

# Privacy Statement

## How we use, share and protect your personal information:

Research+Me is a database monitored by a dedicated team of researchers at the Newcastle Hospitals NHS Trust. Its aim is to increase opportunities for patients with long term conditions to take part in late phase clinical trials as well as support researchers in recruitment.

Research+Me invites individuals to express their interest in taking part in future research projects by registering their details via an online form – this could be as a patient with a chronic condition or as a healthy volunteer. The registry will store and process personal information\* for the reasons outlined in this privacy statement.

The Research+Me registry is hosted the Newcastle upon Tyne Hospitals NHS Foundation Trust. The Trust is registered with the Information Commissioners Office – the UK's independent authority set up to uphold information rights in the public interest. It is registered under number Z6173332.

## This statement outlines four key principles:

1. **What** information we hold about you.
2. **Why** we keep information about you.
3. **How** we will keep your information.
4. **How long** we will keep your information.

It also outlines what laws are relevant to the storage and use of your personal information, including your rights under the General Data Protection Regulations (GDPR). You can find important contacts following this statement.

## 1. What information do we store about you?

**Personal identifiable information** including first name, surname, gender, NHS number and date of birth.

**Contact details** including address, email address, phone numbers. \*\*

Information regarding your **Covid-19 status**.

Information regarding your **significant health conditions**.

\*\* By supplying us with your contact details you are agreeing to us contacting you via one of the means listed.

## 2. Why do we keep the above information?

By registering your details with Research+Me you are agreeing to be contacted by a member of the research team at the NIHR Patient Recruitment Centre Newcastle, with information regarding future clinical trials you may be suitable for and interested in.

In order for us to do this, we need to keep a record of your name and contact details to share any relevant opportunities with you. Information regarding you gender and date of birth is stored to enable us to determine if you're suitable to take part in a particular research project.

Your NHS number is unique to you and helps us identify you correctly and confirm that the information we hold about you is up to date. If you have not supplied us with your NHS number we can obtain it from your medical records using your other identifiable information if necessary.

We request information regarding your Covid-19 status to establish if it is appropriate for you to attend the NIHR Patient Recruitment Centre Newcastle in person, and to identify if you are suitable to participate in any Covid-19 related trials.

Storing your information also gives you the opportunity to receive our bi-annual newsletter and receive any other relevant information, for example information about research open days.

## 3. How is your information kept secure and confidential?

The Trust has a legal obligation to keep the information stored about you secure and confidential.

The information you provide us with will never be disclosed to anyone other than the professionals directly involved in your care and the participation in any trials you may be eligible for. (Unless in extreme circumstances where we believe your safety or that of others is at risk).

The information you provide is held on a secure, password protected electronic database and kept in accordance with current legislation – it can only be accessed by members of the research team at the NIHR Patient Recruitment Centre Newcastle. All staff are trained by the Newcastle upon Tyne Hospitals NHS Foundation Trust to handle your information in the correct manner in order to maintain your privacy and confidentiality.

## 4. How long is your information kept for?

For as long as you are registered with the Research+Me.

If you wish to withdraw from the registry, you are free to do so at any point without it affecting your care or individual rights and we will delete your information from the registry database. Please note that by doing this you will no longer be able to be contacted by a member of the research team regarding future studies.

## What laws govern the handling of your personal data?

- **The General Data Protection Regulations (GDPR) and Data Protection Act 2018.**  
More information can be found here:  
<https://www.gov.uk/government/publications/guide-to-the-general-data-protection-regulation>
- **The Human Rights Act 1998.**  
More information can be found here:  
<https://www.citizensadvice.org.uk/law-and-courts/civil-rights/human-rights/the-human-rights-act-1998/>
- **Freedom of Information Act 2000.**  
More information can be found here:  
<https://www.gov.uk/make-a-freedom-of-information-request>
- **NHS Codes of Practice.**  
More information can be found here:  
<https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice>

## Your rights under GDPR:

Personal information is defined under GDPR (General Data Protection Regulations) as “...any information relating to an identified or identifiable person; an identifiable person is one who can be identified directly or indirectly, in particular by reference to an identifier such as a name, identification number, location data...or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that person”.

These can be summarised in eight simple steps:

1. **The right to be informed** about the collection and use of your personal data.
2. **The right to access** information stored about you.
3. **The right to rectification** – information you consider inaccurate can be rectified.
4. **The right to erasure** – you have the right to be removed from the Research+Me.
5. **The right to restrict processing** – you can stop information being used under certain circumstances.
6. **The right to data portability** – you can have information about you provided in a format which is accessible to you and understandable.
7. **The right to object** to your information being used in certain circumstances.

8. **Rights in relation to automated decision making and profiling** – the right to prevent automated decision making and profiling where there has been no human involvement.

## Useful contacts:

**Research+Me Team** – For general enquiries and requests for amendments to your details.

NIHR Patient Recruitment Centre - Newcastle  
Newcastle upon Tyne Hospitals NHS Foundation Trust  
Campus for Ageing and Vitality  
Westgate Road  
Newcastle upon Tyne  
NE4 6BE

**Email:** [nuth.registryP3@nhs.net](mailto:nuth.registryP3@nhs.net)

**Tel:** 0191 282 3981

**Hazel Forsyth – Senior Research Sister**

NIHR Patient Recruitment Centre – Newcastle  
Newcastle upon Tyne Hospitals NHS Foundation Trust  
Campus for Ageing and Vitality  
Westgate Road  
Newcastle upon Tyne  
NE4 6BE

**Email:** [hazel.forsyth@nhs.net](mailto:hazel.forsyth@nhs.net)

**Tel:** 0191 282 1369

**Richard Oliver - Data Protection Officer**

**Email:** [nuth.dpo@nhs.net](mailto:nuth.dpo@nhs.net)

**Tel:** 0191 213 7368

**Information Governance Team**

**Email:** 0191 213 7368

**Tel:** 0191 233 1805

**The Caldicott Guardian**

**Email:** [nuth.caldicott@nhs.net](mailto:nuth.caldicott@nhs.net)

## Document Amendments

This privacy statement will be reviewed on an annual basis and updated if there are any changes at which point an updated version will be posted on Research+Me website.