NPID
A summary report of the National Pregnancy in Diabetes Audit for England and Wales

National Pregnancy in Diabetes Audit: are services providing good quality care to women with diabetes in pregnancy?

2020
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Report at a glance 2020</td>
<td>3</td>
</tr>
<tr>
<td><strong>Background</strong></td>
<td></td>
</tr>
<tr>
<td>- About this report</td>
<td>4</td>
</tr>
<tr>
<td>- What care to expect</td>
<td>5</td>
</tr>
<tr>
<td><strong>The results</strong></td>
<td>6</td>
</tr>
<tr>
<td>- Characteristics of women in the audit</td>
<td>6</td>
</tr>
<tr>
<td>- Preconception care</td>
<td>6</td>
</tr>
<tr>
<td>- Care during pregnancy</td>
<td>8</td>
</tr>
<tr>
<td>- Outcomes for women and babies</td>
<td>8</td>
</tr>
<tr>
<td><strong>Our recommendations</strong></td>
<td>10</td>
</tr>
<tr>
<td>- For women with diabetes</td>
<td>10</td>
</tr>
<tr>
<td>- For healthcare professionals</td>
<td>11</td>
</tr>
<tr>
<td>- For commissioners and networks</td>
<td>11</td>
</tr>
<tr>
<td><strong>Further information</strong></td>
<td>12</td>
</tr>
<tr>
<td>- What is the National Pregnancy in Diabetes Audit?</td>
<td>12</td>
</tr>
<tr>
<td>- Why do we audit pregnancy and preconception care for women with diabetes?</td>
<td>12</td>
</tr>
<tr>
<td>- Where to go for more information</td>
<td>12</td>
</tr>
<tr>
<td>- Explanation of words used in this booklet</td>
<td>13</td>
</tr>
</tbody>
</table>

**Note:** All results in this document are taken from the National Pregnancy in Diabetes audit 2020 report.
The National Pregnancy in Diabetes audit measures the quality of care provided to women with diabetes through pre-conception, pregnancy and birth. The information in the audit is collected and submitted by staff in specialist services in England and Wales. This report covers 2020.

### The results

#### Characteristics of the Women

**More Women with Type 2 than Type 1 Diabetes**
- More women with type 2 diabetes face additional healthcare inequalities:
  - More likely to live in poverty
  - More likely to be of minority ethnicity

**Before Pregnancy**
- **Women should be well prepared for pregnancy by:**
  - Having HbA1c below 48 mmol/mol
  - Taking 5mg folic acid
  - Not taking potentially harmful medication

**Only 1 in 8** women with diabetes were well prepared, unchanged since 2014

#### During Pregnancy

**Only Half**
- Only half were seen by the antenatal diabetes team in the first 10 weeks of pregnancy

**Over 1 in 10**
- Over 1 in 10 women with type 1 diabetes went into hospital with hypoglycaemia (low blood sugar levels) during pregnancy, this has increased since 2014

#### Birth

**Higher Levels for Women with Diabetes**
- Although overall risk is low there are higher levels for women with diabetes
- Stillbirths
- Neo-natal death
- Congenital abnormalities

**LGA Babies for Women with Type 1 Diabetes**
- LGA babies for women with type 1 diabetes were large for gestational age, increasing the risk of problems during birth

### We Say

There has been no improvements in the care for women with diabetes in pregnancy since the first audit in 2014. Services across England and Wales are experiencing similar challenges which suggests that system-wide change is needed in the high-risk area of care.

Targeted weight management services and diabetes prevention programmes which better meet the needs of the growing numbers of younger women with early-onset type 2 diabetes (or previous gestational diabetes) are vital.
In October 2021, NHS Digital published the National Pregnancy in Diabetes Audit 2020 report. This report has been prepared by Diabetes UK and summarises this information in a way that is more accessible for people with diabetes. This report is also for anyone else interested in the quality of pregnancy care for women with diabetes.

The aim of the audit is to measure the quality of antenatal care and pregnancy outcomes for women with pre-gestational diabetes. Pre-gestational diabetes refers to women who had a diagnosis of type 1 or type 2 (and other) diabetes prior to pregnancy. We try to answer the following questions:

- Were women with diabetes adequately prepared for pregnancy?
- Were appropriate steps taken during pregnancy to minimise adverse outcomes to the mother?
- Were adverse neonatal outcomes minimised?

This report is based on patient information collected from 162 antenatal diabetes services in England and Wales in 2020. 4,540 pregnancies in 4,525 women were recorded in this period. As well as the national level report, we have also published findings for each antenatal diabetes service that took part. This means that staff from each service can look at the quality of care they provide, what they are doing well and what they need to improve on.

