

NHS Research Scotland (NRS)
Diabetes Register



Privacy Information Notice: How NRS Diabetes use your information

DIABETES

Your personal information is in safe hands

We do: respect your privacy

We do: keep your personal information secure

We don't: sell your personal information

Your privacy is very important to us. NRS Diabetes is committed to providing people with the information they need to understand how their personal information is used. This privacy notice is provided by the NRS Diabetes staff.

If you wish to join the NRS Diabetes Register, please make sure you read and keep hold of this Privacy Information Notice.

What is the purpose of this Privacy Notice?

This notice is available electronically, online and upon request in paper copy to anyone who wishes to join the Diabetes Register. The main purpose of this notice is to clearly explain who NRS Diabetes are, what you are giving consent to by joining the Diabetes Register and how your information may be used. It is important that you read the information in this notice prior to or shortly after giving your consent to join the Diabetes Register. If you are unsure about any aspect of the Diabetes Register or you have any questions please contact NRS Diabetes staff on 01382 383 595 or administrator-sdrn@dundee.ac.uk. Alternatively, please write to us using our address on the back of this leaflet.

What is personal data or information?

Personal data, sometimes called personal information, includes your name, address, date of birth and contact details such as email and home address. It also includes information about your health. Health information, such as that recorded in your NHS diabetes computer record (called SCI-Diabetes), is also considered 'special category' or 'sensitive' data. This means that NRS Diabetes needs your explicit consent to use that information and that it needs more protection.

Who is NHS Research Scotland (NRS) Diabetes and what do they do?

NRS Diabetes is a Scotland-wide network for supporting diabetes-related research activity in Scotland. It is one of a number of Research Networks, or Specialty Groups, formed through a partnership of NHS Boards and the Chief Scientist Office of the Scottish Government.

NRS Diabetes acts as an interface between the diabetes research community, the NHS and patients with diabetes, facilitating the development, set up and completion of research projects across Scotland.

NRS Diabetes works with a wide range of stakeholders including patients, carers, researchers, NHS, academic institutions, charities, healthcare delivery professionals and commercial organisations.

Members of the NRS Diabetes Network may be employed by an academic institution, such as a University, or by an NHS Scotland Health Board. Members include Health Care Professionals such as Diabetes Research Nurses and Doctors as well as managerial and administrative research support roles.

NRS Diabetes have a central office and management team who are responsible for the operation of the network. Part of their work includes the management of the Diabetes Register which involves receiving and processing registration forms, conducting searches of the Diabetes Register to match people to research projects and providing details of suitable people to research teams in a controlled way.

How do I give my permission to join the Diabetes Register and allow NRS Diabetes to use my information?

If you wish to join the Diabetes Register you have to give your permission or, in other words, your consent. You can give your consent to join the Diabetes Register by filling out a registration leaflet, completing an online registration form or by sending an email. Your consent allows NRS Diabetes to use both the information you provide directly and the additional information made available in your NHS diabetes computer records (called SCI-Diabetes).

How is the information I personally provide used by NRS Diabetes?

The information you provide to indicate your consent to join the Diabetes Register comprises of your name, postcode and date of birth. You may also provide a telephone number and/or email address. Initially, this information is used by NRS Diabetes to identify you in NHS Scotland's electronic health record for diabetes called SCI-Diabetes. NRS Diabetes can only identify you in SCI-Diabetes if you have been diagnosed with diabetes. Once identified, your SCI-Diabetes record can be flagged to show that you have given your consent to join the Diabetes Register. If a research project would benefit from someone with your health record taking part, your name, preferred method of contact and any other information deemed relevant will be shared with a member of the research team.

By joining the Diabetes Register, what other personal information do I give permission for NRS Diabetes to access?

