



Use of Your Data in research – New UK Data Protection Law

Evaluating protocols for identifying and managing patients with familial hypercholesterolaemia (FH)

IRAS number: 214219

NHS Digital reference: DARS-NIC-115405-P6X6Q

As a participant in the Simon-Broome registry, the University of Nottingham is leading and sponsoring a research study which is using your data to improve patient care. We are providing you with some additional information about the use of your data, as a new law for data protection as been introduced.

Your information retained on the Simon-Broome register is kept strictly confidential, stored in a secure and locked office, and on a password protected database at University College London (UCL). Under UK Data Protection laws University College London is the Data Controller (legally responsible for the data security) and the Principal Investigator of this study (Professor Steve Humphries) is the Data Custodian (managing access to the data). This means UCL are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as your information needs to be managed in specific ways to comply with certain laws and for any approved research to be reliable and accurate. To safeguard your rights UCL will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and read our general privacy notices at:
<https://www.nottingham.ac.uk/utilities/privacy.aspx>
<https://www.ucl.ac.uk/legal-services/data-protection-overview>

The sources of the data include the Simon-Broome registry and NHS Digital (Hospital Episode Statistics and mortality). The data held at the Simon-Broome registry will be linked with Hospital Episode Statistics and mortality data held by NHS Digital. This data will be anonymised (your personal identifiable details will be removed) by University College London and the unidentifiable data will be shared with the collaborators, the University of Nottingham (Chief Investigator, Professor Nadeem Qureshi) and the University of York to complete the project. The Universities of Nottingham and York are considered data processors as they will analyse the data. The anonymised data will be looked at and stored by authorised persons from the University of Nottingham, University of York and University College London who are jointly organising the research. The data may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you and we will do our best to meet this duty.

Your identifiable data will remain held on the Simon-Broome registry and will not be shared. This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (anonymised research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality.



What is the legal basis for this research and the use of my data?

The legal basis for this research is defined under the following Articles:

Article 6(e) "Public task": the processing is necessary to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.

This research is in the public's interest.

Article 9(2) "Processing special category data":

(j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

Processing of your identifiable data for this project is required to link your data to Hospital Episode Statistics (a hospital data set). The data will be linked to allow the research team to look at long term outcomes and whether patients have attended hospital due to any linked conditions or illnesses. This is deemed appropriate for this type of research which is research in the public interest. This project was a commissioned call, funded by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA).

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

If you wish to withdraw and would like your anonymised data to be removed from the project, please contact Professor Steve Humphries via email at steve.humphries@ucl.ac.uk.

Contact details for the Chief Investigator of this research project:

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University of Nottingham
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NG7 2RD
Email: nadeem.qureshi@nottingham.ac.uk

Who do I contact if I wish to make a complaint?

The Data Protection Officer at the University of Nottingham can be contacted via:

Data Protection
University of Nottingham
University Park
Nottingham
NG7 2RD
Email: data-protection@nottingham.ac.uk



The supervisory authority is the Information Commissioner's Office. Their contact details are:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
SK9 5AF
Telephone: 0