

**NHS Research Scotland (NRS) Diabetes  
Privacy Information Notice:  
Sending letters to patients with an  
opportunity to join the NRS Diabetes  
Research Register**



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**Our Contact Details:**

**Telephone:** 01382 383 595

**Email for general enquiries:** [TAY.diabetesresearchregister@nhs.scot](mailto:TAY.diabetesresearchregister@nhs.scot)

**Email to request withdrawal:** [TAY.diabetesresearchregister@nhs.scot](mailto:TAY.diabetesresearchregister@nhs.scot)

**Address:**

NRS Diabetes  
Diabetes Support Unit  
Level 8  
Ninewells Hospital  
Dundee  
DD1 9SY

**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. We are committed to providing people with the information they need to understand how their personal information is used. If you wish to find out more about how we use information in order to send letters to people with an invitation to join the NRS Diabetes Research Register, please make sure you read and keep hold of this Privacy Information Notice. Paper copies of this Privacy Information Notice are available upon request.

### **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 find out more about how we use information in order to send letters to people inviting them to join the NRS Diabetes Research Register.

If you have received a letter and NRS Diabetes Research Register registration leaflet in the post this Privacy Notice explains how we have used your information in order to facilitate the lettering process. If you are unsure about any aspect of this process or you have any other questions please contact us on 01382 383 595 or [TAY.diabetesresearchregister@nhs.scot](mailto:TAY.diabetesresearchregister@nhs.scot). Alternatively, please write to us using our address on the front of this document.

### **What is the NRS Diabetes Research Register?**

NRS Diabetes have a system and process that we call the NRS Diabetes Research Register. If a patient with diabetes joins, it means that NRS Diabetes can check if they are a good match for any research that comes along and contact them to ask if they are interested. A separate Privacy Information Notice, related to what happens after joining the NRS Diabetes Research Register is available on the [NRS Diabetes website](#) or upon request.

### **Who operates the NRS Diabetes Research Register and what do they do?**

The NRS Diabetes Research Register is operated and managed by NRS Diabetes. NRS Diabetes is a Scotland-wide network for supporting diabetes and 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 NRS Diabetes Research Register which involves sending letters to people with diabetes in order to give them the opportunity to join.

### **Why is it important that NRS Diabetes send letters to people with diabetes with an invitation to join the NRS Diabetes Research Register?**

Diabetes research can only happen if there are people with diabetes who are willing to take part. It can be very difficult to find the right people to take part in research and this is often the biggest challenge to being able to make research happen. Likewise, it can be difficult for people with diabetes, who are interested, to find out about research that they may be a good match for.

We understand that many people living with diabetes want to be provided with an opportunity to find out about diabetes research that they may be a good match for. Likewise, we know that many people also feel that they would like to contribute or give back to the NHS in Scotland by supporting research.

NRS Diabetes therefore want to be able to give people with diabetes, living in Scotland, the opportunity to give their permission to be matched to and contacted about research that they are a good match for. This is the purpose of the NRS Diabetes Research Register.

NRS Diabetes want to try and make sure that as many people as possible are given an opportunity to join the NRS Diabetes Research Register.

The best we can achieve this aim is to be able to send letters directly to people with diabetes explaining why they have been contacted and asking them to join the NRS Diabetes Research Register. The letters contain a registration leaflet which can be completed and posted back for free. Alternatively, a registration email address is provided that can also be used to join.

### **Is sending letters to people with diabetes inviting them to join the NRS Diabetes Research Register supported by UK-wide policy?**

Yes, providing an opportunity for people who have diabetes to join the NRS Diabetes Research Register aligns to and supports the vision set out in the [UK](#)

[Policy Framework for Health and Social Care Research](#). The UK policy framework sets out principles of good practice in the management and conduct of health and social care research and commits to an environment where:

“Patients, service users and the public (including carers, relatives of patients and service users and healthy volunteers) are given, and take, the opportunity to participate in health and social care research and to get involved in its design, management, conduct and dissemination, and are confident about doing so.”

[The Future of Clinical Research Delivery: 2022 to 2025 implementation plan](#) sets out the UK and devolved governments vision for the future of clinical research delivery. One of the overarching themes identified in the plan aims to achieve:

“Patient-centred research – to make access to, and participation in, research as easy as possible for everyone across the UK, including rural, diverse and under-served populations”.

## **What is SCI-Diabetes?**

NHS Scotland’s electronic health record for diabetes is called SCI-Diabetes. When a person, who lives in Scotland, is diagnosed with diabetes an electronic record is made in SCI-Diabetes. This record helps to support the care and treatment of people with diabetes in Scotland.

