Cohort Science Ltd

Privacy & Security

Frequently Asked Questions

Effective Date: 23 July 2026

Our Commitments

- We are committed to protecting your privacy and the security of your data.
- We never sell your personal or health data.
- We are certified to ISO 27001 and ISO 9001.
- We hold Cyber Essentials Plus certification.
- We meet or exceed the requirements of the NHS Data Security and Protection Toolkit.
- For US data, we operate in a HIPAA-compliant manner.

Frequently Asked Questions

Who is Cohort Science?

Cohort Science Ltd is the sponsor of research registries such as AccessALL, AccessBrainHealth and other ACCESS studies. We develop and manage patient registries and clinical research studies to advance understanding of disease and improve care.

Who is uMed?

uMed (Umedeor Ltd and its affiliates, including uMed Technologies Inc) is a clinical research support organisation that works with healthcare providers and study sponsors, including Cohort Science. uMed provides patient identification, contact, engagement and operational support services for Cohort Science registries and related studies.

How will my data be used?

In our Cohort Studies we use information that you provide and relevant information from your medical records for the purposes of the study. We only use the information we need.

Data shared with researchers is typically provided in a de-identified or pseudonymised form so that individual patients cannot readily be identified. You will not have any ownership rights in the research data or any resulting intellectual property, and you will not receive any financial benefit from commercial uses of the data.

Full details are set out in the study consent form and our Privacy Notice.

Will I be informed of any results?

Participants typically receive periodic newsletters updating them on study progress. We also welcome feedback from study participants and provide opportunities for this.

Will pharmaceutical companies or other research organisations be involved?

Yes. Pharmaceutical, medical device and academic organisations play an important role in developing new therapies and may collaborate with Cohort Science. Any sharing of data is done under appropriate agreements and, where required, in de-identified or pseudonymised form.

Are there any risks associated with taking part?

While we take strong measures to protect your privacy and wellbeing, participation in medical research can involve some residual risks, such as the possibility of a data breach. Additional

research opportunities (sub-studies) will always require your separate consent, and the specific risks will be explained at that time.

You should carefully consider the information provided before deciding to take part.

Will my healthcare provider be paid?

Participating healthcare institutions and their service providers may receive payment of administrative or service costs associated with their involvement in the study. This does not affect the care you receive.

Will I receive any payment for participating?

No. You will not receive payment for taking part in the main registry. You will also have no rights in any products, ideas or commercial developments that may arise from the research, and you will not benefit financially from them.

What if I no longer want to take part?

You can leave a study at any time without giving a reason by contacting the study support team. Any data already contributed before you withdraw will usually remain in the study database and continue to be used in accordance with the original consent and applicable law, unless you specifically request otherwise where the law allows.

Who should I contact if I need more information or wish to make a complaint?

United States

Study support: +1 888 454 5580

privacyofficer@cohort.science

United Kingdom

Study support: +44 808 304 9869

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