



## London School of Hygiene and Tropical Medicine

### Privacy Notice for use of the National Vascular Registry data in the ESORT-V project

#### Who are we?

The London School of Hygiene and Tropical Medicine (LSHTM) is a university in the UK which focuses on improving health worldwide. We will treat all data received safely and carefully and obey all relevant data privacy laws. At LSHTM we have several general data policies in place:

- [LSHTM Data Protection Policy](#)
- [LSHTM Information Security Policy](#)
- [LSHTM Privacy Notice for Research Participants](#)

#### What data is used for ESORT-V?

The ESORT-V project at LSHTM will use linked data from three sources: **“De-personalised data”** from the [National Vascular Registry](#) (NVR), **de-personalised data** from Hospital Episode Statistics (HES) and **identifiable data** from the Office for National Statistics (ONS). De-personalised data means that information which can be used to identify an individual (for example: your name or date of birth) will not be included in the data that LSHTM receives. The identifiable data from ONS is the date of death for patients who have died.

This data is necessary to enable us to answer questions about the benefits of having surgery at different points in time. It is particularly important in helping us determine whether particular sub-groups of patients (e.g. women) benefit from having surgery earlier or later. The **identifiable** data on date of death will be used to provide us with information on patient outcomes identified as important to both patients and clinicians. For example, death within 90 days of leaving hospital.

National Vascular Registry data will be sent to LSHTM from the National Vascular Registry by secure transfer. HES and ONS data will be sent to LSHTM from NHS England by secure transfer. To enable LSHTM to link records for the same patients in the different datasets it will be provided with “**study ID**” in the data it receives from the National Vascular Registry and NHS England. Each patient has a different study ID and it is a way for LSHTM to link records without having identifiable data such as date of birth or NHS number.

To enable study ID to be included in the data provided to LSHTM by both the National Vascular Registry and NHS England it is necessary for study ID and **identifiable data** to be sent by secure transfer from the National Vascular Registry to NHS England. The identifiable data is:

- Date of birth
- Postcode
- Gender
- NHS number

The identifiable data is used by NHS England to ensure that HES and ONS records are matched to the correct patient from the National Vascular Registry data. No other data is sent from the National Vascular Registry to NHS England. Once NHS England have matched the records then they add study ID to the de-personalised HES data and ONS data that will be sent to LSHTM. The identifiable data sent from the National Vascular Registry to NHS England will be securely destroyed.

LSHTM will hold de-personalised National Vascular Registry data, de-personalised HES data and identifiable (date of death) ONS data linked by study ID in a single dataset for analysis. The ESORT-V's projects outcome measures will be derived from the identifiable ONS date of death data. Once this has been done the identifiable ONS date of death data will be removed from the analysis dataset and stored as a separate dataset. It will only be added back if there is a need to derive alternative outcomes for the analysis. The identifiable ONS date of death data will be securely destroyed once the ESORT-V project's findings have been published.

#### What protections are in place for using this data?

As this data includes patient-specific information, it will be handled with care at LSHTM:

- The data will be used for the ESORT-V project only and will not be used for any other research
- Access to the data will be restricted to researchers who have permission to use it
- The data will be stored on the secure server at LSHTM
- The data will be held at LSHTM until 30<sup>th</sup> October 2025 to allow us to complete the ESORT-V project and will then be destroyed.
- The date of death will be retained in a separate dataset with the linkage key (study ID) and will be removed from the linked dataset once all outcomes have been derived.
- It is possible that we may need to derive alternative outcome measures. This could occur during the process of submitting findings for publication in a journal. For example, in response to a request from a peer reviewer. If this happens then we will add the date of death data back to the linked dataset to carry out further analysis.
- We will securely destroy date of death data once all findings have been published.

We have secured approval from the [Health Research Authority's](#) (HRA) Confidentiality Advisory Group in order to gain access to this data. The approval process that LSHTM has undertaken is available [here](#). In addition, the ESORT-V project has undergone an ethics approval process with the LSHTM ethics committee (LSHTM Ethics Ref: 27065; email: [ethics@lshtm.ac.uk](mailto:ethics@lshtm.ac.uk)).

### Why are we using this data?

The National Vascular Registry collects data relating to the quality and outcome of care for patients who have received vascular procedures/surgeries at NHS hospitals. The dataset undergoes rigorous validity checks to ensure the quality of the data available. The National Vascular Registry data will be used to investigate the effectiveness and cost-effectiveness of surgery.

National Vascular Registry has approval for collecting health care information and sharing patient-level data which complies with [General Data Protection Regulation](#) (GDPR).

### How long will we use the data for?

The data will be destroyed by the IT services department at LSHTM on 30<sup>th</sup> October 2025. The data will be destroyed in accordance with the Data Protection Act 1998.

### How can I opt out of having my data included in this study?

It is possible to opt out of having your data included in the National Vascular Registry. The National Vascular Registry have their own [privacy notice](#) which contains information on how to do this. If you wish to opt out of having your data included in the ESORT-V project specifically, you will need to contact the National Vascular Registry who will then issue us with your study ID so that we can manually delete your data. The study ID will not enable us to directly identify you. Requests for opt out should be made by 29<sup>th</sup> February 2024 so the data can be locked for analysis on 31<sup>st</sup> March 2024.

### Legal basis for using personal data?

LSHTM is a public authority as described under Schedule 1 of the Freedom of Information Act 2000. LSHTM holds a [Royal Charter](#) “for the purpose of and with the objects of promoting original research, consultancy and the study of and education in public health and tropical medicine”. Under Article 6(1)(e) and Article 9(2)(j), the outcomes of this study are in the public interest as it will allow health care services to better plan and prioritise care for patient subgroups and inform national guidelines. To this end, the study meets the conditions detailed in Data Protection Act 2018 Schedule 1 Part 1 (4). The GDPR Recital 52(2) determines that this is an appropriate derogation from the prohibition on processing special categories of personal data.

### Contact details for queries

Please contact us if you have any questions about the privacy policy, the ESORT team contact details are available on the ESORT project website.

As we cannot identify individuals in the data (the data is “de-personalised”) we are unable to confirm if an individual’s information is included in the dataset used for

the ESORT-V project – please contact National Vascular Registry ([National Vascular Registry@rcseng.ac.uk](mailto:NationalVascularRegistry@rcseng.ac.uk)) for details on personal information.

LSHTM has a data protection officer and they can be contacted by email: [dpo@lshtm.ac.uk](mailto:dpo@lshtm.ac.uk)

### Glossary

- GDPR – General Data Protection Regulation
- HES – Hospital Episode Statistics
- HRA – Health Research Authority
- ONS – Office for National Statistics
- NVR – National Vascular Registry