

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

Privacy Notice Statement for Study Participants

STUDY NAME: Diabetes Alliance for Research in England (DARE)

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.

Processing personal identifiable data for research

The Royal Devon University Healthcare NHS Foundation Trust is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The Royal Devon University Healthcare NHS Foundation Trust will keep identifiable information about you indefinitely or until we stop the DARE Study.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Your personal data will not be used in any automated decision making or profiling.

You can find out more about how we use your information: <https://www.royaldevon.nhs.uk/about-us/information-governance/fair-collection-privacy-notice/patient-privacy-notice/>

Legal basis for processing under the General Data Protection Regulation (GDPR)

The Royal Devon University Healthcare NHS Foundation Trust will use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Our legal basis for processing personally-identifiable is:

Article 6(1)(e) – processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

Where we process special categories data, for example data concerning including health, racial or ethnic origin our legal basis is:

Article 9(2) (j) – processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

Specific DARE Study Processing

- Participation in the DARE Study is voluntary.
- Unauthorised individuals will not have access to your information.
- 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.
- 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 University of Exeter Medical School, College of Medicine and Health and the Royal Devon University Healthcare 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.
- The only people at the Royal Devon University Healthcare NHS Foundation Trust who will have access to information that identifies you will be people who need: to contact you about your involvement in the DARE study, inform you of other research studies if you have agreed to this/ticked the relevant boxes on the consent form, audit the data collection process and to contact NHS England in order to follow up your future health status if you have agreed to this (consented).

Auditing the data collection process

Monitoring and auditing will be carried out to check that the research study is being carried out in line with the law and good clinical practice. Data collected during the study may be looked at by individuals from the Royal Devon University Healthcare NHS Foundation Trust and regulatory organisations where it is relevant to your taking part in this research.

Contact with NHS England

Information held by NHS England 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 England with your NHS number, date of birth, postcode, gender and your unique study ID number. This information will be provided to NHS England in a spread sheet format every 6 months.
- Once these identifiers have been tracked on MIDAS, NHS England will supply the Royal

Devon University Healthcare NHS Foundation Trust bi annually with current status reports about all participants taking part in the study. These reports will contain the same identifiable information supplied to NHS England 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.
- If you no longer wish that we share your data obtained for the DARE Study with data held by NHS England 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**
NIHR Exeter Clinical Research Facility
RILD Building
Barrack Road
Exeter
EX2 5DW

Tel: 01392 408181

Email: crf@exeter.ac.uk

If you have any concerns about how we handle your personal data, you can contact our Data Protection Officer:

Address: **Information Governance Manager**
Information Governance Team
Wonford Hospital
Barrack Road
Exeter
EX2 5DW

Email: rduh.dpo@nhs.net

If you are not satisfied with the response from the DPO or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Address: **Information Commissioner's Office**
Wycliffe House
Water Lane
Wilmslow
Cheshire

Email: casework@ico.org.uk