

PANDORA

Pregnancy and Neonatal Diabetes Outcomes in Remote Australia Information Sheet

This information sheet is for you to keep

We would like to invite you to take part in the PANDORA project. It is important for the health of both you and your baby that your blood sugar is as good as possible during pregnancy. High blood sugars in pregnancy can cause problems for the mother and newborn baby and also increase the risk of your baby becoming overweight or diabetic as a child, teenager or young adult. This is particularly important for the NT, as rates of diabetes are very high in Indigenous Australians. We want to act now, during the important time of pregnancy, to further improve the health and well-being of Indigenous Australians and all Territorians.



Why do we want to do this research?

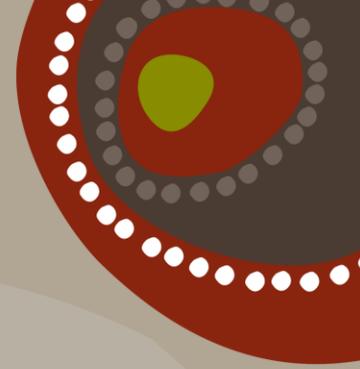
We need to develop good systems to pick up and then treat diabetes in pregnancy as early as possible and throughout pregnancy. We want to find out the best ways for our health teams to treat you in pregnancy. To work out the best systems and care, we would like to invite you to help us record details about you and your baby's health at several times: during pregnancy, soon after birth and then regularly until your child is 12.

What is involved in this research?

The majority of the tests in this research are part of your current standard medical care (routinely done) for diabetes in pregnancy. The main extra tests that we would like to do are:

- **A test of blood sugar and hormones** related to diabetes and body shape on blood from your baby's cord
- **Measurement** of your baby's body at the arm, leg, chest and waist (using a tape measure) and arm, tummy and back (using calipers to measure "skinfolts").





Other information listed below will be collected also (most of these are done as part of normal care):

- **Tests to measure your body size.** We will measure your height & check your medical records for your weight in pregnancy.
- **Questions about your health:** smoking, how much alcohol you drink, other substances used
- **Questions about you:** your house, language, education, income source, work, family
- **Recording** the medical information that is on the NT Diabetes Clinical register
- **Your health during pregnancy:** with your permission we would like to contact your health team/clinic/hospital for this information
- **Your health after pregnancy:** with your permission we would like to contact your health team/clinic/hospital records for this information over the next 12 years
- **Your baby's health and growth:** with your permission we would like to contact your health team/clinic/hospital for information relating to your child's risk of diabetes and related conditions until your child is 12 years old
- **Information** from your health team/clinic/hospital about how to contact you over the next 12 years

What are the risks? Measuring your baby's body is not painful but may be uncomfortable for you or your baby. If this happens, let the project worker know and they will stop.



What are the benefits? This project will help us to improve care and outcomes related to diabetes in pregnancy. This includes reducing the future risk of diabetes and related conditions for you and your baby, thereby improving the health and well-being of all Australians, especially Indigenous Australians who are at high risk of these conditions.

You are free to withdraw from the study at any time.

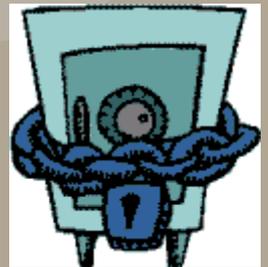
You do not have to answer any questions that you do not want to.

Please do not hesitate to contact Dr Louise Maple-Brown if you have any concerns by phoning (08) 8922 8888.

What will happen with your results?

Any clinically relevant results from these tests will be returned to you in plain language and your local health care team as soon as possible. Results of this study will be presented in publications. With your permission, your results will be included with others as a whole group and you will not be named. Individual results will be confidential.

It is standard practice in medical research to store blood samples of children for 25 years. If you give consent, we will keep your baby's cord blood for 25 years. You or your baby's name will not be kept with your samples or your results. No other person will be given your results or your blood samples without your permission. After samples have been kept for 25 years it is your choice as to whether your samples are destroyed or are kept to use in future related research.



If you have questions about the project **please contact the project officer Marie Kirkwood at Menzies School of Health Research.**

Phone: (08) 8922 8837

Email: marie.kirkwood@menzies.edu.au

If you have any concerns or complaints about the project, you may contact the Secretary of the Human Research Ethics Committee of NT Department of Health and Menzies School of Health Research

Phone: (08) 89227922

Email: ethics@menzies.edu.au