

DARE

Diabetes Alliance for
Research in England

The following document can be found on the [Diabetes Genes](#) website.

STUDY NAME: Diabetes Alliance for Research in England

Privacy Notice Statement: DARE Study Participants

Thank you for taking 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.

Currently more than 12,000 people within the Exeter area are taking part in this study and we have recruited more than 60,000 people nationwide.

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

- Participation in the DARE Study is voluntary.
- All information about you that is collected during the research project is recorded, handled and stored in such a way that maintains appropriate confidentiality but allows access and use as applicable, whilst satisfying the requirements of the [Data Protection Act 2018](#).
- Unauthorised individuals will not have access to your information.
- The Royal Devon & Exeter Hospital NHS Foundation Trust is the registered Data Controller responsible for determining the purpose for which and the manner in which any personal data collected for clinical research are, or are to be processed.
- Identifiable information about you is held by the DARE Study team at the NIHR Exeter Clinical Research Facility (Exeter CRF) which is a partnership between the College of Medicine and Health, University Of Exeter Medical School, and the Royal Devon & Exeter NHS Foundation Trust.
- Where identifiable data is electronically recorded by the DARE study team (such as your name, address, date of birth and NHS hospital number), this is kept separately in password-protected databases on secure NHS computers.
- Your information will be used:
 - to communicate with you about your involvement in the DARE study
 - for research purposes related to the study
 - to follow-up on your future health status
- Your information may also be used by recruiting researchers to inform you about future research studies and invite you to participate. We will only do this if you have agreed to this at the start of the study by ticking the relevant boxes on the consent form.
- Researchers who carry out data analysis will only have access to anonymised data and will only know your unique study ID number.

- When study results are presented in research articles your personal information is never revealed.
- In order to check that this research study is being carried out in line with the law and good clinical practice, monitoring and auditing will be carried out by independent authorised individuals. Data collected during the study may be looked at by authorised individuals from the University of Exeter, from regulatory authorities, or from the NHS Trust where it is relevant to your taking part in this research.
- Information held by NHS Digital via the Personal Demographics Service (PDS) held on the Medical Research Information Service (MRIS) Integrated Database and Administrative System (MIDAS) and the Office for National Statistics (ONS) may be given to the researchers and be used to provide information about your current status in order to keep the information we hold about you accurate and up-to-date. The process for this is described below:
 - The DARE Study team will provide NHS Digital with your NHS number, date of birth, postcode, gender and your unique study ID number. This information will be provided to NHS Digital in a spread sheet format every 6 months.
 - Once these identifiers have been tracked on MIDAS, NHS Digital will supply the Royal Devon and Exeter NHS Foundation Trust with quarterly current status reports about all participants taking part in the study. These reports will contain the same identifiable information supplied to NHS Digital as well as latest identifiers and if relevant, date of death and cause of death.
 - Updated data will then be added to the secure DARE Study database to ensure no contact is attempted with patients who have passed away.
 - We will only obtain information from these organisations if you have agreed to do so at the start of the study by ticking the relevant boxes on the consent form.
 - If you no longer wish that we share your data obtained for the DARE Study with data held by NHS Digital and the Office for National Statistics you are free to opt out of this by contacting the DARE Study team using the details below. You do not need to give a reason and this will not affect your clinical care. Please understand that any information collected up until the point you withdraw cannot be erased and may still be used in the study.
- All data will be kept indefinitely or until we stop the DARE Study. More information about the DARE Study including the patient information sheet and consent form can be found on the [Diabetes Genes](#) website.
- If you believe that there is an error or omission in any personal information that we hold about you, please contact the DARE Study team and let us know.

If you have any questions, please contact us:

Address: **DARE Study team**
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 Exeter
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