

Help prioritise diabetes and pregnancy research

Women, their families, and healthcare professionals are invited to help prioritise research that will benefit women and families affected by diabetes and pregnancy.

Diabetes affects around 38,000 women giving birth in the UK (5%) and rates are increasing. Although most women have healthy babies, diabetes can increase the risk of complications such as pre-term birth, and long-term risks such as cardiovascular disease in mothers and babies.

However, many women report a lack of information relating to diabetes and pregnancy, and many questions remain unanswered by research. A new project, led by the University of Oxford, will identify the areas of research that are most important to the people concerned by diabetes before, during and after pregnancy.

Project co-lead, Dr Goher Ayman, from the National Perinatal Epidemiology Unit, Nuffield Department of Population Health, University of Oxford, said 'More research is needed to help provide the best healthcare for women with or at risk of diabetes, who are planning pregnancy or are pregnant.

'We want to work with women, their support networks, and healthcare professionals to identify uncertainties about the prevention, diagnosis, treatment, and health impacts of pregnancy with diabetes of any type. We are currently inviting people to tell us their questions about diabetes and pregnancy by completing our survey. Their questions will be used to produce a shortlist of priority research topics.'

The project will follow an established process developed by the James Lind Alliance, an initiative that aims to help direct research funding towards the issues that matter most to patients and clinicians.

Over about 18 months, the project team will work with women, their families and healthcare professionals to identify where little is known, or where there are uncertainties about, healthcare and wellbeing in diabetes and pregnancy. Those involved will agree a top ten list of priority research questions, which will be shared with funders of health research.

Karen Addington, UK Chief Executive of the type 1 diabetes charity JDRF, said 'This is a superb opportunity for women living with type 1 diabetes to help shape diabetes research, via their own insights and experiences. We need the outcomes that matter to them to be increasingly at the heart of research design.'

Sonya Carnell was diagnosed with type 2 diabetes after the birth of her first child and had diabetes during her second pregnancy. She said 'Despite having a family history of diabetes, I wasn't aware of the risks relating to diabetes and pregnancy. Once I had been diagnosed, I read a lot about it and asked lots of questions, but I still found that there was a lack of information. I hope that by involving those with direct experience of the issue, this project will help to direct funding to the unanswered questions that affect me and many other women.'

To find out more or participate in the project, please visit <https://www.npeu.ox.ac.uk/jla-ppsp>. The project team are looking for input from those affected by all types of diabetes, including pregnancy with pre-existing diabetes, and gestational diabetes which develops during pregnancy.

The project is funded by the University of Oxford John Fell Fund, the Nuffield Department of Population Health, and the Diabetes Research & Wellness Foundation. Project partners are: the Diabetes Research & Wellness Foundation, Diabetes UK, the James Lind Alliance, JDRF the type 1 diabetes charity, the Oxford Biomedical Research Centre, and the Oxford Centre for Diabetes, Endocrinology and Metabolism.

ENDS

Notes to editors

Please see below for two case studies.

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The Nuffield Department of Population Health (NDPH) is a world-leading research institute, based at the University of Oxford, which investigates the causes and prevention of disease. NDPH has over 500 staff working in several world-leading research groups, including the Clinical Trial Service Unit and Epidemiological Studies Unit (CTSU), the Cancer Epidemiology Unit (CEU), the National Perinatal Epidemiology Unit (NPEU) and other groups working on public health, health economics, ethics and health record linkage. It is also a key partner in the new Oxford University Big Data Institute. ndph.ox.ac.uk

The National Perinatal Epidemiology Unit (NPEU) is a multi-disciplinary research unit which conducts methodologically rigorous research to provide evidence to improve the care and outcomes for women, babies and their families during pregnancy, childbirth, the newborn period and early childhood, as well as promoting the effective use of resources by perinatal health services. The unit runs randomised controlled trials, national surveillance programmes and surveys, confidential enquiries, aetiological studies and a disease register. The results of its research sit at the nexus of public and population health sciences, clinical care and health policy development. The Unit was established at the University of Oxford in 1978. npeu.ox.ac.uk.

