



CAPO Study Privacy Notice

What is the CAPO study?

The cerebrovascular accident and acute coronary syndrome and peri-operative outcomes (CAPO) study is a research project being carried out by the University of Nottingham and the Health Services Research Centre (HSRC). The study will involve analysing existing patient data. There will be no direct patient involvement in the study.

What is the aim of the CAPO study?

The aim of the CAPO is to investigate how a previous heart attack or stroke affects the risk of complications, including death, associated with any future surgical operations. This is important to know, as if there is a high risk in the first few months after a heart attack or stroke then delaying surgery might be in a patient's interest. On the other hand, if there is a time after which risks do not decrease any more then there is probably little point in delaying surgery beyond this. Hence it is hoped the results of this study will help the planning of surgery for patients who have previously had heart attacks or strokes.

What information will be used in the CAPO study?

The CAPO study will analyse existing patient information from four data registries.

1. Hospital episode statistics (HES). This is a database managed by NHS Digital containing details of all admissions to NHS hospitals in England. Each HES record contains clinical information about diagnoses and operations, as well as patient, administrative, and geographical information.
2. Myocardial ischaemia national audit project (MINAP). This is a national cardiac clinical audit managed by National Cardiovascular Outcomes Research (NICOR) that collects information about the diagnosis, treatment and outcome of patients admitted to hospital with heart attacks in the United Kingdom.
3. The Office for National Statistics hold information related to deaths in England and Wales.

Information from these sources will be combined by NHS digital before being transferred to the study team at the University of Nottingham to

analyse it. NHS digital will be able to identify individual patients while they combine the data. The study team at the University of Nottingham will not be able to identify individual patients from the combined data they receive.

The study will use data from these sources for any patient who had an operation in England between 2007 and 2017. Data from these patients will be used regardless of whether they had a previous heart attack or stroke.

Legal basis for processing personal data

Under GDPR the following legal bases apply: processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller (Article 6(1)(e)) and processing is necessary for reasons of public interest in the area of public health such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and medicinal products or medical devices (Article 9 (2)(i)).

Under Common Law Duty of Confidentiality (CLD), CAPO uses Section 251 as its legal basis to meet the CLDC.

CAPO currently has approval under Section 251 for NHS digital to use identifiable patient information to create the study data set (CAG reference: 19/CAG/0013).

More information on section 251 is available here:

<https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/legal-frameworks/>

The rationale for this is that data used in the study will be collected from approximately 44 million patient episodes. It would therefore not be feasible to ask all patients whose data will be used in the study for their consent.

How we protect your data

Both NHS Digital and the University of Nottingham takes the security of your data seriously. In order to prevent unauthorised access or disclosure, we have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information used in the study.

The CAPO team are based at the University of Nottingham. The University of Nottingham conforms to General Data Protection Regulation (GDPR) and other legislation that relates to the use of patient data, and has strict safeguards in place to safeguard patient information. The data held by the University of Nottingham will be stored on a secure computer to which only authorised study team members have access. The IT system has various levels of security built into it, including:

- ID password security: the data is stored on a password protected system, which prevents unauthorised users gaining access.
- The stored data files are encrypted.

The data will be held by the University of Nottingham for 3 years for analysis. After this period the data will be destroyed.

No data will be transferred outside the University of Nottingham including to any third countries or international organisations.

Data will not be used in profiling or automated decision-making.

Patient confidentiality and level of data used in the study

NHS digital will process identifiable patient information to combine the data from the different data sources. Once the data has been combined NHS digital will convert the data into a pseudoanonymised format, with individual patients only distinguished by a computer-generated sequence of numbers. The original identifiable data will be destroyed.

This pseudoanonymised data will then be transferred to the study team at the University of Nottingham. They will not be able to identify any individuals from the data. The University of Nottingham will be the data controller of the pseudoanonymised linked dataset.

The results of the study will be published in the form of aggregated data. There will be no reference to data on an individual patient level.

Who is the data controller for the study data?

The University of Nottingham will be the data controller for the pseudoanonymised linked dataset.

University of Nottingham, University Park, Nottingham, NG7 2RD. Phone 0115 9515151.

The University of Nottingham's Data Protection Officer (DPO) is Mr Simon Gill, he can be reached at dpo@nottingham.ac.uk.

What if I do not want my information used in the CAPO study?

If you had surgery in England between 2007 and 2017 and were over 18 at the time your data might be used in the study. You can choose to opt out of having your data used in the study. Opting out will not affect any future care you receive. Please e-mail Dr Lindsay msaw15@exmail.nottingham.ac.uk and put "Patient request to opt out of CAPO" in the subject line or phone 0115 748 4098.

If the data from the data sources has already been combined and pseudoanonymised we will be unable to remove your data from the study as it will no longer be identifiable.

There is also a national data opt-out service that allows patients to opt out of their confidential patient information being used for research or planning (<https://digital.nhs.uk/services/national-data-opt-out>)

Who can I contact about this notice?

If you have any queries about this privacy notice or the CAPO study please e-mail Dr Lindsay msaw15@exmail.nottingham.ac.uk or phone 0115 748 4098.

For more information on the data registries that will be used in the study please visit:

- NHS digital - <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics>
- MINAP - <https://www.nicor.org.uk/national-cardiac-audit-programme/myocardial-ischaemia-minap-heart-attack-audit/>
- ONS - <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths>

You also have the right to lodge a complaint with the Information Commissioner's Office (ICO), the supervisory authority in the UK responsible for the implementation and enforcement of data protection law, if you have concerns about the way your personal data is being handled. You can contact the ICO via their website – <https://ico.org.uk/concerns/> or by calling their helpline – 0303 123 1113.