

ADVANCE Study Privacy Notice (Feb 2019)

New data protection legislation came into force from May 25th 2018, known as the 'General Data Protection Regulation' (GDPR). This legislation strengthens protection for you as a Data Subject (participant) for this study. The information sheet below details the information we are required to give you under GDPR regarding your rights and how your data is used.

Who are we?

We, as the ADVANCE team, represent a consortium of research institutions including King's College London and Imperial College London working in partnership with the Ministry of Defence at facilities such as Defence Medical Rehabilitation Centre (DMRC), Stanford Hall, in order to carry out this important research.

Why do we process your personal information?

We process your personal information in order first to keep in contact with you for the length of the study (up to 20 years after your initial visit after which data may be retained for a further 15 years). Second, the information you share with us as a result of your clinical tests and via the questionnaires you are given will be used in a pseudo-anonymised way (removing personally identifying data) for research purposes over the course of the study.

What is our 'legal basis for processing' your data collected for this study, as per the General Data Protection Regulation (GDPR)?

(1) You have actively given us your permission (or 'consent').

You may withdraw your consent at any time by contacting the project's responsible Data Protection Officer – please see the section '*What are your rights and who can you contact if you have a concern?*' below.

By providing us with your personal data, including sensitive personal data such as on your health, you consent to the collection and use of any information you provide in accordance with the purposes stated in this privacy statement.

(2) It is required for our public purpose as a consortium of research institutions.

(3) It may be required to protect your (or somebody else's) life. Clinical data gathered as part of the study may indicate health conditions that you and your GP may need to be alerted to.

Do you have to provide your personal information and what are the consequences of not doing so?

You must provide the personal information requested in the course of participating in the study as part of your given consent. If you do not, we may not be able to maintain contact with you for the duration of the study, and the research outcomes will be affected if data is missing or incomplete for both contact and clinical purposes.

How long do we keep your information for?

We will keep your information for the duration of the project (twenty years from your first 'baseline' visit) plus fifteen years in order to complete the long-term goals of the project for researching and understanding outcomes for veterans.

Do we share your information with other organisations?

Your contact details are not shared with any organisations or individuals external to the ADVANCE study team.

Clinical and questionnaire data will be pseudo-anonymised (personally identifying information will be removed) and shared with the project consortium's research partners for research purposes.

Beyond this we will not share your 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).

What are your rights and who can you contact if you have a concern?

To find out more about your rights under 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/>

If you have a concern, the responsible Data Protection Officer for the ADVANCE study is Deputy DPO Martin Ellis who you can contact at the following e-mail address: Martin.Ellis238@mod.gov.uk.