



This information is for people who are taking part in the studies:

UNIVERSITY OF LEEDS

Evaluation of the Methods and Management of Acute Coronary Events

EMMACE 3, EMMACE 4 and EMMACE XL

We wanted to contact you to make sure you understand how we use the information we collect about you in the EMMACE study. This is because a data protection law (called the General Data Protection Regulation, or GDPR for short) came into force in the UK on 25th May 2018. The GDPR means that you must have clear information about how information about you is collected and used.

You will have already been given a participant information leaflet before you started the study. This included some details about how we collect information about you. We want to remind you about this, and also make sure you know how we use your information once we have it.

We have been carrying out the EMMACE study (EMMACE3 and-4 recruited between 2011 and 2015), which is ethically-approved research in the public interest.

- The University of Leeds is the sponsor for this study based in the United Kingdom. The University of Leeds has used information from you and your medical records in order to undertake this study and acts as the data controller for this study. This means that the University of Leeds are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for 30 years after the study has finished.
- Your rights to access, change or move your information are limited*, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
- You can find out more about how we use your information at <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf> or by contacting the University of Leeds Data Protection Officer, at dpo@leeds.ac.uk or by post to University of Leeds, 11.72 EC Stoner Building, Leeds, LS2 9JT, UK.
- Your hospital has collected information from you and your medical records for this research study in accordance with our instructions.
- Your hospital will use your name, NHS number, address (including full postcode), phone number to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from University of Leeds and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your hospital will pass these details to the University of Leeds along with the information collected from you and your medical records. The only people in the University of Leeds who have access to information that identifies you are people who need to contact you to send you questionnaires after you have joined the study or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number, or contact details.
- Your hospital will keep identifiable information about you from this study for 20 years after the study has finished.

**The lawful basis we are processing the data under is GDPR article 6(1)(e) task in the public interest and Article 9(2)(j) archiving in the public interest, scientific or historical research or statistical purpose.*

EMMACE GDPR transparency information V1.0 28/05/2020

IRAS Project ID: 2762020

- When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.
- This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.
- When you consented to the study you agreed that, as part of the follow up for this study we could collect information from NHS Digital to find out about the long-term health of EMMACE study participants after they have taken part in the study.
- As part of you consenting to us obtaining further health data from NHS Digital about you, we securely sent them your **first name, surname, NHS number and trial number** to NHS Digital so that they could identify the people we wanted information about. NHS Digital then send **health data** to us about participants of the EMMACE study.
- Collecting information from NHS Digital means less burden for trial participants to give time to trial visits. It is also more efficient and cost-saving for the NHS, compared with asking people to make extra hospital visits. NHS Digital have strict rules about sharing their data for research projects like EMMACE. You can find out more on the NHS Digital transparency notice <https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/gdpr/gdpr-register>.
- Collection of this data has been approved by an independent research ethics committee and NHS Digital. University of Leeds is responsible for what data is collected, what it is used for and making sure it is used correctly and legally (this means they are called the 'data controller').
- The data we collect will be stored securely at University of Leeds. Only people that have need to access the data for analysis purposes will have access to it. We will keep the data for the length of time agreed with NHS Digital. Currently this will be until 2023, but we may ask to keep the data for longer if we plan to use it for further research in the public interest. When the agreement with NHS Digital expires, we will securely destroy the data.
- We will only collect data that we need for the study, and will not use it for any other purpose. We will not share the data with anyone else.

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/

We would like to take this opportunity to thank you again for taking part in the EMMACE study.

On behalf of the EMMACE study team

Prof Chris Gale
EMMACE Chief Investigator