

DARE

Diabetes Alliance for
Research in England

NEWSLETTER Winter 2017/18

A note from the study team

We would like to say a big **THANK YOU** to everyone who has taken part in the DARE study. The DARE Study is a community-wide collaboration between patients and professionals to provide a research resource to enable further study into the causes and complications of diabetes. In July 2017, the DARE Study stopped recruiting any new volunteers but will continue to follow up those already taking part and carry on with our data analysis, in order to understand how environmental and genetic factors influence the progression of diabetes and related conditions. Since the study started in 2007, a very impressive total of over **12,000** people have volunteered within the Exeter area and more than **60,000** people nationwide. Your support has been an invaluable contribution to the progress of our research by helping doctors and scientists improve diabetes diagnosis and treatment.

We would also like to thank those of you who have joined our local research database to be contacted about future studies. DARE in Exeter has provided a further 120 studies with large numbers of pre-screened participants, making recruitment more efficient.

Study Highlights

Your participation in the DARE Study has made a valuable contribution to diabetes research in Exeter

A non-invasive way to measure insulin production

A C-peptide test is a blood test which is used to measure if patients with diabetes are making their own insulin. It is often used to find out whether someone has Type 1 or Type 2 diabetes. However, this blood test has been shown to be less reliable in patients whose kidneys are not working properly.

Dr Tim McDonald, a Principal Clinical Scientist at the Royal Devon and Exeter Hospital and his colleagues from the University of Exeter have discovered that the use of a simple urine test, "urinary C-peptide/creatinine ratio (UCPCR)" offers a practical non-invasive alternative to blood testing. The urine test better reflects the amount of insulin produced than repeated C-peptide blood tests in patients with diabetes and kidney damage.



Targeted drug treatment for Type 2 diabetes

Some treatments for Type 2 diabetes appear to suit people differently. The same treatment may work well for one person but do little for another. Results from the **PRIBA Study - Predicting Response to Incretin Based Agents** led by **Dr Angus Jones**, a Clinician Scientist at the University of Exeter, have shown that a group of glucose-lowering drugs called GLP-1 agonists appear to have little effect in people who make only small amounts of their own insulin. Therefore, this group of people may benefit from alternative treatments.

Blood pressure difference and heart disease risk

A group of DARE patients have been involved in a study looking at inter-arm differences in blood pressure. This study involved them having their blood pressure measured in both arms during their study visit. **Dr Christopher Clark**, an Academic Clinician at the University of Exeter, has found that inter-arm blood pressure differences could delay or prevent the diagnosis of high blood pressure and underlying health problems if the lower-arm reading is recorded. These results help to support the recommendation that blood pressure should be measured in both arms of patients diagnosed with diabetes.



Study Update: Fair Processing

The DARE Study collects information (data) about you and we wish to clarify with you what we do with the data

- ◇ Information about you, your health and the treatment you receive is collected from you and from your NHS health records.
- ◇ **Identifiable information** about you (such as your name, date of birth, postcode, NHS hospital number) is stored by the DARE Study Team at the NIHR Exeter Clinical Research Facility (Exeter CRF).
- ◇ Exeter CRF is a partnership between the **University of Exeter** and the **Royal Devon & Exeter NHS Foundation Trust**. The Royal Devon & Exeter NHS Foundation Trust is the registered **data controller**, responsible for determining the purpose for which, and the manner in which, information is processed.
- ◇ Identifiable information which is entered, stored and captured electronically is kept separate from your research data and held in **password-protected** databases on **secure** NHS computers.
- ◇ Researchers who carry out data analysis will only be given your **unique study ID number**. When study results are presented in research articles, your personal information is never revealed.
- ◇ Information held by **NHS Digital** via the **Personal Demographics Service (PDS)** which uses the **Medical Research Information Service (MRIS) Integrated Database and Administrative System (MIDAS)** and other UK NHS bodies such as the **Office for National Statistics (ONS)** may be shared with the research team and used to provide information about your current status in order to keep the information we hold about you **accurate and up to date**.
- ◇ On a regular basis, we will provide NHS Digital with a spreadsheet containing your identifiable information, gender and your unique study ID number.
- ◇ NHS Digital will then track these identifiers on MIDAS and supply us with quarterly current status reports confirming your latest status. These reports will contain your identifiable information that we supplied to NHS Digital as well as your latest identifiers and if relevant, date of death and cause of death.
- ◇ This updated information will be added to a secure database to ensure no contact is attempted with patients who have passed away.
- ◇ All data is kept indefinitely or until we stop the DARE Study.
- ◇ When you agreed to take part in the DARE Study by signing the consent form, you agreed for us to share information with NHS Digital. If you **no longer wish that we share your data** obtained for the DARE Study with data held by NHS Digital, you are **free to opt-out of this**. You do not need to give a reason and this will not affect your clinical care. Any information collected up until the point you withdraw cannot be erased and may still be used in the study. **Please contact the DARE Study team using the details below.**



For more Information: The full privacy notice, study information sheet and consent form can be found at:

www.exeterlaboratory.com/dare/



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