During the process of recording your consent to join the Diabetes Register, NRS Diabetes will be able to access additional personal information about you that is already available in your NHS diabetes computer record called SCI-Diabetes. This information includes your Community Health Index (CHI) number, the name of your General Practice, your home address and your gender. Once your consent has been recorded, NRS Diabetes staff are able to check, or search, more of your diabetes-related personal health records in SCI-Diabetes to understand whether you are a match for a particular research project. If you are a good match, your Community Health Index (CHI) number, name, contact details and any other relevant information is provided to the research team. Prior to contacting you, the research team may need to carry out further checks of your health records to understand if you are a good match.

Can I be provided with more information on the type of personal records NRS Diabetes have access to if I join the Diabetes Register?

Yes, if you would like a description of the diabetes-related health categories available in the Diabetes Register, please contact NRS Diabetes using the details provided on the back of this leaflet.

Examples of the type of data that NRS Diabetes can access include diabetes-related laboratory results from your most recent blood tests or the type of diabetes medicine, if any, you are currently taking.

Where does my diabetes-related personal information in SCI-Diabetes come from?

The information in SCI-Diabetes is collected from various NHS Scotland healthcare services such as your General Practice or the Eye Screening service. When new information about your diabetes-related healthcare is available, it is automatically updated in your SCI-Diabetes record. For example, following a routine appointment at your General Practice any new diabetes-related results or measurements will be uploaded and made available in SCI-Diabetes.

How do NRS Diabetes use my diabetes-related personal information that is already available in SCI-Diabetes?

When NRS Diabetes need to find suitable participants for a research project, a search of the Diabetes Register is carried out on an NHS computer. Each search produces a list of those who match the search terms. The list contains the CHI numbers, names and preferred methods of contact of people who have joined. Each list also contains specifically selected, diabetes-related, personal healthcare information that is relevant to the research project. This personal health information allows NRS Diabetes to carefully check whether each person may be a good match for the research project.

If NRS Diabetes central office are able to identify potential participants for the research project, a list containing each person's CHI number, name, preferred method of contact and any other relevant information is sent to a member of the clinical research team. All lists are sent and received within the secure NHS computer network.

During the process described above both NRS Diabetes central office and the research project team members may save, make additional records of or print lists using their NHS computers. These actions help to both record and administer the work required to further match and contact people.

NRS Diabetes central office can also use the Diabetes Register to help understand how many people may be available for a potential research project. This process can help to plan projects.

What information is sent to the research team and how making contact with me be managed?

By consenting to join the Diabetes Register, you allow NRS Diabetes central office to send your Community Health Index (CHI) number, name, preferred method of contact and any other relevant information to a member of the research team. Prior to this, NRS Diabetes will have carefully matched you, as a potential participant, to the research project in question. If you don't match, no information about you is sent to the research team. First contact will be made by a member of the research team or the central NRS Diabetes team who will provide you with study information via your preferred method of contact. If you have chosen post as your preferred method of contact you will be able to detach a reply slip from the letter you have received and post it back or use any other response method provided in the letter. If you have chosen email, you can reply to the email you have been sent or respond to any other email address or link provided. If you have chosen telephone you can provide a verbal confirmation of your decision on the call. If you are interested in the research project you may be invited to visit the study team. In some cases, you

may be given the option of taking part directly by completing an online questionnaire.

If the research team is unable to reach you with your preferred method of contact they may choose to try and contact you using an alternative method from information you provided or from other contact information available in your health records.

In certain circumstances, the research team may be limited in the types of contact method they can use. On these occasions, the research team may choose whichever method is appropriate. For example, if they are unable to make telephone calls, a letter may be issued.

Who are the research teams that NRS Diabetes share my information with?

The clinical research team members who receive your information are supported by NRS Diabetes, while other members may receive funding for their posts from elsewhere. Most members of a clinical research team are made up of Diabetes Research Nurses and medical doctors with an interest in diabetes research as well as administrative support staff. Research teams can be employed at various locations across Scotland by NHS Boards or Universities.

For more information on where different research teams are working and who employs them please contact NRS Diabetes using the details provided on the back of this leaflet.

Who approves the research projects that my information may be used for?

The NRS Diabetes management team are responsible for carefully reviewing and approving which diabetes-related projects can use the Diabetes Register. Most, but not all research projects, are clinical studies which require an NHS Research and Development approval and a Research Ethics Committee approval. These approvals ensure that each research project has been carefully reviewed to meet the strict standards required by the NHS.

