



2016

**NPID**

NATIONAL PREGNANCY  
IN DIABETES AUDIT

**SUMMARY  
REPORT**

**DiABETES UK**  
KNOW DIABETES. FIGHT DIABETES.

## **National Pregnancy in Diabetes Audit:**

are services providing good quality care  
for women with diabetes in pregnancy?

A summary report of the National Pregnancy in Diabetes Audit  
for England and Wales 2016

**nda**  
NATIONAL DIABETES AUDIT

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Date of publication:  
**September 2018**  
 Next review date:  
**Winter 2019**

**Note: All results in this document are taken from the National Pregnancy in Diabetes audit 2016 report**

# Report at a glance 2016

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 (of respondents to the 2016 audit)

This report includes information on



# 3,304

PREGNANCIES IN WOMEN WITH DIABETES

## ENCOURAGING

### TAKING POTENTIAL HARMFUL MEDICATIONS



### IMPORTANCE OF GOOD GLUCOSE CONTROL



In the vast majority of pregnancies for women with diabetes there are no adverse outcomes for the mother or the baby. Good glucose control to reduces risks during pregnancy

## IMPROVEMENT NEEDED

### BEING WELL PREPARED FOR PREGNANCY



having HbA1c below 48 mmol/mol, taking 5mg folic acid, not taking potentially harmful medication

### HYPOGLYCAEMIA



women with Type 1 diabetes went into hospital with hypoglycaemia during their pregnancy

### LGA BABIES FOR WOMEN WITH TYPE 1 DIABETES



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

## WE SAY

The results of the 2016 audit show that there has been little or no improvement in the care for women with diabetes in pregnancy since the first audit in 2014. Few women are well prepared for pregnancy. This means an increased chance of complications for mothers and babies. There are big variations in pregnancy and pre-conception care between:

- different services
- women with Type 1 and Type 2 diabetes
- women of different ages, ethnicities and different levels of social deprivation

Finding out why will be an important part of improving care for women with diabetes.

# Background

In October 2017, NHS Digital published the [National Pregnancy in Diabetes Audit 2016 report](#). This report has been prepared by Diabetes UK and summarises the information in the report 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 172 antenatal diabetes services in England and Wales in 2016. 3304 pregnancies in 3297 women were recorded in this period. As well as the national level report, we have also published findings for the 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 2016 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 2016 audit report
- Recommendations for improvements to care for women 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 people with women with diabetes in pregnancy. There is also a glossary and details of where to find more information.

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 to the mother include:

- 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

Some of the risks to the baby include:

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

## Background

# What care to expect

Getting the right care, before conception and throughout pregnancy, is very important.

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 48 mmol/mol
- Using safe, effective contraception if HbA1c is above 86 mmol/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

### 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 48 mmol/mol

### 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<sup>+0</sup> and 38<sup>+6</sup> weeks of pregnancy
- Consider elective birth before 37<sup>+0</sup> 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

## Preconception care

### How many women achieved the recommended blood glucose levels?

NICE guidelines recommend that HbA1c levels in the first trimester (first 12 weeks of pregnancy) should be below 48 mmol/mol. Having an HbA1c level below 48 mmol/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 HbA1c of 48 mmol/mol or less and those with HbA1c of 86 mmol/mol or higher.

	TYPE 1 DIABETES	TYPE 2 AND OTHER DIABETES
HbA1c less than 48 mmol/mol	14.9%	38.1%
HbA1c 86 mmol/mol or higher	12.5%	7.4%

Women with Type 1 diabetes were much less likely to have an HbA1c under 48 mmol/mol than women with Type 2 diabetes. They are also more likely than women with Type 2 diabetes to have an HbA1c level of 86 mmol/mol.

There were significant variations in the proportion of women reaching an HbA1c level of 48 mmol/mol or less depending on age, ethnicity and social deprivation. There were also significant variations across different services and geographical locations.

### 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.

There were significant variations in the proportion of women taking the recommended 5mg folic acid depending on age, ethnicity and social deprivation. There were also significant variations across different services and geographical locations.

The table below shows the percentage of women with Type 1 and Type 2 diabetes taking folic acid before and during pregnancy.

	TYPE 1 DIABETES	TYPE 2 DIABETES
Taking 5mg folic acid	41.8%	22.8%
Taking less than 5mg folic acid	6.2%	8.8%
Taking no folic acid	41.4%	56.1%
Not known	10.5%	12.2%

## The results

### 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.

Since the first audit in 2014, the number of women with Type 1 diabetes who were taking medications that are potentially harmful during pregnancy has fallen significantly.

