

Privacy Notice

Information about you

This privacy notice explains why information is collected about you and the ways in which this information may be used by the UK-COMPLex Aneurysm Study (UK-COMPASS) vascular research team in the Royal Liverpool University Hospitals NHS Trust (RLBUHT) and Liverpool Clinical Trials Unit (LCTU). It will be published in the following website: <https://www.rlbuht.nhs.uk/about-the-trust/trust-statements/gdpr>

Glossary

Where we refer in this privacy notice to your 'personal data', we mean any recorded information that is about you.

Information about UK-COMPASS

Abdominal aortic aneurysm (AAA) is a condition where the aorta, the biggest artery in the body, begins to bulge abnormally. Usually this expands over years and can eventually burst, causing fatal internal bleeding. When an emergency life-saving operation is possible, they have high failure rate. A planned AAA repair operation prevents a burst aneurysm.

The renal artery is one of two blood vessels leading off from the abdominal aorta that goes to the kidneys. When an AAA is close to the renal artery it is called a complex AAA. Operations to treat complex AAA carry significant risks and are expensive.

There are two main surgical options for AAA repair and The National Institute for Health – Health Technology Assessment (NIHR- HTA) has commissioned the study to compare different treatment

strategies for the management of juxtarenal aortic aneurysms.

The study will aim to identify overall survival rates, treatment failure, long term follow up and safety, in terms of deaths and complications due to operations. The study will also aim to identify whether different patient characteristics (physiological and anatomical) affect the clinical outcome.

Why the UK-COMPASS team at RLBUHT and LCTU collects information about you

The UK-COMPASS team are conducting a study to determine the clinical and cost-effectiveness of different treatments for complex aortic aneurysms. This will guide the management of complex aortic aneurysms for future patients.

How we use your data

NHS Digital will provide the UK-COMPASS team with a list of all patients undergoing repair of their AAA between the 1st of November 2017 and the 31st of October 2019. This data is limited to an NHS number and date of birth. The Computer Tomography (CT) scans of these patients will then be requested from the NHS Picture Archiving and Communication System (PACS) and transferred to a secure server at the Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT).

A review of your pre-operative computer tomography (CT) scan will then be carried out in our Corelab. If your aneurysm has certain features such as involvement of the arteries that supply the kidneys or an angulated neck we will deem it “complex” and you will be included in our study.

Should your aneurysm meet our criteria we will then request further information from NHS Digital and the National Vascular Registry (NVR) to assess how your treatment went. This data will include operative details, information regarding your post-operative recovery and any further treatment you required. We will also have access to follow up outpatient data and data pertaining to accident and emergency attendances. We will continue to access data for a further 5 years after your initial operation to ascertain any future treatments required as a result of your aneurysm repair. Following the collection of your pseudonymised data we will securely store it for 16 years.

Legal aspects

In order to conduct this study, we need to use and process the information held about you in a pseudonymised form. This means that we cannot directly identify you from the information, NHS Digital would be able to identify individual patients if required.

The ways in which we use your information are governed by law. The principal legislation that applies is the EU General Data Protection Regulation (GDPR), which came into force on 25 May 2018 and is incorporated into a new Data Protection Act 2018.

In most instances we will rely on [Article 6\(1\)e](#) and [Article 9\(2j\)](#) of the GDPR to use your information for research. Details can be found [here](#).

We also have in place approval to collect data under the National Health Service Act 2006 – Section 251 “Control of patient information”. This was granted by the Confidentiality Advisory Group at the NHS Health Research Authority on the 13th of December 2017 with the reference 17/CAG/0176.

Details can be found [here](#).

Information sources

The study has been designed to incorporate routinely collected data from NHS Digital and the National Vascular Registry which is part of the National Healthcare Quality Improvement Partnership (HQIP). The data collected will be gathered from data sets from NHS Digital which relate to imaging (CT scans), post-operative critical care treatment, in-patient treatment and subsequent out-patient care including further operations.

NVR data will provide operative details along with physiological and anatomical information to the UK-COMPASS team.

The analysis will include all patients who undergo elective repair of complex aortic aneurysms in England between the 1st of November 2017 to the 31st of October 2019.

Data Controller

The Data Controller for this research study will be:

The Royal Liverpool and Broadgreen University Hospitals NHS Trust

Prescot Street

Liverpool

L7 8XP

Your personal information

We have designed the data flow and data management in a manner that reduces the research teams access to personal data. This data has had all identifying information removed and can not be re-identified by any of the UK-COMPASS research team. We have asked permission from the Confidentiality Advisory Group (appointed by the NHS Health Research Authority) to link the personal data (operative, anatomical and physiological data) between the NVR and NHS Digital as trusted third party. This information will not be available to the UK-COMPASS team.

Where we store or use your data

Health records are kept electronically, and we have a legal duty to keep these confidential, accurate and secure at all times in line **with** Data Protection laws.

All pseudo-anonymised health data that will be stored on the Trust network or on any portable device will be kept secure and in an encrypted format in accordance with Data Protection laws.

We aim to maintain high standards, adopt best practice for our record keeping and regularly check and report on how we are doing. Your information is never collected for direct marketing purposes, and is not sold on to any third parties. Your information is not processed overseas.

Who we may share information with

The UK-COMPASS research team will not share patient information with any third party.

Retaining your data

We intend to keep the **non-identifiable** data for 16 years following recruitment to this study. The data will not be used for any research other than that which has been described here.

Your Rights

Data Protection laws give individuals rights in respect of the personal information that we hold about you. These are:

- To be informed why, where and how we use your information.
- To ask for access to your information.
- To ask for information to be corrected if inaccurate or incomplete.
- To ask for your information to be deleted or removed where there is no need for us to continue processing it.
- To ask us to restrict the use of your information.
- To ask us to copy or transfer your information from one IT system to another in a safe and secure way, without impacting the quality of the information.
- To object to how your information is used.
- To challenge any decision without human intervention (automated decision making).

Contact

If you wish to raise any queries or concerns about this privacy policy, please contact our Data

Protection Officer on dpo@rlbuht.nhs.uk

Further Information

You can also contact the Data Protection Officer via the Information Governance Team at the Royal Liverpool University Hospital on

Tel: 0151 706 3671.

Text phone number: 0151 706 3671