What will a research project team do with my information?

The research team member will receive your Community Health Index (CHI) number, name, preferred method of contact and any other relevant information in a list sent through the NHS computer network. From there, the research team, or the NRS Diabetes central management team, will use your information to contact you. The research team may also save, add notes, make copies or print the list using their NHS computer. These actions allow the research team to manage the work required to contact people.

What is a CHI number and why is that sent to the research team?

CHI stands for Community Health Index (CHI). It is a ten-digit number used by NHS Scotland to uniquely identify you. For example, another person may have the same name as you but no one else can have the same CHI number. The number is normally made up of your date of birth, two randomly generated digits,

a digit identifying your gender and a final digit. As with all of your NHS Scotland medical records, your CHI number is used in your diabetes record (SCI-Diabetes) to uniquely identify you. When NRS Diabetes check your SCI-Diabetes records to assess whether you are a good match for a research project, your CHI number will always be associated with your information. This helps to ensure that your information uniquely refers to you. If NRS Diabetes identify you as a good match for a research project, your CHI number will also be sent to a member of the NRS Diabetes Network in the research team. Your CHI number helps NRS Diabetes and NRS Diabetes members in the research team keep accurate records of who has been matched or contacted.

How will I know if I am being contacted as part of the Diabetes Register?

When the research team member receives your CHI number, name, preferred method of contact and any other relevant information she/he will prepare to get in touch with you. Each method of contact will acknowledge that you are being contacted as a result of being part of the Diabetes Register. If you have chosen post or email as your method of contact, the research team will use wording that confirms that you are on the Diabetes Register. For letters, a tear-off reply slip or similar response option will allow you to indicate your interest or confirm that you do not wish to find out more about the research project. For email, you will be able to simply reply to the research team with your decision or respond to any email address provided. For telephone contact, you can express your interest or decline. In some cases, you may be given the option of taking part directly by completing an online questionnaire.

How is my personal information kept safe by NRS Diabetes?

NRS Diabetes securely stores or saves the personal information you provide to join the Diabetes Register.

The process of entering your details and searching your information through the Diabetes Register is securely carried out within SCI-Diabetes, NHS Scotland's electronic health record for diabetes. Access and use of SCI-Diabetes is strictly controlled and monitored by the NHS Scottish Care Information – Diabetes Collaboration. This means only the NRS Diabetes management team have access to search the Diabetes Register and use your diabetes-related healthcare information to check whether you may be a good match for a research project.

Following a search, any results from the Diabetes Register are contained and saved on the NHS computer system within an access-controlled folder available only to the NRS Diabetes management team.

If your diabetes-related healthcare information suggests that you may be a good candidate for a research project, your CHI number, name, contact information and any other relevant information will be sent and received using the NHSmail system. All research team members who receive your information have a strict duty of confidentiality. This means they are ethically and legally obliged to keep your information confidential and safe within the NHS unless you explicitly consent to it being passed elsewhere.

How long will my personal information be held for?

NRS Diabetes will securely store the information you provided to join the Diabetes Register unless you ask for that information to be destroyed.

The contact information you provided will also be saved electronically in SCI-Diabetes. This information will be saved either until you withdraw from the Diabetes Register and ask for this information to be erased or your health record is removed from SCI-Diabetes.

When someone dies, their health record will automatically be removed from the Diabetes Register.

If the information I provided changes can I update it?

Yes, if you provided either a telephone number or email address when you joined the Diabetes Register you can update this by contacting NRS Diabetes using the details provided on the back of this leaflet.

However, if your name, address or any other details about you change, you won't need to contact NRS Diabetes. You can update this information by contacting your General Practice or by letting someone know when you next have an appointment with an NHS Scotland healthcare service.

Once your details are updated, your NHS diabetes computer record (SCI-Diabetes) will automatically change and NRS Diabetes will have access to your new information.