	TYPE 1 DIABETES	TYPE 2 DIABETES
Taking potentially harmful medications	1.8%	6.5%

### How many women were well prepared for pregnancy?

To be well prepared for pregnancy women with diabetes should:

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

**Only 1 in 12 women in 2016 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. There are many opportunities to reduce variations and improve preparation for pregnancy:**

- 🔄 Between services and localities
- 🔄 For women with Type 1 diabetes and Type 2 diabetes
- 🔄 For women in the most deprived socio-economic groups

## The results

### Care during pregnancy

#### How many women with diabetes presented to 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 under 3 in 5 women with Type 2 diabetes had an appointment with the joint diabetes antenatal teams early in pregnancy (before 10<sup>+</sup> weeks).

More women with Type 1 diabetes present early to the joint diabetes antenatal team early in pregnancy. This reinforces existing evidence that women with Type 2 diabetes are less well informed/supported and less prepared for pregnancy.

	TYPE 1 DIABETES	TYPE 2 DIABETES
<b>Having appointment with joint diabetes service before 10+0 weeks</b>	<b>76.0%</b>	<b>58.1%</b>

#### How many women achieved the recommended blood glucose levels throughout pregnancy?

Ensuring the best possible glucose control throughout pregnancy is essential in reducing risks to mother and baby. Pregnant women should aim for an HbA1c of less than 48 mmol/mol. Pregnant women should have regular contact with their joint diabetes and antenatal team throughout pregnancy to get support and advice about managing glucose levels and to monitor for risks.

	TYPE 1 DIABETES	TYPE 2 DIABETES
<b>% achieving HbA1c level less than 48 mmol/mol in early pregnancy</b>	<b>14.9%</b>	<b>38.1%</b>
<b>% achieving HbA1c level less than 48 mmol/mol in late pregnancy</b>	<b>41.3%</b>	<b>75.4%</b>

More women with Type 1 and Type 2 diabetes achieved HbA1c levels of less than 48 mmol/mol in late pregnancy (after 24 weeks) than in early pregnancy (before 13 weeks). HbA1c levels naturally fall during pregnancy because of biological changes in the body so it is not possible to say how much of the increase in women achieving lower HbA1c levels is due to better glucose management.

However, the percentage of women achieving an HbA1c level below 48 mmol/mol varied greatly between services. A significantly higher percentage of women with Type 1 diabetes in the least deprived group had an HbA1c of 48 mmol/mol than in the most deprived group.

This suggests that there are opportunities for services to increase the percentage of women achieving the target blood glucose level.

## The results

### 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. In the audit data collection, 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.

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.

	TYPE 1 DIABETES	TYPE 2 DIABETES
Admitted to hospital with hypoglycaemia	9.7%	3.2%
Admitted to hospital with DKA	2.7%	0.3%

## 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 48 mmol/mol. Both hypoglycaemia and DKA are preventable risks to women with diabetes and their babies.**

## Pregnancy outcomes

### Are there links between blood glucose levels in early pregnancy and pregnancy outcomes?

#### Birthweight

Having a baby born weighing 4kg (just under 9lbs) or more, is a recognised complication of pregnancy for women with diabetes. Having a baby who is large for gestational age (babies born weighing more than the usual amount for the number of weeks of pregnancy) is also common for women with diabetes.

The table below shows the percentage of babies born to women with Type 1 diabetes or Type 2 diabetes with a high birthweight or who were large for gestational age (LGA).

	TYPE 1 DIABETES	TYPE 2 DIABETES
Birthweight of 4kg or more	17.7%	10.5%
Large for gestational age	47.6%	22.9%

In the general population only 10% of babies will be large for gestational age. 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.

Having an LGA baby is a risk for all women with diabetes, even those who have good blood glucose control. However, any attempt to lower HbA1c to below 48 mmol/mol during pregnancy will help reduce the risk of having an LGA baby.

## The results

### Stillbirths and neonatal deaths

Almost all pregnancies in women with diabetes end successfully. 99.0% of the registered births recorded in the 2016 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 out of every 1,000 births. In the 2016 audit the rate for women with Type 1 and Type 2 diabetes was 10 out of every 1000 births.

The neonatal death rate for women in the general population was fewer than 3 deaths per 1,000 live births. In the 2016 audit the rate for women with Type 1 and Type 2 diabetes was 10 per 1000 live births.

It is important to be cautious about making comparisons between the stillbirth and neonatal death rates found in the 2016 audit and other rates. For example, women in the 2016 audit were generally older than women in the national figures – the risk of stillbirth and neonatal death increases for older mothers.

