

Privacy Notice - University of York - National Vascular Registry dataset

Outline

This privacy notice is to provide you with details of the ways in which personal data received from the Healthcare Quality Improvement Partnership (HQIP) is processed by the University of York, including how it is gathered, used, stored and shared. Contact details are provided in case of any queries regarding the privacy notice, or in case of any concerns with the current management of your data.

Who is responsible for the data?

For the purposes of this privacy notice, the University of York is a Data Controller as defined in the EU General Data Protection Regulation (the 'GDPR') and the U.K. Data Protection Act 2018 (together the 'Data Protection Laws').

The University of York ('York') are registered with the Information Commissioner's Office and its entry can be found [here](#). Registration number: 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

Who is conducting the research?

The research is conducted by researchers at the University of York.

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

The Centre for Health Economics will use National Vascular Registry (NVR) data to conduct an economic analysis of the National Abdominal Aortic Aneurysm Screening Programme (NAAASP). The aim is to study how the outcomes of the patients in the programme differ according to their socioeconomic status, and how this affects lifetime health inequalities in England. The NVR data will be used to estimate socioeconomic differences in the types of surgery being conducted and post-operative mortality.

What data do we have?

All the data we receive from HQIP are pseudonymised which means that we have no means of identifying an individual. We have patient record data, including special category data on health as per in the Information Commissioner's Office (ICO) definitions.

The NVR data York holds contains information on patient characteristics (including age, sex and ethnicity), the care participants received (including procedures, hospital admissions) and post-operative outcomes (including 30-day mortality).

York holds the minimum amount of data necessary for the study.

What is our legal basis for processing your data?

Under the Data Protection Laws, York has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data.

In line with York's charter which states that it advances learning and knowledge by teaching and research, York processes personal data for research purposes under Article 6 (1) (e) of the GDPR: Processing is necessary for the performance of a task carried out in the public interest.

Special category data is processed under Article 9 (2) (j): Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes.

How do we use your data?

York will process data for the purposes outlined in this privacy notice, which is to enable York to make a detailed analysis of the effects of the NAAASP on the costs and outcomes of patients with AAA by socioeconomic status. Your data will not be subject to automated processing or profiling.

Who do we share your data with?

Permitted employees of York working on the research project will use the data. Information will be treated as confidential and shared on a need-to-know basis only. Data will not be shared with any third parties. York may need to disclose the data to a regulator or to otherwise comply with the law.

How will we keep your data secure?

The Centre for Health Economics and the University of York have implemented appropriate technical and organisational measures to protect personal data. Access to information is restricted on a need-to-know basis and the University is committed to the principle of data protection by design and default. The data security arrangements at the Centre for Health Economics and the University form part of the Data Sharing Agreement with HQIP.

Will we transfer your data internationally?

No. Data will not leave the UK.

Will we identify you in any research outputs?

No. The data we hold does not allow us to identify individuals

How long will we keep your data?

York will destroy the data one year following receipt of the data. At the end of this time, the data will be destroyed safely and in accordance with the Data Protection Laws.

What rights do you have in relation to your data?

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 have withdrawn 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. For further information see: <https://www.york.ac.uk/records-%20management/generaldataprotectionregulation/individualsrights/>.

However, as we do not know the identity of the individuals in the pseudonymised data we receive from HQIP, we are not able to request your consent directly nor are we able to tell if your details are included in the data we hold, hence we are unable to remove data relating to named individuals. If you would like to opt out and not have your data used for research of this kind, information on how to do so can be found on the following website: <https://www.vsgip.org.uk/resources/information-governance/nvr-privacy-notice/>.

Questions or concerns

If you have any questions about this privacy notice or concerns about how your data is being processed at the University of York, please contact the University of York's Data Protection Officer at dataprotection@york.ac.uk.

Right to complain

If you are unhappy with the way in which your personal data has been handled, 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>