Privacy Notice
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-300282-G9Q0Q

This privacy notice sets out the ways in which the University of Nottingham gathers, uses, stores and shares your data. It also sets out how long we keep your data and what rights you have in relation to your data under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

1. Who is responsible for the data? For the purposes of this privacy notice, University of Nottingham are joint Data Controller with the University of York, as defined in the GDPR. We are registered with the Information Commissioner's Office and our entry can be found here. Our registration number is: Z5654762. We have an appointed Data Protection Officer who can be contacted as follows: Data Protection Officer, Legal services A5, Trent Building, University of Nottingham, University Park, Nottingham. NG7 2RD mailto:dpo@nottingham.ac.uk. We will place any updates to this privacy notice on this web page.

2. Who is conducting the research? This research is conducted by researchers at the University of Nottingham and the University of York, in collaboration with the University College London, University of Southampton, University of Aberdeen, Cardiff University and University Hospitals Southampton NHS Foundation Trust.

3. What are the objectives of the research and the purpose of using your data? The University of Nottingham's charter is for the advancement of learning and knowledge through teaching and research. We will use the data to understand the clinical characteristics of patients with familial hypercholesterolaemia and their relatives, their likelihood of having the genetic mutation for familial hypercholesterolaemia, their risk of cardiovascular disease and death and the costs of treating them. This will help us make a detailed analysis of the benefits of diagnosing and treating familial hypercholesterolemia.

4. Where do we get your data from and what data do we have? For this research, we will use data from multiple sources. All data is stripped of personal identifiers (without names, NHS numbers, postcodes, and year of birth). We have received the data in the Simon Broome Register. The Simon Broome Register collected data on clinical characteristics from people with familial hypercholesterolaemia. Also from the people in the Simon Broome Register, we will receive their records of hospitalisations, which are collected by NHS Digital obtained from patients using the National Health Service (NHS); and we have the records on the date and cause of death from the Office of National Statistics; We have received data on people who have a diagnosis of familial hypercholesterolaemia in their primary care records. The data consists of their characteristics, cholesterol test results, cardiovascular events, prescribed medication, health care provided in NHS primary care from the Clinical Practice Research Datalink, records of hospitalisations in NHS hospitals collected by NHS Digital and records on the date and cause of death from the Office of National Statistics. We have received data on people who were diagnosed with familial hypercholesterolaemia and their relatives who were tested for the disease from the University Hospitals Southampton NHS Foundation Trust, in the NHS in Wales and in the NHS in Scotland. The data consists of their demographics (e.g. age, sex), clinical signs and symptoms that are indicative of familial hypercholesterolaemia and the genetic test results for the disease. We have received Health Survey for England data from a representative sample of the UK general population to know the cholesterol level of the UK general population by age and sex. This will allows us to compare the cholesterol level of people with familial hypercholesterolaemia with the UK general population to know if cholesterol level can be used to diagnose familial hypercholesterolaemia.

5. What is our legal basis for processing the data? The legal basis for processing your personal data on this occasion under Article 6(1e) of the General Data Protection Regulations "processing is necessary for the performance of a task carried out in the public interest". Our public task functions are as set out in our University charter. In addition to the legal basis for processing your personal data, we must meet a further basis when processing any special category data, including: personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation. Our legal basis for processing your special category personal data under this privacy notice is that such data processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

6. How we process your data? Your data will not be subject to automated processing or profiling.

7. Who do we share your data with? Permitted employees and agents of the University working on the research project will use the data. Although we do not anticipate the requirement to share the data with third parties, should this be required disclosures would be made only in full accordance with data protection legislation and only where necessary. You will be advised of such disclosures through this privacy notice unless exceptional circumstances apply.

7. How do we keep your data secure? The University of Nottingham takes information security extremely seriously and has implemented appropriate technical and organisational measures to protect personal data and special category data. Access to information is restricted on a need-to-know basis and security arrangements are regularly reviewed to ensure their continued suitability. For further information see, https://www.nottingham.ac.uk/it-services/security/index.aspx

8. How do we transfer your data safely internationally? If data is transferred out of the European Union we will endeavour to only transfer to countries who are on the EU list of adequate countries or to apply adequate safeguards as stated above to protect your privacy.

9. How long will we keep your data for? We will retain your data in line with legal requirements. Retention timeframes will be determined in line with the University's Records Retention Schedule. If any data is stored in excess of the University's Records Retention Schedule it would be in a form which would be fully anonymised.

10. What rights do you have in relation to your data? Under the General Data Protection Regulation, you have a right of access to your data, a right to rectification, erasure (in certain circumstances), restriction, objection or portability (in certain circumstances).

11. Questions or concerns If you have any questions about this privacy notice or concerns about how your data is being processed, please contact the University's Data Protection Officer at mailto:dpo@nottingham.ac.uk

12. Contact details for the Chief Investigator of this research project:
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13. Right to complain If you are unhappy with the way in which the University has handled your personal data. You have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see http://www.ico.org.uk/concerns.