If I join the Diabetes Register, will my contact information be used for anything other than diabetes-related research?

NRS Diabetes may contact you to ask if you still want to be on the Diabetes Register and check if your telephone number or email address needs to be updated. NRS Diabetes may need to post you a letter to ask you these questions even if you didn't choose this as your preferred method of contact.

NRS Diabetes may also contact you with other carefully selected and important diabetes-related information connected to research in the NHS. Any such information will have been scrutinised by NRS Diabetes to ensure that it is relevant, useful and timely.

Can I withdraw from the Diabetes Register and have the information I provided erased?

Yes, you can withdraw from the Diabetes Register at any time by contacting NRS Diabetes using the details provided on the back of this notice. The process is simple and choosing to withdraw will not affect the care you receive from NHS Scotland in anyway.

When you withdraw, you can also ask for the contact details you provided to join the Diabetes Register to be erased.

Who are the 'controllers' of my personal information?

The General Data Protection Regulation (GDPR) requires that you know who the 'controllers' are of your personal information. A 'controller' is an organisation, or individual, that relies on your consent and determines the purposes and means of processing your personal information. Because NRS Diabetes is funded by the Scottish Government it includes a number of different organisations who employ members of the NRS Diabetes network. Depending on where diabetes-related research is taking place, these organisations may be considered 'controllers' of your personal information. For example, the University of Dundee is a controller of the information you provide. When your information is provided to a research team the controller may change.

Any of the organisations listed below will be considered a 'controller' if they employ a research team member working on a project that uses the Diabetes Register. Although this list intends to detail all known, research-active organisations and organisations that may be involved in future research, it should not be considered exhaustive. If you require more information, please contact NRS Diabetes.

NHS Scotland Health Boards:

NHS Ayrshire and Arran
NHS Borders
NHS Dumfries and Galloway
NHS Fife
NHS Forth Valley
NHS Grampian
NHS Greater Glasgow and Clyde
NHS Highland
NHS Lanarkshire
NHS Lothian
NHS Orkney
NHS Shetland
NHS Tayside
NHS Western Isles

Universities:

University of Aberdeen
University of Dundee
University of Edinburgh
University of Glasgow
Glasgow Caledonian University
Glasgow School of Art
Heriot-Watt University
University of the Highlands and Islands
Queen Margaret University Edinburgh
Robert Gordon University
University of St Andrews
University of Stirling
University of Strathclyde
University of the West of Scotland

What should I do if I have any concerns or further questions about any aspect of the Diabetes Register?

If you have a concern or any questions about any aspect of the Diabetes Register, please do not hesitate to contact NRS Diabetes using the details provided on the back of this leaflet.

Alternatively, you can contact the Data Protection Officer at the University of Dundee by emailing dataprotection@dundee.ac.uk.

If you are dissatisfied with the way NRS Diabetes may have processed your personal information you have the right to complain to the Information Commissioner's Office (ICO). Before contacting the ICO directly, please

consider raising any issues with the NRS Diabetes management team who'll do their best to help.

What is lawful bases we rely on for processing your information?

Under the UK General Data Protection Regulation (UK GDPR), the lawful bases we rely on for processing your information is: We need it to perform a public task. In addition, we rely on explicit consent as the condition for processing special category data under Article 9 of the UK GDPR.

Your rights

The General Data Protection Regulation (GDPR) provides you with individual rights and the information provided in this notice is intended to make sure that these rights are being met.

Specifically, the GDPR provides you with the right to be informed, request access, request rectification, have personal data erased, restrict and/or object to processing, request data portability and rights related to automated decision making including profiling. For more information please visit www.ico.org.uk/for-the-public/

If you have any questions or if you would like to withdraw from the Diabetes Register please contact NRS Diabetes at:

Telephone: 01382 383 595

Email to request withdrawal: TAY.diabetesresearchregister@nhs.scot

Email for general enquiries: administrator-sdrn@dundee.ac.uk

Address:

NRS Diabetes

Diabetes Support Unit

Level 8

Ninewells Hospital

Dundee

DD1 9SY