

Privacy Notice for Research

How your personal information is collected, used and stored for the purposes of research



How you access your information

We aim to ensure that any information we hold about you is accurate and up to date. You can request to see this information at any time. You can also ask us to destroy permanently any records we hold about you, if you wish.

Please send any requests to view, amend or delete your data in writing, along with proof of your identity, to the address at the bottom of the page. Feel free to contact us for guidance before you make your request on 01225 476420.

Making a complaint

If you are not satisfied with the way we've handled or stored your personal data, you can ask us to investigate the matter via the contact details below.

The storage and use of personal data is governed by the General Protection of Data Regulations (GDPR) and the Information Commissioner's Office (ICO) can be contacted at www.ico.org.uk

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How we protect your information

Appropriate technical controls are in place at ReMind UK and with any suppliers we may use, to protect your personal and medical data. We have security procedures in place to guard against unauthorised access, improper use, alteration, destruction or accidental loss of personal information.

Your information can only be accessed by appropriately trained staff (and where appropriate, volunteers) for the specific purpose provided.

How long we keep your information

If you participate in research at ReMind UK, the timeframe within which we hold your information is specific to the research or clinical trial, determined by the regulatory body overseeing the research. This will be explained to you on signing up as a research participant.

ReMind UK does not keep any personal data for longer than necessary.

All records will be destroyed securely and confidentially, once we have reached the end of the specified retention period.



About this notice

ReMind UK is a registered charity focused on essential research and providing support for people with dementia, their families and carers.

This leaflet explains the personal information ReMind UK might collect about you, why we collect it, how we might use it and what protections are in place to keep it secure. ReMind UK is the 'Data Controller'.

What do we collect?

To deliver the data required for our research and to ensure your care and support during the trials we hold a variety of information about you including:

- Your name, date of birth and NHS number
- Your address, telephone numbers, email addresses
- Your next of kin/carer information – the details of a close family member or friend
- Details of clinical trial research appointments and any contact you have with us
- Your medical information, including medications and treatments, medical history, assessment and test results
- Allergies and health conditions
- Information required by the clinical trial/research, for which you will give separate, explicit consent.

Why we collect and how do we collect your information?

ReMind UK collects your information in order to be able to give you the most appropriate care, treatment and support.

The information we collect and hold about you ensures that we can deliver our research, give you the best possible care and communicate with you and others involved in your care, treatment or support.

As well as administration and delivery of your appointments, care and treatment, and data required for the success of our research we may also process your data to communicate with you where we believe we have a legitimate interest to do so.

This may include communications about the support we offer, support which is available more widely for people affected by dementia or associated conditions or how we can further support you.

We may from time to time send you communications about ReMind UK's work, how you can stay in touch or get involved should you wish to. We will always balance any potential impact of sending the communication and your rights against the legitimate interest and make it easy for you to opt out of receiving information and communications should you wish to do so at any time.

Sharing your information

We will only share your information with other people involved in your care when you have given us your explicit consent to do so, or where there is a legal requirement to share it.

We may share your information with:

- Your GP and their 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 your care
- Your family and carers (with your explicit consent)

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 for your data to be shared
- When you have implicitly consented to the sharing for direct care purposes

Where we share your medical data we ensure that we only share the minimum necessary for the specific purpose. We do not sell any information we hold about you or share with any third parties for marketing purposes.