Privacy notice – University of York

This privacy notice sets out the ways in which the University of York 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 York is a Data Controller 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: Z4855807.

We have an appointed Data Protection Officer who can be contacted as follows: Data Protection Officer, University of York, University of York, Heslington, York, YO10 5DD, UK. dataprotection@york.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 York, in collaboration with the University of Nottingham and at the University College London.

The University of Nottingham and the University College London have their own privacy statements in relation to personal data which you will find on the Heart UK website.

3. What are the objectives of the research and the purpose of using your data?

The University of York’s charter is for the advancement of learning and knowledge through teaching and research.

We will use the data to understand the risk of cardiovascular disease and death of patients with familial hypercholesterolaemia and the costs of treating them. This will help us make a detailed analysis of the benefits of diagnosis and treating familial hypercholesterolemia.

4. Where do we get your data from and what data do we have?

We will receive the data in the Simon Broome registry stripped of personal identifiers (without names, NHS numbers, postcodes, and birthdate) from the University of Nottingham. We will also receive the records of hospitalisations by the individuals included in the Simon Broome registry (without names, NHS numbers, postcodes, and birthdate), which are collected by NHS Digital obtained from patients using the National Health Service.

5. What is our legal basis for processing the data?

The GDPR requires us to establish a legal basis for processing your information. For the purpose of this privacy notice the 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. 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 York 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.york.ac.uk/it-services/security/.

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).

Current patients on the Simon-Broome registry can opt out of their data being used in this project via contacting the data controller, Professor Steve Humphries, via the Heart UK website.

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 dataprotection@york.ac.uk.

12. 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 www.ico.org.uk/concerns.