

If you wish to participate in this study, you will be asked to agree to the consent statements below in the presence of a member of the research team.

### CONSENT STATEMENTS

1. I confirm that I have read this leaflet and have had the opportunity to ask questions, and have had these answered satisfactorily.
2. I am happy to participate in this study by providing information about my diabetes for use in this project and allowing the research team to contact my clinicians about medical information relevant to this project.
3. I am happy to provide blood and urine samples for use by this study and for DNA to be extracted from my blood sample.
4. I understand that my participation is voluntary and that I may withdraw at any time without my clinical care being affected.
5. I give permission for individuals from regulatory authorities or the NHS Trust to have access to relevant sections of my medical notes and data collected during the study, relevant to my taking part in research.

### OPTIONAL CONSENT STATEMENTS

6. I am happy to gift samples taken during this study and as part of my routine diabetes care as well as associated non-identifiable data to the Peninsula Research Bank for use in future research. I understand this research will be approved by a Steering Committee and my samples will **not** be used for any of the following: sold for profit; used in animal research; used in research into the termination of pregnancy or reproductive cloning; screened for markers predictive of disease (e.g. Huntingdon's). My samples may be provided anonymously to researchers from the UK and abroad, including academic organisations and commercial companies.
7. I agree that information held by the NHS and in my medical records may be used to follow up on my future health status
8. I am happy for my contact details to be used by the recruiting researchers to inform me about future studies and I give consent for NHS-based staff to access my medical records to check my eligibility for future research.

### I am interested in participating. What must I do?

If you would like to participate please contact us on 01392 408181

# DARE

Diabetes Alliance for  
Research in England

## Do You DARE?

We are looking for people to take part in a research study that is exploring the causes and complications of diabetes

### Participation involves:

- A 30 minute clinic appointment
- Donation of small blood and urine samples
- Providing us with information about your diabetes

**Can you help us to improve diabetes treatment, diagnosis and care?**

**Call us at NIHR Exeter Clinical Research Facility on  
01392 408181 to make an appointment**

## Why are we conducting this research?

In order to understand the cause of diabetes and its complications such as heart disease, eye disease and kidney disease, and to improve treatment and prevention of these important illnesses, we need to find both the genes (the inherited code which may be passed down through generations) and also non-inherited factors that make some people more likely to get diabetes and its complications.

## What does the participation involve?

You will be invited to attend a 30 minute appointment at a research facility, your GP surgery or another mutually convenient location. At this appointment, you will be asked to provide a urine sample and to donate up to 30ml of blood. DNA will be extracted from your blood and this will be analysed alongside your urine and blood samples to help understand the causes and complications of diabetes. The research nurse/practitioner will take measurements such as height and weight and will ask you to provide information about your medical history. We will ask your permission for us to contact your GP and other doctors about aspects of your medical record related to this project. We will register your involvement in this study with the Office of National Statistics to follow up your health status.



We will also contact you periodically during the project to ensure that your data is up-to-date and that we have adequate information to understand your diabetes and its progression. We will only ask you attend one appointment for this project, but with your permission we may invite you to participate in other related studies.

## What are the risks and benefits of participation?

The risk of taking part in this research is minimal and is the same as any normal clinical appointment where blood is taken by trained professionals. By joining DARE, you will be helping doctors and scientists better understand diabetes and this may help improve diagnosis and treatment in the future.

## Gifting your samples to be used for future research

Samples that you have donated during this study and samples left over from routine care tests may be discarded or gifted to help future research. You have the option to gift your urine and blood samples and your clinical data to the Peninsula Research Bank, which will provide your samples anonymously to medical research projects approved by a Steering Committee. This research may take part in the UK or overseas, and may include work with scientists within companies. Samples will not be sold for profit, will not be used in animal research or reproductive cloning, will not be tested for rare severe diseases (e.g. Huntingdon's), nor shared with non-research organisations.

## Will I be told the results?

Non-genetic results will be fed back via your GP if they would clearly help your diabetes care. We will not feedback specific results of your genetic tests.

## Do I have to take part in this study?

No, participation is entirely voluntary. It is up to you to decide to join the study. If you agree to take part, we will ask you to sign the consent form overleaf. You are free to withdraw at any point. Participation in the study will not effect your treatment as an NHS patient.

## Will my participation be kept confidential?

Your name and contact details will not be shared with organisations outside of the NHS. Personal identifiers will be removed from data and samples before being sent to external researchers. You will be given the option to be contacted by the research team about future studies.

## Who can I ask about participation in research?

The Patient Advice and Liaison Service (PALS) can provide independent advice about research participation, and can provide assistance if you have any concerns or complaints (tel: 01392 402093 or email [rde-tr.PAL@nhs.net](mailto:rde-tr.PAL@nhs.net))

## Who has reviewed this study?

This project has been reviewed by the South West (Exeter) NHS Research Ethics Committee.