Why have you received this information leaflet?

Your antenatal diabetes clinic is taking part in an important project to check that women with diabetes are being provided with good care during pregnancy. This project is called the National Pregnancy in Diabetes (NPID) audit.

The information that is collected will help your clinic know if they need to improve the care they provide to women with diabetes.

You don't need to have any additional tests or complete any questionnaires.

What information is collected?

The NPID audit collects information about how many pregnancies there are in women with diabetes, how many babies are born healthy and how many women have problems relating to pregnancy or diabetes.

We would like to know what diabetes and pregnancy care is like across the NHS. That means we need to look at information about your care from all of the healthcare professionals you have seen before and during your pregnancy.

To do this we need to use your NHS number (everyone has a unique number which is used by the NHS) and your date of birth. Your NHS number and date of birth will allow us to look at the care you have received from all services – your GP, antenatal clinic and hospital.

Only information that is normally collected and recorded for your diabetes and pregnancy care is used in the audit. For example, we collect information about your diabetes treatment, other medications and results of HbA1c, blood pressure and eye screening tests. Some of these checks are done by your GP and some by your antenatal clinic.

You can find the full details of what information is collected on the NPID audit website http://content.digital.nhs.uk/npid or you can ask the person who gave you this leaflet.
How is the information we collect about you used?

The information we collect about you is studied along with the information from all other antenatal diabetes clinics in England and Wales. The information we collect about you will be:

- Sent to NHS Digital using a secure web portal. This information will include your NHS number and date of birth, which can identify you.
- Other information which is recorded by the NHS and NHS Digital relating to your diabetes and your pregnancy will also be used. This includes information about your diabetes care from your GP or specialist service, and information about your pregnancy from your hospital, such as any hospital admissions during the time you were pregnant including information about your labour.
- NHS Digital will use your NHS number and date of birth to link information that is collected from your antenatal clinic.
- Once your information has been linked, data which can identify you as an individual will be removed. All published data will remain anonymised.
- Your anonymised information may be used for audit and research to improve diabetes care.

The information that is collected by the NPID audit will be included in national and regional reports, which will be published on the NPID audit website. Information that we publish or share will never identify a particular person.

We may share the audit data for research purposes, only if this is allowed by law and meets the strict rules that are in place to protect your privacy.

How will your information be kept safe?

There are very strict rules about what happens to your information. Staff at your antenatal diabetes clinic must get special permission to be able to use your information for this project and they must agree to use the information properly. They will each be given their own password which will allow them to enter your information using a secure web portal.

Outside of your antenatal diabetes clinic, only the technical team at NHS Digital will be able to see the information that is collected about you.

Saying ‘no thanks’

The legal basis for this audit has changed from patient consent to being directed by NHS England and therefore you will no longer be asked to consent to your data being used. This change in legislation does not affect your rights or the care you will receive in any way.

If you do not want your information to be used for this audit, you may opt out by advising your clinician and they will ensure that your information is not included. This only refers to your current pregnancy. If you have consented during a previous pregnancy and no longer want any of your information used for this audit, then please contact NHS Digital using the details provided in this leaflet. If you have attended clinics at different locations, you will either need to inform them separately or inform NHS Digital. This will not affect your care.

FURTHER INFORMATION

If you would like more information about the National Pregnancy in Diabetes (NPID) audit, please ask your antenatal team. You can also:

Email: enquiries@nhsdigital.nhs.uk
Telephone: 0300 303 5678
Website: http://content.digital.nhs.uk/npid
Address: Clinical Audit and Registry Management Service
NHS Digital
1 Trevelyan Square
Boar Lane
Leeds LS1 6AE