About this report

This report summarises the key findings from the 2020 audit report. In the report we explain:

- What the national guidelines say about good quality care for women with diabetes in pregnancy
- The main findings from the 2020 audit report
- Recommendations for improvements to care for people with diabetes in pregnancy

Before writing this summary report, we talked to people with diabetes to find out what information they wanted to see and how to present the findings.

At the back of the report we explain what the audit is and why it is important to look at care for women with diabetes in pregnancy. There is also a glossary and details of where to find more information.
What care to expect

Getting the right care, both before conception and throughout pregnancy, is very important. Most women with diabetes have successful pregnancies and babies that are born safely. However, there are risks and these can lead to health problems for the mother, the foetus or the new born baby.

Some of the risks include:

**TO MOTHER**
- Having a severe low blood glucose episode (hypo)
- Problems with eyes and kidneys
- Having a large baby, which increases the chance of problems with birth

**TO BABY**
- Developing a birth defect
- Being stillborn or dying in the 28 days after birth
- Health problems that may require special or intensive hospital care

The National Institute of Health and Care Excellence (NICE) have developed guidelines to ensure that women have the right care, support and information to help them and their baby stay well. The NICE guidelines should be followed by all healthcare professionals.

Prior to pregnancy

Healthcare services should help women with diabetes to prepare for pregnancy by:
- Having good blood glucose management with an HbA1c level of below 48mmol/mol (where this is achievable without causing problematic hypoglycaemia)
- Using safe, effective contraception if HbA1c is above 86mmol/mol to avoid pregnancy until they are able to achieve better blood glucose control
- Taking 5mg folic acid to reduce risks of brain and spinal defects
- Stop taking certain medications that may potentially be harmful eg statins and ACE inhibitors/ARBs

During pregnancy

Healthcare services should provide the following antenatal care:
- Offer immediate contact with a joint diabetes and antenatal clinic
- Measure HbA1c levels at the booking appointment
- Continue measuring HbA1c levels in the second and third trimesters
- Be aware that level of risk to pregnancy increases with an HbA1c level above 48mmol/mol
- Undertake retinal screening at booking if not already done recently and at 16–24 weeks if needed

Birth and neonatal care

Healthcare services should:
- Advise women with no other complications to have an elective birth by induction of labour or caesarean section between 37° and 38° weeks of pregnancy
- Consider elective birth before 37° if there are any complications for the mother or the baby
- After birth, keep the baby with the mother unless there are clinical complications or clinical signs that warrant admission for intensive or special care
The results

Characteristics of women in the audit
There are now more pregnancies in women with type 2 diabetes than type 1 diabetes.

<table>
<thead>
<tr>
<th>Percentage of women included in the 2020 NPID audit</th>
<th>TYPE 1 DIABETES</th>
<th>TYPE 2 DIABETES</th>
<th>OTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>44%</td>
<td>54%</td>
<td>UNDER 2%</td>
</tr>
</tbody>
</table>

Women with type 2 diabetes were older, had a higher Body Mass Index (BMI) and had a shorter duration of diabetes than women with type 1 diabetes.

Women with type 2 diabetes face additional healthcare inequalities. They are more likely to live in poverty and/or be of minority ethnicity.

Preconception care
To be well prepared for pregnancy women with diabetes should:

- Have a first trimester HbA1c below 48mmol/mol
- Be taking 5mg folic acid daily
- Stop taking medications that could harm their baby in the womb

Being well prepared for pregnancy matters because having a higher than target HbA1c, not taking 5mg folic acid and continuing certain medications can lead to increased risk of the baby developing congenital abnormality, being stillborn or dying within the first 28 days of life. A congenital abnormality means a health problem or physical abnormality which occurs in the womb.

How many women were well prepared for pregnancy?

7 out of 8 women were not well prepared for pregnancy. This is similar for women with type 1 diabetes and type 2 diabetes. This has not improved since the first audit in 2014.

Current approaches to pregnancy preparation are not working for most women with diabetes, particularly Black women and those living in poverty.

For the first time we compared pregnancy preparation in pregnancies known to be second or subsequent pregnancies with those that were first pregnancies. There was no improvement in pregnancy preparation between first and subsequent pregnancies. This highlights that current approaches are not working.
How many women achieved the recommended blood glucose levels in early pregnancy?

NICE guidelines recommend that HbA1c levels in the first trimester (first 12 weeks of pregnancy) should be below 48mmol/mol. Having an HbA1c level below 48mmol/mol helps reduce the risk of miscarriage, birth defects in babies, stillbirth and neonatal deaths.