## **How do NRS Diabetes use my personal information that is available in SCI-Diabetes to be able to send me a letter giving me the opportunity to join the Diabetes Register?**

NRS Diabetes aim to reach as many people with diabetes as possible in order to give them the opportunity to join the Diabetes Register. The main route through which NRS Diabetes achieves this is by sending a letter and registration leaflet directly to people with diabetes.

In order to facilitate the lettering process, NRS Diabetes use a set of criteria that defines who is eligible to receive a letter. These criteria have been thoughtfully defined. For example, they help make sure that some people who receive a letter are not being contacted directly following diagnoses and that they are more likely to understand their diagnosis. If you would like to find out more about these criteria, please contact us using the details on the front of this document.

NRS Diabetes will use Community Health Index (CHI) numbers during the processing of information. Everyone registered with a Scottish GP practice has their own unique CHI number. CHI numbers help make sure information about your healthcare is not mixed up with someone else’s. The CHI number is ten numeric digits in length, contains a person’s date of birth and another digit which is always an even number for females and an odd number for males.

When NRS Diabetes are ready to send letters, we are able to ask that the criteria is applied to SCI-Diabetes so that lists containing CHI numbers, names and addresses can be generated. NRS Diabetes then use this information to prepare letters before sending them in the post. Following completion of the lettering process NRS Diabetes securely retain the CHI numbers to ensure that, in the future, individuals are not sent another letter.

The information that NRS Diabetes uses to prepare letters (CHI numbers, names and addresses) is securely accessed and electronically transferred from within the NHS. NRS Diabetes uses two methods for preparing and issuing letters. The first method involves printing, packing and posting letters from within NRS Diabetes central office, based in NHS Tayside. The second method involves using a Scottish Government approved service with Royal Mail and its approved print partner CFH to securely print, pack and post letters. When using Royal Mail and CFH, the information needed to send letters is uploaded to a secure file transfer service. Royal Mail and CFH are then able to securely facilitate the lettering process on behalf of NRS Diabetes. Information used by Royal Mail and CFH to facilitate lettering is erased following completion of the process.

### **What type of personal information is processed to allow for letters to be sent?**

- First Name
- Surname
- Address
- Postcode
- Community Index Number

### **How we store your personal information**

Your information is securely stored within the NHS.

We may store the following information:

- First Name
- Surname
- Address
- Postcode
- Community Index Number

### **What is the lawful bases for processing this information?**

Under the UK General Data Protection Regulation (UK GDPR), the lawful bases we rely on for processing this information is:

- 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.
- 9(2)(j) - Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes in accordance with Article 89(1).

## **Your data protection rights**

Under data protection law, you have rights including:

**Your right of access** - You have the right to ask us for copies of your personal information.

**Your right to rectification** - You have the right to ask us to rectify personal information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

**Your right to restriction of processing** - You have the right to ask us to restrict the processing of your personal information in certain circumstances.

**Your right to object to processing** - You have the the right to object to the processing of your personal information in certain circumstances.

You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

Please contact us using any of the details below if you wish to make a request.

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### **Address:**

NRS Diabetes  
Diabetes Support Unit  
Level 8  
Ninewells Hospital  
Dundee  
DD1 9SY

## **Who are the 'controllers' and 'processors' of my personal information?**

The controllers of the information held in SCI-Diabetes are the 14 regional NHS Scotland Healthboards listed below:

**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

NHS Research Scotland (NRS) Diabetes is funded by the Scottish Government. The staff members of NHS Research Scotland (NRS) Diabetes who facilitate the lettering process outlined in this Privacy Notice are based in NHS Tayside and employed by the University of Dundee. NHS Tayside and the University of Dundee are both processors and controllers of your information. No information is shared with or processed within the University of Dundee.

**To find out more about NHS Tayside’s data protection information please visit:**

[https://www.nhstayside.scot.nhs.uk/YourRights/PROD\\_263958/index.htm](https://www.nhstayside.scot.nhs.uk/YourRights/PROD_263958/index.htm)

**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 lettering process outlined in this Privacy Notice, please do not hesitate to contact NRS Diabetes using the details provided on the front of this document.

Alternatively, you can contact the Information Governance team by emailing [tay.informationgovernance@nhs.scot](mailto:tay.informationgovernance@nhs.scot) or by post:

Information Governance and Cyber Assurance Team  
Maryfield House (South)  
30 Mains Loan  
Dundee  
DD4 7BT

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.

### **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. For more information please visit [www.ico.org.uk/for-the-public/](http://www.ico.org.uk/for-the-public/)

### **If you have any questions please contact us at:**

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