

NEUROPROGRESSIVE
AND DEMENTIA

NHS Research Scotland (NRS)
Neuroprogressive and Dementia
Research Register

Privacy Information Notice:
How NRS Neuroprogressive and
Dementia use your information





Your personal information
is in safe hands

We respect your privacy

We keep your personal
information secure

We do not sell your
personal information

Permission to contact for future research

When you provide personal information to an organisation, it is important both your privacy is maintained and that you understand how this information is used.

The following privacy notice explains exactly how **NRS Neuroprogressive and Dementia Research Network** (referred to as the Network within this privacy notice) stores, processes and uses the information you have provided and why.

In summary, we use your information to get in touch with you about future research opportunities, and ensure that we offer you the right types of research opportunities.

The collection and storage of data for this purpose is called the **Permission to Contact scheme**. Please read and hold on to this privacy notice, as it explains this scheme in detail.

If you have any questions about Permission to Contact, or the Network, get in touch using any of the details on page 6.

Why have I been given this privacy notice?

If you have received this privacy notice, it is because you have expressed an interest in taking part in research. One way to hear about research opportunities is to provide the Network access to your contact details and personal information so they can get in touch with you about appropriate studies. This is called the Permission to Contact (PTC) scheme.

If you would like to be part of the PTC scheme, it is important you understand why the Network is asking for this information, and what we do with it. Please read this notice, and if you need help ask a family member, friend or carer to go through it with you.

If you provide us with your personal data, we will understand that you accept and consent to the practices described in this document. If you do not agree with these terms, please do not provide us with your information; or get in touch with the Network in the first instance to discuss.

Do I have to take part in the PTC scheme?

No. If you have received this notice you are under no obligation to take part in the PTC scheme, and we will not contact you unless you provide us with your information.

Who are the Network?

NRS Neuroprogressive and Dementia is an organisation of researchers distributed across mainland Scotland. The Network is funded by the Scottish Government through the Chief Scientist Office. It is responsible for running different types of studies across Scotland for people with dementia or other neuroprogressive conditions, such as Parkinson's disease.

Where will you keep my information?

If you have provided information on a reply slip, this is physically stored in a safe in the Network central office in NHS Tayside. The information written on the slip will be entered into a database which is based in the Health Informatics Centre (HIC), NHS Scotland, hosted by the University of Dundee.

Who will have access to my information?

Your information will be accessed by members of the Network. All members of the Network work in NHS Scotland, and will have received training on data protection and security as part of their induction.

More specifically, your information will only be accessed by members of the Network who also have access to HIC. Accessing HIC can only be done through an NHS computer and if you have a password-protected login.

Who are the controllers of my information?

The information that you provide us is controlled by the Network, which is based in NHS Scotland. Your health records are controlled by your NHS health board.

What will you do with my information?

We will use your information to get in touch with you. We need information like your date of birth and postcode to ensure we get in touch with the right person.

Importantly, we may ask for your Community Health Index (CHI) number, so we can identify you and your health records (please see why below).

The CHI number is made up of your date of birth and four random numbers. If you don't know your CHI number, we will be able to

identify you through the combination of your name, date of birth and postcode.

Why do you need to identify and access my health records?

Some studies have inclusion or exclusion criteria for its participants, and the most common of these relate to potential participants' health, including what type of medication they may be taking or if they have a particular condition. Before we get in touch, if permission is granted, we will access your health records to make sure that we only offer you studies that you are likely to be able to take part in.

Your health records will only be viewed by members of the Network and will not be passed to any third parties without your explicit consent.

When will you get in touch with me?

If there is a study that you may be suitable for, a member of the Network will get in touch with you. If you do not hear from us, it may be because there are no research studies that are appropriate for you at the time, although a study may come along in the future.

What kind of studies do you run?

The Network runs lots of types of studies, including questionnaire based studies, focus groups and clinical trials.

The Network management are responsible for reviewing and approving the studies that it runs. 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.

In addition to studies, we may also ask if you are interested in joining a research interest register, such as Join Dementia Research (JDR) or the Scottish Brain Health Register (SBHR). Being signed up to a register may give you access to different studies. If you are interested in taking part in a register, we will send you all the necessary paperwork to join.

Do I have to take part in a study?

No. You are not under any obligation to take part in a research study. Even if you do decide to take part in a research study, you are always free to change your mind and can stop taking part at any time, and you do not have to provide a reason.

How long do you keep my details?

Your details will be kept on HIC indefinitely, unless you ask us to remove them.

What happens if my details change?

If your details change, such as your phone number or address, get in touch with us by phone or email and let us know. We will update the information on HIC to reflect the change.

Can I remove my details from Permission to Contact?

You can remove your details at any time and no reason needs to be provided for this. The best way to do this is by phoning the Network on 01382 423086 and requesting removal of all information previously supplied. Removing your details will not affect your rights or standard of care.

Alternatively, you can contact the Data Protection Officer at the University of Dundee by calling **01382 384441** or sending an email to dataprotection@dundee.ac.uk

What are my rights?

The General Data Protection Regulation (GDPR) provides you with individual rights about how information (data) about you is used. This notice was written to make sure that these rights are being met.

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:

<http://www.ico.org.uk/for-the-public>

If you have any questions or would like to withdraw from the register please contact NRS Neuroprogressive and Dementia at:

Email:

tay.ndntayside@nhs.scot

Telephone:

01382 423086

Post:


Corridor M, Level 5,
Ninewells Hospital & Medical School,
Dundee,
DD1 9SY

Twitter:

@NRS_NDN

Facebook:

[fb.me/NHSNDN](https://www.facebook.com/NHSNDN)



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 01382 423086