The table below shows the percentage of women with type 1 diabetes and type 2 diabetes with a first trimester HbA1c of 48mmol/mol or less. The proportion of women achieving this target has not improved since the first audit in 2014.

<table>
<thead>
<tr>
<th></th>
<th>TYPE 1 DIABETES</th>
<th>TYPE 2 DIABETES</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbA1c less than 48mmol/mol</td>
<td>17.5%</td>
<td>38.8%</td>
</tr>
</tbody>
</table>

How many women were taking 5mg folic acid before and during pregnancy?

NICE guidelines recommend that all women with diabetes should take 5mg of folic acid daily, starting well before conception and continuing for the first 12 weeks of pregnancy. This is a much higher dose than is available over the counter so you must have a prescription from your doctor for this. Folic acid helps reduce the risk of brain and spine defects in babies. The risk is higher in babies born to mothers with diabetes.

Just over 2 in 5 women with type 1 diabetes were taking the recommended 5mg folic acid before pregnancy. Only 1 in 5 women with type 2 diabetes took the recommended dose of folic acid.

How many women were taking potentially harmful medications while pregnant?

The only medications for treating diabetes that are known to be safe to take while pregnant are insulin and metformin. NICE Guidelines recommend that women taking tablets other than metformin to control their blood glucose levels should stop doing so before pregnancy starts and use insulin instead during their pregnancy.

Women with diabetes may also be on treatment for high blood pressure, such as angiotensin-converting enzyme inhibitors (ACE inhibitors) and angiotensin receptor blockers (ARBs) or treatment for high cholesterol (statins) to lower their risk of complications of diabetes. Women should stop taking these medications before pregnancy or as soon as they know they are pregnant.

The percentage of women with type 1 (3.2%) diabetes on adverse medication was significantly lower than women with type 2 diabetes (12.2%). This means that over 1 in 10 women with type 2 diabetes were taking medications that are potentially harmful during pregnancy.

We Say

There is a clear link between early pregnancy HbA1c and risk of serious adverse outcomes for babies. It is deeply concerning that so few women are well prepared for pregnancy and that little has changed since the first audit in 2014. A real step-change is needed here. It’s vital that all women with diabetes between the ages of 15 – 50 years are offered access to safe and effective contraception and family planning advice.
Care during pregnancy

How many women were admitted to hospital for severe hypoglycaemia or diabetic ketoacidosis (DKA) during pregnancy?

Hypoglycaemia, or hypo, happens when there is too little glucose in the blood. A hypo is a blood sugar reading of below 4.0 mmol/L and a severe hypo is a blood sugar reading of 3.0 mmol/L or below. Hypoglycaemia carries significant preventable risks for pregnant women and their babies.

Over 1 in 10 women with type 1 diabetes went into hospital with hypoglycaemia during their pregnancy. A smaller percentage of women with type 2 diabetes went into hospital with hypoglycaemia during their pregnancy. These figures increased between 2014 and 2019.

DKA mainly happens in people with type 1 diabetes when a severe lack of insulin means the body cannot use glucose for energy and switches to burning fatty acids. This produces acidic ketones which can cause severe illness and even death.

3.2% of women with type 1 diabetes were admitted to hospital with DKA during their pregnancy.

WE SAY

Having regular appointments with the joint diabetes and antenatal team is very important to care for and support pregnant women with diabetes. Both hypoglycaemia and DKA are preventable risks to women with diabetes and their babies.

Outcomes for women and babies

What are some of the adverse outcomes that can happen for the baby?

Birthweight

Large for gestational age (LGA) describes babies that are above the highest 10% of the population for size at birth. Most babies who are LGA are delivered normally without any problems. However, there is an increase in the risk of problems during birth and the need for help delivering the baby. Small for gestational age (SGA) describes babies that are below the lowest 10% of the population for size at birth.

Over half of babies born to mothers with type 1 diabetes and a quarter of babies born to mothers with type 2 diabetes were LGA. This has increased significantly since 2014. 5% of babies born to women with type 1 diabetes and 10% of babies born to women with type 2 diabetes were SGA.

Stillbirths and neonatal deaths

Almost all pregnancies in women with diabetes end successfully. However, women with diabetes have a higher chance than women in the general population of having a stillborn baby or a baby that dies within the first 28 days of life (called a neonatal death).
Admissions to neonatal care units
Half of singleton babies (ie not twins or other multiple births) born to women with type 1 diabetes and a third of those born to women with type 2 were admitted to neonatal care in 2020. These percentages haven’t changed since the first audit in 2014.

The average length of stay in neonatal care units was 6 days for babies of women with type 1 diabetes and 5 days for women with type 2 diabetes.

