



2018

NPID

NATIONAL PREGNANCY
IN DIABETES AUDIT

**SUMMARY
REPORT**

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

National Pregnancy in Diabetes Audit:

are women with diabetes being provided
with good quality care in pregnancy?

A summary report of the National Pregnancy in Diabetes Audit
for England and Wales 2018

nda
NATIONAL DIABETES AUDIT

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Note: All results in this document are taken from the National Pregnancy in Diabetes audit 2018 report

Report at a glance 2018

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.

The results

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

DURING PREGNANCY

NEARLY HALF

of women with type 2 diabetes were not seen by the antenatal diabetes team in the first 10 weeks of pregnancy



OVER 1 IN 10

women with type 1 diabetes went into hospital with hypoglycaemia (low blood sugar levels) during pregnancy

BIRTH

HIGHER LEVELS FOR WOMEN WITH DIABETES

-  stillbirths
-  neo-natal death
-  congenital abnormalities

than for the general population

LGA BABIES FOR WOMEN WITH TYPE 1 DIABETES

OVER 1 IN 2 

were large for gestational age, which increases the risk of problems during birth

This report includes information on



4,400
PREGNANCIES IN 2018

FOR THE FIRST TIME, PREGNANCY IN WOMEN WITH TYPE 2 DIABETES WAS MORE COMMON THAN IN WOMEN WITH TYPE 1 DIABETES

WE SAY

There have 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 this high-risk area of care.

We need a national strategy that brings together:

-  maternity networks
-  diabetes networks
-  public health
-  women with diabetes

Background

In October 2019, NHS Digital published the [National Pregnancy in Diabetes Audit 2018 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 care for women with diabetes in pregnancy.

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 164 antenatal diabetes services in England and Wales in 2018. 4,400 pregnancies in 4,390 women were recorded in this period. As well as the national level report, NHS Digital have also published findings for antenatal diabetes services 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 2018 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 2018 audit report**
- 🌐 **Key findings after five years of NPID audit**
- 🌐 **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.

Background

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) has 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:



- Ensuring that women have good blood glucose management with an HbA_{1c} level of below 48mmol/mol (where this is achievable without causing problematic hypoglycaemia)
- Advocate using safe, effective contraception if HbA_{1c} is above 86mmol/mol to avoid pregnancy until they are able to achieve better blood glucose control
- Prescribe taking 5mg folic acid to reduce risks of brain and spinal defects
- Advise to stop taking certain medications that may potentially be harmful e.g. 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 HbA_{1c} levels at the booking appointment
- Continue measuring HbA_{1c} levels in the second and third trimesters
- Be aware that level of risk to pregnancy increases with an HbA_{1c} 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⁺⁰ and 38⁺⁶ weeks of pregnancy
- Consider elective birth before 37⁺⁰ if there are any complications for the mother or the foetus
- 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

For the first time, there were more pregnancies in women with type 2 diabetes than type 1 diabetes.

	TYPE 1 DIABETES	TYPE 2 DIABETES	OTHER
Percentage of women included in the 2018 NPID audit	47%	51%	2%

There is considerable regional variation in the percentage of women who have type 2 diabetes – from 39% of women in the south-west to 67% of women in London.

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.

Over 80% of women with type 1 diabetes were white compared to less than 50% of women with type 2 diabetes.

For women with type 1 and type 2 diabetes there were more pregnancies in women with higher levels of social deprivation.

Preconception care

How many women achieved the recommended blood glucose levels?

NICE guidelines recommend that HbA_{1c} levels in the first trimester (first 12 weeks of pregnancy) should be below 48mmol/mol. Having an HbA_{1c} 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 HbA_{1c} of 48mmol/mol or less.

	TYPE 1 DIABETES	TYPE 2 DIABETES
HbA_{1c} less than 48mmol/mol	15.6%	36.3%

Women with type 1 diabetes were much less likely to have an HbA_{1c} under 48mmol/mol than women with type 2 diabetes.

