

NOTICE TO THE PUBLIC

Marfan Syndrome Mortality and Morbidity Outcomes Study

Re: Use of patient data for research purposes only

Description and Purpose:

Barts Heart Centre will be conducting a research study, generously funded by the Barts Charity and sponsored by Barts Health NHS, to identify the UK incidence and outcomes of aortovascular surgery in Marfan Syndrome (MFS) patients.

This study will help us to further understand the burdens that aortovascular problems place on Marfan Syndrome patients. It will also allow us to evaluate the effectiveness of the care we provide to this patient group.

Data needed for the study

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.

Who will be included in the study:

All Marfan Syndrome patients who had aortovascular surgery in England and Wales between 1 January 2010 – 31 December 2019.

If you are one of these patients and you prefer that your data will not be included in the analysis for this study, please contact the Principal Investigator, Mrs Rosalie Magboo via email: rosalie.renamagboo@nhs.net or simply scan the QR code:



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. The Data Protection Officer can be reached via: 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/>

In collaboration with:



NHS
Liverpool Heart and Chest Hospital
NHS Foundation Trust