Are there links between blood glucose levels in early pregnancy and pregnancy outcomes?
The risk of having a premature baby (before 37 weeks gestation), a large for gestational age baby and the baby needing admission to neonatal care increased with higher Hba1c in late pregnancy.

4 in 10 women with type 1 diabetes meet the target HbA1c levels in late pregnancy. Over 7 in 10 women with type 2 diabetes meet this target. The percentage of pregnancies meeting these targets has not changed since 2014.

Women who use an insulin pump are more likely to have a late pregnancy HbA1c within target than women using multiple daily injections of insulin.

Our experts by experience (women with diabetes who have had a recent pregnancy) say:

Good blood glucose control is essential to avoid risk to pregnant women and their babies. We cannot underestimate the challenges of providing pregnancy care and support for women with diabetes during the COVID-19 pandemic and are grateful for the work services have put into caring for women with diabetes. But we remain concerned that women are missing out of necessary checks and support.
Our recommendations

For women with diabetes

Thinking about having a baby
- Ask someone from your diabetes team for information and advice before you stop using contraception
- Try to keep your blood glucose on target (HbA1c below 48mmol/mol)
- Speak to a healthcare professional if you need help to reach these HbA1c levels
- If your HbA1c is more than 86mmol/mol continue or start to take safe, effective contraception to avoid an unplanned pregnancy
- Start using 5mg folic acid – you will need a prescription from your doctor for this

When you get pregnant
- Try to keep your blood glucose level on target (HbA1c below 48mmol/mol)
- Make sure you are referred to your local diabetes antenatal team and attend all the recommended appointments
- Continue to take 5mg folic acid until the end of week 12 of your pregnancy
- Make sure you get all the health checks you need, including eye screening, kidney test, baby scans and blood tests
- Ask for a medication review to ensure you are not taking any medication that is unsuitable for pregnant women
For healthcare professionals

- Continue to submit your data to NPID
- Look at your local level NPID data to prioritise areas for improvement and measure the effectiveness of changes in pathways and treatment
- Develop communications to help all women with diabetes, irrespective of social and cultural barriers, understand the importance of preparing for pregnancy
- Use the Diabetes UK diabetes, contraception and pregnancy Information Prescription
- Ensure that locally commissioned diabetes education programmes include information about contraception and pregnancy preparation
- Develop clear pathways for newly pregnant women into timely and responsive joint antenatal diabetes services
- Develop services that help women with diabetes receive high quality support to optimise glucose control and minimise risk to women and their babies

For commissioners and networks

At regional network level

- Develop initiatives and test communication, education, pathway and treatment changes through collaborative working between commissioning, primary care, maternity, diabetes and public health teams

At national level (NHS England, NHS Wales, Public Health England and Public Health Wales)

- Publicise and promote the need for universal step-changes in the approaches to this uncommon but high risk health challenge
- Lead on promoting local cross-disciplinary teams to develop and test innovative approaches to the complex challenges of effective pregnancy preparation and antenatal care
- Advocate and support local network communication and pathway initiatives
- Support and promote new evidence based therapies when they emerge
- Ensure ongoing measurement of service effectiveness using NPID
Further information

What is the National Pregnancy in Diabetes audit?

The audit is a project that checks the quality of diabetes care provided to women with diabetes who become pregnant. The first audit took place in 2013. Since then it has collected information each year about pre-conception, pregnancy and birth for women with diabetes. Specifically, we look at:

- How well women with diabetes are prepared for pregnancy
- Whether the treatment and care given to women reduces the risk of certain complications during pregnancy
- Whether the treatment and care minimises the risk of the baby developing abnormally, or dying before or shortly after birth

Why do we audit pregnancy care for women with diabetes?

The National Institute for Health and Care Excellence (NICE) produces the guidelines for the treatment of women with diabetes throughout pregnancy. All services should follow these guidelines to provide good quality diabetes care to women who become, or want to become pregnant. The findings from the audit show services how they compare to other services. The information collected helps highlight areas where diabetes care is good and where there is a need for improvement and changes that will help services raise their overall standards.

The audit findings are publicly available, so anyone can see their local service’s findings. You can find your service’s audit findings on the NHS Digital website.

Where to go for more information

The National Diabetes Audit


Diabetes UK

For more information about diabetes, including living with diabetes, go to [www.diabetes.org.uk/guide-to-diabetes](http://www.diabetes.org.uk/guide-to-diabetes) or call Diabetes UK’s Helpline on 0345 123 2399 for advice and support.

