

ADVANCE Study Privacy Notice

In accordance with UK General Data Protection Legislation (UK-GDPR) and the Data Protection Act 2018, this Privacy Notice explains how the *Armed Services Trauma Rehabilitation OutCome Study team* (ADVANCE) processes your personal data. It applies to all participants over the long-term study period. This Privacy Notice should be read in conjunction with the study Participant Information Sheet (PIS) you would have received.

Who are we?

The study is a Consortium consisting of the Defence Medical Rehabilitation Centre (DMRC) Stanford Hall in collaboration with the research institutions of King's College London (KCL) and Imperial College London (ICL). All processing is carried out in accordance with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018.

The members of the ADVANCE consortium are acting as joint controllers of your personal data, meaning they together determine how and why your information is processed.

Why we process your personal information?

We use your personal data to carry out a long-term study on the effects of traumatic injuries. This includes comparing the health and wellbeing of injured service personnel with those who were not injured. The research looks at medical conditions (such as heart disease and arthritis) and wider wellbeing. The aim is to better understand long-term outcomes, improve support for those affected, and help reduce risks for future service personnel.

We use your contact details to share wider project updates and research developments.

How is your personal data collected?

We collect your personal data predominantly from what you have shared with us directly by participating in this study at our clinical sites. This includes information you provide through questionnaires, clinical assessments, and your contact details.

With your consent, we may also obtain relevant healthcare information about you from your medical records and NHS Digital to support the research.

What is our 'legal basis for processing' your data collected for this study.

Our legal basis for using your personal data is:

- (1) you have actively given us your permission (or 'consent') to contact you and add you to a mailing list which is used to send general project updates and newsletters and similar studies.
- (2) to carry out research tasks in the public interest, acting as a consortium of research

institutions, Article 6(1)(e). Where we process special category data, such as health data, we do so under Article 9(2)(j) of the UK-GDPR. This allows us to use this data for scientific or historical research and archiving purposes in the public interest.

- (3) in limited circumstances to protect your vital interest 6(1)(d). For example, clinical data collected during the study may identify a health condition that you and your GP may need to be alerted to.
- (4) you have consented to study participation and collection of special category and personal data and access NHS data. You may withdraw your consent to participate at any time by contacting the project's responsible officer please see the section '*Your rights and how to exercise them*' below.

How do we use your personal data?

We process your contact details in order to keep in contact with you for the length of the study. This is to invite you to follow up visits and, where opted in, to update you on study progress.

All clinical and questionnaire data will be, at minimum, pseudonymized before being shared for analysis with research partner organisations or academic collaborators involved in the project. This means that personal identifiers are removed or replaced, and individuals cannot be directly identified from the shared data.

Do you have to provide your data and what happens if you do not?

It is your choice whether to take part. If you do, you will be given a participant information sheet and asked to sign a consent form. You are free to withdraw at any time without giving a reason, and this will not affect your current or future care.

If you withdraw, we will stop collecting new data about you and delete any identifiable personal data where possible. However, anonymised data (which can no longer be linked to you) may continue to be used for research and cannot be removed.

How long do we keep your information for?

We will retain your personal information for the duration of the research project. This is a long-term study which is expected to collect your data over 20 years to support its objectives of researching and understanding long term outcomes for those who have suffered traumatic injuries.

The ADVANCE study will keep your personal data for:

10 years after the study has finished in relation to data subject consent forms and contact details.

10 years after the study has completed in relation to primary research data.

Do we share your information with other organisations?

Your personal contact details and identity will not be shared with any organisations or individuals outside the ADVANCE study team, except with your GP where necessary to protect your vital interests. Identifiable clinical data collected by ADVANCE may also be shared with your GP for this reason.

If you have consented to Data Linkage your identity may be shared with NHS Digital. Beyond this we will not share your identifiable information with any external organisations. On rare occasions, we may be required or permitted to share personal information by law (e.g. for law enforcement purposes).

To communicate our research to the public and the academic community your anonymised data is likely to form part of a research publication or conference presentation or public talk. Where researchers wish to use any information that would identify you, specific consent will be sought.

Your rights and how to exercise them

You have rights in relation to the personal data we hold about you. Some of these only apply in certain circumstances. For completeness, your rights are:

1. The right to be informed
2. The right of access to your personal data
3. The right to rectification if information is inaccurate or incomplete
4. The right to the erasure of your personal data
5. The right to restrict processing
6. The right to data portability
7. The right to object to processing

To find out more about your rights under UK-GDPR, please see the relevant section of the Information Commissioner's website: <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>. (EMBED)

If you have any questions or are unsure how to exercise your rights related to the ADVANCE study, you can contact the MoD Data Protection Team (cio-dpa@mod.gov.uk) or The ADVANCE research team (dmrc-advancestudyteam@mod.gov.uk).

Privacy notice version history

2026, May: Updated to reflect changes following the UK's departure from the EU and align to UK-GDPR. Updated to better explain the legal basis, how we use data, and how individuals can exercise their rights.

2021, April: Updated to align to the General Data Protection Regulation (GDPR)