For type 1 diabetes, younger women (aged 15–24) are much less likely to have HbA_{1c} level of less than 48mmol/mol than older women.

For type 2 diabetes, Black and Asian women are less likely to have a 1st trimester HbA_{1c} of less than 48mmol/mol. Women who have had type 2 diabetes for longer are less likely to have a 1st trimester HbA_{1c} of less than 48mmol/mol.

For both type 1 and type 2 diabetes, as deprivation increases, the chance of having HbA_{1c} levels of less than 48mmol/mol is lower. Also, as BMI increases, the chance of having HbA_{1c} levels less than 48mmol/mol is lower.

The results

Q 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.

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

Q 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 medication before pregnancy or as soon as they know they are pregnant.

The percentage of women with type 1 diabetes on adverse medication was significantly lower than women with type 2 diabetes. 1 in 10 women with type 2 diabetes were taking medications that are potentially harmful during pregnancy.

Q How many women were well prepared for pregnancy?

To be well prepared for pregnancy women with diabetes should:

-  Have a first trimester HbA_{1c} below 48mmol/mol
-  Be taking 5mg folic acid daily
-  Stop taking medications that could harm their baby in the womb

Only 1 in 8 women in 2018 were well prepared for pregnancy. This is similar for women with type 1 diabetes and type 2 diabetes. This has not changed since the first audit in 2014.

WE SAY

It is concerning that so few women are well prepared for pregnancy and that little has changed since the first audit in 2014. Whilst there is considerable local variation in the percentage of women well prepared for pregnancy, the data suggests that much of this could be explained by characteristics of the women rather than differences in clinical practice.

The results

Care during pregnancy

How many women with diabetes were seen by the joint diabetes antenatal team early in pregnancy?

NICE guidelines recommend that all pregnant women with diabetes should have an appointment with a joint diabetes and antenatal team at the earliest opportunity.

3 in 4 women with type 1 diabetes and just over 2 in 4 women with type 2 diabetes had an appointment with the joint diabetes antenatal teams early in pregnancy (before 10 weeks).

The percentage of women being seen by the diabetes antenatal service prior to 10 weeks has not changed since 2014.

How many women were admitted to hospital for severe hypoglycaemia or diabetic ketoacidosis 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. This figure increased between 2014 and 2017.

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

WE SAY

Good blood glucose control is essential to avoid risk to pregnant women and their babies. Having regular appointments with the joint diabetes and antenatal team is very important to achieve and maintain an HbA1c level of below 48mmol/mol. Both hypoglycaemia and DKA are preventable risks to women with diabetes and their babies.

The results

What percentage of women with diabetes have early preterm or preterm births?

1 in 10 women with type 1 diabetes and 1 in 20 women with type 2 diabetes had an early preterm birth (before 34 weeks gestation). These rates have remained steady between 2014 and 2018.

Over 2 in 5 women with type 1 diabetes and over 1 in 5 women with type 2 diabetes had a preterm birth (before 37 weeks gestation). For women with type 1 diabetes this represents a significant increase between 2014 and 2018.

Women with type 1 diabetes are more likely to have a preterm birth if:

-  They are younger (aged 15–24)
-  Living in more deprived areas
-  Have had diabetes for more than 15 years
-  Having a 1st trimester HbA_{1c} of 48mmol/mol or higher

Women with type 2 diabetes are more likely to have a preterm birth if they have a 1st trimester HbA_{1c} of 48mmol/mol or higher. Black and Asian women are less likely to have a preterm birth.

Pregnancy outcomes

What are the outcomes for babies of women with diabetes?

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.

More than 2 in 4 babies born to mothers with type 1 diabetes and more than 1 in 4 babies born to mothers with type 2 diabetes were LGA. This has increased significantly since 2014. More than 1 in 10 babies born to women with type 2 diabetes were SGA.

