

## **PRIVACY NOTICE**

### **Study Title: Mortality and morbidity outcomes after aortovascular surgery in patients with Marfan Syndrome: A UK experience**

#### **Who is responsible for your data?**

The data controller and processor for this study is Barts Health NHS Trust, who is the sponsoring organisation.

We have permission to conduct this study without consent under Section 251 of the NHS Act 2006. The study relies on accessing a large number of historical patient records. It requires access to these health records without individual patient consent on the basis that the scale data needed to address its aims would otherwise be reasonably unobtainable.

The study has support from the Health Research Authority following advice by the Confidentiality Advisory Group under Regulation 5 of the Health Service (Control of Patient Information) Regulation 2002 to conduct the study without study-specific consent (i.e for linking, transferring, processing and analysing the data) – CAG reference number: 21/CAG/0133.

#### **Personal data we collect about you**

We will be using routinely collected national data from NHS England (Civil Registration Mortality and Hospital Episode Statistics data) and National Institute for Cardiovascular Outcomes Research (NICOR). Data obtained from these three sources will be linked together using patients' identifiable information, such as NHS number, date of birth and date of surgery. Immediately after the data is linked, all patient's identifiable information will be removed, so that data analysis and results presentation will be based on pseudonymised data. Importantly, while the information received is specific to each study participant, no individual person will be identifiable in any publication arising from this work.

Data providers will use a service provided by NHS England to identify potential participants who have indicated that they do not wish their data used for research purposes (<https://www.nhs.uk/your-nhs-data-matters/>). The data providers will remove these patients before transferring the data to us.

Your personal data will not be shared with any third parties and will not be used for any automated decision making or profiling. If you would like to have this data withdrawn, please contact the Principal Investigator (PI) using the details given below.

#### **How we use your personal data**

Research is a task we perform in the public interest. Barts Health NHS Trust, as sponsor, is the data controller. This means that we, as Barts researchers, are responsible for looking after your information and using it properly.

We will use the minimum personally-identifiable information possible.

The legal basis for the processing and storage of personal data for this study is that it is 'a task in the public interest' (article 6 (1)(e)) and that 'sensitive personal data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes (article 9 (2)(j)), based on Article 89 (1).

### **How long we keep your data**

Patients identifiable information will be deleted immediately after data linkage. All pseudonymised data will be kept for 5 years following completion of the study according to Barts Health NHS Trust policy of electronic storage of research materials.

### **How we protect your data**

The sponsor has security policies in place to protect your personal data against unauthorised access, unlawful use, accidental loss, corruption or destruction. These policies are reviewed regularly to ensure best practice.

The study will use secure computer systems, secure networking, NHS standard encryption, secure disposal of confidential waste and computer storage media, and staff with a contracted obligation to ensure data protection.

### **Sharing data**

The deidentified personal data collected and managed by the sponsor will only be used for research purposes. The deidentified data will not be combined with any data sources that could identify you.

### **Withdrawing from the study**

If you decide you do not want your data to be used for this study, you can withdraw at any time without affecting your medical care. There are several ways to do this. You can register with the NHS Opt-out scheme (<https://digital.nhs.uk/services/national-data-opt-out>) to ensure your data are not used for research. Data providers will use a service provided by NHS Digital to identify potential participants who have indicated that they do not wish their data used for research purposes (<https://www.nhs.uk/your-nhs-data-matters/>). The data providers will remove these patients before transferring the data securely to the study office at Barts Health NHS Trust.

You can also contact the PI ([r.magboo@qmul.ac.uk](mailto:r.magboo@qmul.ac.uk)) directly to inform us that you do not wish your data to be used. We will remove your data from the dataset before linking the NHSD and NICOR data.

### **Data controller and contact details**

The Data Controller for this study is Barts Health NHS Trust and can be reached via email: [c.g.colechin@qmul.ac.uk](mailto:c.g.colechin@qmul.ac.uk). The Data Protection Officer can be reached via: [dpo.bartshealth@nhs.net](mailto:dpo.bartshealth@nhs.net).

### **Your right to complain**

We work to high standards when it comes to processing your personal information. However, if you have a concern about how our organisation handles your personal information, you have the right to complain to the Information Commissioner's Office: <https://ico.org.uk/make-a-complaint/>