital.nhs.uk (please include ‘National Pregnancy in Diabetes Audit’ in the subject line).

Alternatively you can call our contact centre on 0300 303 5678 or write to CARMS, NHS Digital, 1 Trevelyan Square, Boar Lane, Leeds, LS1 6AE.

Confidentiality, Transparency and Security

Patient identifiable data is collected by the NPID audit and obtained by linkage to other data sources. This information is held securely and with restricted access. Identifiable data is only released by NHS Digital where the release meets NHS Digital Information Governance procedures.

For Wales, the NPID audit only receives data about women who have consented for their data to be included in the audit. Antenatal diabetes services participating in the audit provide women with a patient information leaflet outlining the data that will be collected and how it
will be used. If they agree for their data to be recorded in the audit, the women are asked to sign a consent form.

Women can withdraw their consent at any time and ask for their information to be removed by asking their antenatal diabetes service to inform NHS Digital or by contacting NHS Digital directly.

Although in England NPID data is collected under direction, women are able to opt-out of the data collection at any time. Patient information leaflets and posters are available in all clinics in England and there is detailed information on who to contact to opt out.