### Congenital anomalies

Most of the key stages in the development of the baby's organs (heart, lungs and nervous system) happen very early in pregnancy (before 10 weeks). If something goes wrong in early pregnancy, it may result in the baby having a congenital anomaly such as spina bifida or congenital heart disease.

HbA1c in early pregnancy was significantly higher for women with both Type 1 and Type 2 diabetes where:

-  The pregnancy ended in miscarriage
-  There was a congenital anomaly
-  The pregnancy resulted in a still birth or neonatal death

The table below shows the median HbA1c levels in the first 12 weeks of pregnancy and the outcome of the pregnancy. The 'median' is the middle value in a range of values when they are all put in order.

	TYPE 1 DIABETES	TYPE 2 DIABETES
Baby without complications	60 mmol/mol	51 mmol/mol
Stillbirth or neonatal death	72 mmol/mol	54 mmol/mol
Miscarriage	68 mmol/mol	59 mmol/mol
Anomaly	68.5 mmol/mol	59 mmol/mol

### WE SAY

**Fortunately, the vast majority of pregnancies in 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 achieve the best possible blood glucose levels before and during pregnancy.**

# 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 48 mmol/mol)
- ✓ Speak to a healthcare professional if you need help to reach these HbA1c levels
- ✓ If your HbA1c is more than 86 mmol/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 48 mmol/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

### For diabetes and maternity services

- ✓ Look at the NPID findings for your local service here. Identify any areas your local team can work on to improve care and outcomes for women with diabetes

### Improve preparation for pregnancy

- ✓ Raising awareness of the issues around pregnancy in women with diabetes
- ✓ Informing women about the importance of safe, effective contraception including what their options are
- ✓ Promoting access to pregnancy preparation support
- ✓ Think about ethnicity, age and social deprivation when designing and delivering pregnancy and pre-conception care

### Improve early contact with specialist support by:

- ✓ Creating clear pathways for referral to specialist teams
- ✓ Publicising the care pathways to primary care, family planning services and women with diabetes
- ✓ Working proactively with women to help them achieve safe blood glucose levels during pregnancy

### For primary care, family planning and community teams

- ✓ Develop a clear plan for all women with diabetes to ensure awareness of the importance of pregnancy preparation
- ✓ Make discussion about pregnancy a normal part of consultations
- ✓ Use the Diabetes UK [information prescription](#)
- ✓ Have a clear understanding of referral pathways to specialist care

### For specialist diabetes services

- ✓ Routinely discuss pregnancy with all appropriate women
- ✓ Consider access to new technologies to support blood glucose management
- ✓ Develop skills in supporting self-management
- ✓ Use NPID results to lead quality improvement in antenatal diabetes care

# 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 of 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 Diabetes Audit

Information about the National 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 <https://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 [https://www.diabetes.org.uk/get\\_involved/campaigning/diabetes-voices](https://www.diabetes.org.uk/get_involved/campaigning/diabetes-voices)

To find out more about Diabetes UK's activities in your area, go to [https://www.diabetes.org.uk/in\\_your\\_area](https://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](https://www.fpa.org.uk)

### National Institute for Health and Care Excellence (NICE) guidelines

For information about how NICE develops guidelines, go to <https://www.nice.org.uk>

## Further information

### 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

<https://www.hqip.org.uk/involving-patients>

### Patient Advice and Liaison Service (PALS)

If you have a question about local health services or an enquiry about health matters, you can contact PALS. Find more information or your local PALS at

[www.nhs.uk](http://www.nhs.uk)

### Community Health Councils (CHC) in Wales

If you need help and advice about NHS Services in Wales, you can contact CHC. Find out more at <http://www.wales.nhs.uk>

### NHS Choices (England)

NHS Choices provides information about your health, including finding and using NHS Services in England. Find out more at

<https://www.nhs.uk/pages/home.aspx>

### NHS Wales

NHS Wales provides information about your health, including finding and using NHS Services in Wales. Find out more at [www.wales.nhs.uk](http://www.wales.nhs.uk)

## 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.

## Further information

### 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

### Large for gestational age (LGA)

Large for gestational age is used to describe babies who are born weighing more than the usual amount for the number of weeks of pregnancy. LGA babies have birthweights greater than the 90<sup>th</sup> percentile for their gestational age. This means that they weigh more than 90% of all babies of the same gestational age.

### 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

Learning disability

Severe mental illness

Transition

### NPID: National Pregnancy in Diabetes Audit

NDFA: National Diabetes Foot Care Audit

NaDIA: National Diabetes Inpatient 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.

