

RICE

Improving the lives of people living with dementia through research, diagnosis, treatment and support.

The Research Institute for the Care of Older People

RICE Privacy notice for clinical trials and research



To provide you with appropriate care for your participation in our clinical trials or research we hold a variety of information about you. However, we recognise the importance of your privacy and RICE is committed to ensuring that your privacy is protected.

This notice tells you what personal information RICE collects about you, why we need it, how we use it and what protections are in place to keep it secure.

About this notice

RICE is a registered charity focused on essential research and providing support for people with dementia, their families and carers, dedicated to improving the quality of life of everyone involved.

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What do we collect?

To provide you with the care you need we hold a variety of information about you including such information as:

- Identification information - name, date of birth, NHS number
- Contact information - address, telephone numbers, email addresses
- Next of kin, carer information – the contact details of a close family member or friend
- Details of clinical trial or research appointments and contact with us
- Medical information including medications and treatments, medical history, assessment and test results
- Information about allergies and health conditions
- Information required under the specific protocols of the clinical trial or research you are participating in,

which will be explained to you and for which you will be asked to give your explicit consent

This is not an exhaustive list.

When/how do we collect your personal information

We collect your information at various points throughout your participation in clinical trials or research with us, including during the following times:

- When you register with us as a potential research patient and consent to us holding your information for this purpose
- When you become a clinical trial study patient or research patient of RICE
- In the course of managing your ongoing participation, care and treatment with us
- When we receive data from a third party, i.e. the organisation running the clinical trial or research study, your GP, healthcare practitioners and other health and social care practitioners involved in your care and treatment.

Why we collect and use your personal information

We collect your information in order to be able to give you the appropriate care and treatment in relation to your participation in clinical trials or research with us. The information we collect and hold ensures that we can give you the best possible care and can communicate appropriately with others involved in your care.

Sharing your information

We will only share your information with other people involved in your care and treatment when you have given us your consent to do so, or where we are legally obliged to.

We may share your information with:

- Your GP and other NHS staff for the purposes of providing care and treatment
- Social workers and other non NHS staff involved in providing your care
- Private healthcare organisations involved in providing your care
- Family and carers (with your explicit consent)
- Information required under the specific protocols of the clinical trial or research you are participating in

Your confidential patient-identifiable information is only shared with other organisations where there is a legal basis for it as follows:

- When there is a Court Order or a statutory duty to share patient data
- When there is a statutory power to share patient data
- When you have given explicit consent to the sharing
- When you have implicitly consented to the sharing for direct care purposes

Where we share your information we ensure that we only share the minimum necessary for the specific purpose. We do not sell your information or share it for any marketing purposes .

How we protect your information

Appropriate technical controls are in place to store and protect personal data. We have security procedures in place to guard against unauthorised access, improper use, alteration, destruction or accidental loss of your personal information. Information is only accessible by appropriately trained staff (and, where appropriate, volunteers) for the specific purpose of their work at RICE. Information is kept securely within NHS guidelines and/or the specific protocols of the clinical trial or research you are participating in.

How long we keep your information

Clinical trial and research patient records are retained in line with the specific protocols of the clinical trial or research you are participating in and the retention schedule as determined by the regulatory bodies which set out the appropriate length of time for each type of clinical trial and research.

RICE does not keep clinical trial and research patient records for longer than necessary.

All records are destroyed confidentially once their retention period has been met, and RICE has made the decision that the records are no longer required.

How you access your information

We aim to ensure that the information we have for you is accurate and up-to-date. You can request to see this information and if, for example, you believe that something is incorrect or you do not wish us to retain it you can ask to have it corrected or deleted.

If you would like to request access to the information we hold please send your request in writing outlining a description of the information you want to obtain and a proof of your identity to **The RICE Centre, Royal United Hospital, Combe Park, Bath, BA1 3NG**. We do not accept requests of this nature by email as we must ensure that we only provide personal data information to the individual it relates to. For further guidance please contact us on 01225 476420.

If you wish to raise a complaint on how we have handled your personal information you can ask us to investigate the matter. Contact info@rice.org.uk or call us on 01225 476420.

If you are not satisfied with our response or believe we are processing your personal data not in accordance with the law you can complain to the Information Commissioner's Office <https://ico.org.uk/>

The RICE Centre,
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