About JDRF

- JDRF is the leading global organisation funding type 1 diabetes research. Our mission is to accelerate life-changing breakthroughs to treat and cure type 1 diabetes
- Our volunteers around the globe are dedicated to campaigning for our vision of a world without type 1 diabetes. Together we raise funds, awareness and understanding
- We will find the cure for type 1 diabetes. It's simply a question of time, money and great research
- For more information, please visit jdrf.org.uk or follow us on Twitter: @JDRFUK

Case studies

Sonya Carnell

When Sonya Carnell found out that she was pregnant with her first child, she didn't have diabetes and wasn't particularly concerned about it, despite a family history of the disease. It wasn't until after she had delivered a large baby at 37 weeks that her doctor began to wonder whether she had had gestational diabetes – a condition that is more likely to develop if one of your parents or siblings has diabetes.

'I didn't have any checks for diabetes during my first pregnancy,' said Sonya. 'It was about a year after my first child was born that I was diagnosed with type 2 diabetes and my doctor began to wonder whether this had

been triggered by diabetes developed during my pregnancy. I hadn't had any checks for diabetes and wasn't given any information about the disease either before getting pregnant or during the pregnancy.'

Sonya's second pregnancy involved weekly visits to clinics and numerous checks, but she still felt that vital information was missing.

'There were so many questions that I would like to have asked. I was repeatedly told that I was 'high risk' but I wasn't given much advice on how to manage the risks, or how my pregnancy might differ from others because of my diabetes. Information on the problems that can occur due to diabetes and pregnancy, and how to mitigate risks through lifestyle changes would have been really useful.'

Sonya would like to know whether there are links between diabetes, pregnancy and postnatal depression. She also believes that more information should be provided to women with diabetes before they become pregnant so that they can consider how best to manage the disease and how their medication might change as their pregnancy progresses. Those without diabetes should be made aware of risk factors such as family history of diabetes, having a baby over 4.5kg previously, or having a body mass index (BMI) over 30.

Sonya is now managing her diabetes to try to ensure that it doesn't progress. 'It doesn't stop me doing things but I am much more conscious of it,' she said. Her experience of diabetes and pregnancy and her interest in the topic has resulted in her joining the steering group for a new project that will draw upon the perspectives of women, their families and healthcare professionals to identify priority research questions. 'I hope that asking people about their questions will help to raise awareness of diabetes and pregnancy as well as ensuring that funding is directed towards questions that really matter to women.'

Iuliana Berneantu

I am a type 1 diabetic mum of two wonderful children. One is two and a half and one is three months old. My experience in hospital has made me want to help improve the care that diabetic mothers receive after birth.

The care I received during pregnancy and birth was exceptional. Unfortunately, the care I received after birth was not. My blood sugar levels were only tested two or three times during the five days that I was in hospital after having my first child. My blood sugar levels were not tested at all after having my second child. There were no meals customised for diabetics which meant that my blood sugar levels increased.

Our older child was crying from the moment he was born till his first few feeds (which were formula as my milk didn't come till 5 days later after birth). He was tested four hours after birth and his blood sugars were low.

With our second baby, I was better prepared. I managed to express some colostrum before she was born and she was fed that straight after birth. This improved her blood glucose but not enough unfortunately. She needed 48 hours of intensive care to be able to manage her blood glucose by herself.

Managing diabetes is hard, but being a diabetic mum is even harder. This is due to the breastfeeding which adds another layer to managing diabetes, as breastfeeding lowers sugar levels and may require changes to medication.

I received very little specialist care for my diabetes whilst I was in hospital after birth. This is why I am part of this project - to be able to help other diabetic mothers have a better experience in hospitals after birth. I think that diabetic mothers should receive customised care to include close blood glucose monitoring, and healthy meals and snacks.