Stillbirths and neonatal deaths

Almost all pregnancies in women with diabetes end successfully. 98.6% of the registered births recorded in the 2018 audit were live births. 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).

The stillbirth rate for women in the general population was 4.2 out of every 1,000 births. In the 2018 audit the rate for women with type 1 and type 2 diabetes was 13.7 out of every 1,000 births.

The neonatal death rate for women in the general population was fewer than 3 deaths per 1,000 live births. In the 2018 audit the rate for women with type 1 and type 2 diabetes was 10.4 per 1,000 live births.

WE SAY

Fortunately, the vast majority of babies born to mothers with diabetes have no adverse outcomes for the mother or the baby. However, these findings show how important it is for all women with diabetes to get the support they need to reduce the risks to themselves and their babies.

Key findings after five years of NPID audit

More women with type 2 diabetes are becoming pregnant than women with type 1 diabetes. These women are more likely to come from areas with higher social deprivation.

Since 2014, there has been:

- No change in the percentage of pregnancies where 1st trimester HbA_{1c} levels are less than 48mmol/mol
- No change in the percentage of pregnancies where 5mg folic acid has been taken prior to pregnancy
- No change in the percentage of pregnancies who were well prepared for pregnancy

Neonatal death, stillbirth, congenital anomaly, large and small for gestational age babies and neonatal unit admissions all remain very high in comparison with the general population.

These findings are a cause of considerable concern.

The processes and outcomes for women with diabetes and their babies remain poor and unchanged over 5 years. The reasons for this are complex and cannot be fully addressed by local services. Analysis of the audit data suggests that all services are experiencing similar challenges. Improvement is likely to require widespread changes to systems and/or treatment technologies and co-ordinated national initiatives. Some systems wide changes that may help include:

- Increased use of continuous glucose monitoring (CGMs) for women with type 1 diabetes (planned for England starting 2020) and other technologies as evidence emerges
- Targeted and improved patient education and support around contraception and pregnancy preparation, focusing on identifying and supporting those at highest risk
- Greater empowerment of women to make routine self-management decisions
- Increased awareness and training for all healthcare professionals
- Development and implementation of new pathways for identification, referral and treatment

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 (HbA_{1c} below 48mmol/mol)
- ✓ Speak to a healthcare professional if you need help to reach these HbA_{1c} levels
- ✓ If your HbA_{1c} 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 (HbA_{1c} 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

Our recommendations



For healthcare professionals

- ✓ Continue to submit your data to the NPID audit
- ✓ Look at your local level NPID audit 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 Information Prescription for diabetes, contraception and pregnancy
- ✓ Ensure that locally commissioned diabetes education programmes include information about contraception and pregnancy preparation
- ✓ Develop clear pathways for newly pregnant women for better access 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 the NPID audit

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](https://www.nice.org.uk) (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's 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](https://www.nhs.uk) website.

Where to go for more information

The National Pregnancy in Diabetes audit

Information about the National Pregnancy in Diabetes Audit and copies of the full report is available on the NHS Digital website <https://digital.nhs.uk/data-and-information/publications/statistical/national-pregnancy-in-diabetes-audit>

Diabetes UK

For more information about diabetes, including living with diabetes, go to 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

To find out more about Diabetes UK's activities in your area, go to 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

National Institute for Health and Care Excellence (NICE) guidelines

For information about how NICE develops guidelines, go to 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

Further information

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.

HbA_{1c}

The HbA_{1c} 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.

NDA PUBLICATIONS

NDA: National Diabetes Audit
Care processes and treatment targets
Complications and mortality
Insulin pump
Transition

NPID: National Pregnancy in Diabetes Audit
NDFA: National Diabetes Foot Care Audit
NaDIA: National Diabetes Inpatient Audit
NDPP: National Diabetes Prevention Programme Audit

We welcome
your views on how
we can improve
this report

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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.

