Information about data protection

For this study, the University of Leeds and the ESAIC are acting as joint data controllers (person, company, or other body that determines the purpose and means of personal data processing). ESAIC (Rue des Comédiens 24, 1000 Brussels, Belgium) is responsible for looking after your data and using it properly by respecting your rights. According to the General Data Protection Regulations (GDPR) you have the right to access and correct the personal information about you, to restrict its use or storage, the right of data portability at any time. Please, note that your rights are not absolute and will be subject to a case-by-case analysis by the Data Protection Officer (DPO) of ESAIC.

The data will be stored securely, and your personal data will remain at your local hospital and be stored separately from the medical data collected for the study for at least ten years. All the coded data relating to the study in the ESAIC Central database will be stored electronically for at least 10 years. At the end of this period, the data will be destroyed.

At the end of the study your data might be shared with research teams in other organisations for further research, subject to appropriate approvals. These organisations may be within the UK, the European Economic Area (EEA) or outside the EEA. In this case no personal identifiable data will be shared. If your data is transferred outside of the EU, ESAIC is responsible for protecting your personal data. It will ensure that either the country that will receive your data is recognized as having an adequate level of data protection, or appropriate safeguards will be put in place by ESAIC to ensure the protection of your personal data. You have the right to ask for a copy of these safeguards by contacting the Data Protection Officer of ESAIC.

You can find out more about how we use your information by contacting the ESAIC data protection officer on privacy@esaic.org. Please note that contacting the DPO carries the risk of you losing your anonymity.