For information about getting involved in making a difference to diabetes treatment and care, go to [www.diabetes.org.uk/get_involved/campaigning/diabetes-voices](http://www.diabetes.org.uk/get_involved/campaigning/diabetes-voices)

To find out more about Diabetes UK’s activities in your area, go to [www.diabetes.org.uk/in_your_area](http://www.diabetes.org.uk/in_your_area)

Family Planning Association

Information and advice about contraception, including an easy-to-use tool to find the best contraceptive methods for you. Go to [www.fpa.org.uk](http://www.fpa.org.uk)

National Institute for Health and Care Excellence (NICE) guidelines

For information about how NICE develops guidelines, go to [www.nice.org.uk](http://www.nice.org.uk)

Healthcare Quality Improvement Partnership (HQIP)

To find out more about clinical audits – and patient involvement in national clinical audits – you can visit the HQIP website at [www.hqip.org.uk/involving-patients](http://www.hqip.org.uk/involving-patients)
Explanation of words used in this booklet

**Audit**
A way of gathering information and measuring local NHS organisations’ performance and quality of care against national guidelines, from which come recommendations for improvements.

**Blood glucose**
The main sugar the body makes from the food we eat. Glucose travels in the bloodstream, providing energy to all the body’s living cells. However, the cells cannot use glucose without the help of insulin.

**Complications of diabetes**
Harmful effects that may happen when a person has diabetes.

Some effects, such as hypos, can happen any time. Others develop when a person has had diabetes for a long time. These include damage to the retina of the eye (retinopathy), the blood vessels (angiopathy), the nervous system (neuropathy), and the kidneys (nephropathy).

Studies show that keeping blood glucose levels as close as possible to those of a person without diabetes may help prevent, slow, or delay harmful effects to the eyes, blood vessels, kidneys, and nerves.

**Congenital anomaly**
Abnormal development of the baby’s limbs, spine or internal organs. Most congenital anomalies develop during the early stages of pregnancy.
**Diabetes**

Diabetes is the shortened name for the health condition called diabetes mellitus. Diabetes happens when the body cannot use blood glucose as energy because of having too little insulin or being unable to use insulin. See also Type 1 diabetes and Type 2 diabetes.

**Diabetic Ketoacidosis (DKA)**

DKA is a dangerous complication that happens when the body of a person with diabetes starts running out of insulin. During DKA, when the body has no insulin to use, it switches to burning fatty acids. This produces acidic ketones, which can cause severe illness and death.

While DKA mostly happens to people with type 1 diabetes, DKA can also develop in people with type 2 diabetes.

**Gestational age**

Gestational age is the term used to describe the length of a pregnancy from the date of the mother’s last menstrual period.

**HbA1c**

The HbA1c test uses a blood sample to measure a person’s average blood glucose level over the previous 2 or 3 months. The result is given in mmol/mol.

**Hypoglycaemia (or Hypo)**

Hypoglycaemia happens when there is too little glucose in the blood. In the audit data collection, a hypo is a blood sugar reading of below 4.0 mmol/L.

**NICE**

The National Institute for Health and Care Excellence (NICE) is the independent regulatory body providing national guidance to the NHS on new and existing medicines, treatments, and procedures.

**Type 1 diabetes**

Type 1 diabetes develops when the body permanently destroys its own insulin-producing cells. When this happens a person needs regular insulin, given either by injection or an insulin pump.

**Type 2 diabetes**

A condition in which the body either makes too little insulin, or cannot use the insulin it produces to turn blood glucose into energy. Diet and exercise is often enough to control a type 2 diabetes condition, but some people also need diabetes medication or insulin.
The National Diabetes Audit (NDA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit (NCA) programme. The NDA is managed by NHS Digital, formerly known as the Health and Social Care Information Centre (HSCIC), in partnership with Diabetes UK and is supported by the National Cardiovascular Intelligence Network (NCVIN), Public Health England.

The NDA receives invaluable support from people with diabetes, clinical staff and other health professionals across England and Wales.

We welcome your views on how we can improve this report

Please contact:
Samantha Dottin
Diabetes UK
Wells Lawrence House
126 Back Church Lane
London E1 1FH
T: 020 7424 1013
E: sam.dottin@diabetes.org.uk

NDA publications

NDA: National Diabetes Audit
- Care processes and treatment targets
- Complications and mortality
- Transition
- Type 1 diabetes
- Young people with type 2 diabetes

NPID: National Pregnancy in Diabetes Audit

NDFA: National Diabetes Foot Care Audit

NaDIA: National Diabetes Inpatient Audit
- NaDIA Harms

Non-diabetic Hyperglycaemia and Diabetes Prevention Programme audit