

Privacy Notice – University of York – Research Using NHS Digital Data

This privacy notice is to provide you with details of the ways in which personal data received from NHS Digital is processed by the University of York, including how it is gathered, used, stored and shared.

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 General Data Protection Regulations (EU) 2016/679 (the 'GDPR') and the U.K. Data Protection Act 2018 (together the 'Data Protection Laws').

The University of York ('York') is 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

What is the purpose of the health and care research?

The Centre for Health Economics will use data on the use of services by the public in order to conduct *economic analyses of health and social care*. The aim is to study the way in which services are provided and the outcome of those services in order to improve health and healthcare services in the NHS.

Information about the research we undertake can be found here [<https://www.york.ac.uk/che/research/>]. There are five research areas within the overall project, *Economic Analysis of Health and Social Care*, which uses the data. The projects are investigating the following topics:

- Measuring the effectiveness, efficiency and productivity of NHS care.
- Evaluating the costs and patient outcomes delivered by healthcare providers.
- Evaluating the impact on costs and outcomes of health and care policy and the way in which services are organised and paid for.
- Measuring inequalities in access to services and documenting the health outcomes associated with inequalities.
- Investigation of the links between primary and secondary care and between health and social care and how services are co-ordinated.

In all the projects the results inform health care policy nationally and/or locally in order to support decision-making, with the aim of making improvements to health and to health and care services delivered in the NHS. Further details of the projects can be obtained by contacting che-admin2@york.ac.uk

What data do we have?

All the data we receive from NHS Digital are pseudonymised which means that we have no means of identifying an individual. We have data from:

1. *Hospital Episode Statistics (HES)*. These data relate to all people who attended hospital as inpatients, outpatients and/or received critical care and who have attended Accident & Emergency departments. We do not have names, addresses or any other information that could be used to identify individuals. We have age, gender, ethnicity, a "diagnostic code" that tells us what medical condition they were treated for and what procedures they

received, a code that signifies the hospital consultant responsible for care, an indicator of whether they were alive at certain periods of time after they were admitted, indicators about duration of stay and place of discharge and which hospital was attended.

2. *Mental Health Services Dataset* (previously known by other names). This data relates to people who have been in contact with mental health services. We do not have names, addresses or any other information that could be used to accurately identify individuals. The data we have is similar to that for HES but relates only to providers of mental health care services. In addition, we have data on detentions under the Mental Health Act.
3. *Patient Reported Outcomes Measures (PROMs)*. This data provides information on the outcomes and quality of care delivered by healthcare providers, using measures of health status and quality of life scored by patients receiving treatment for a range of surgical procedures. We do not have names, addresses or any other information that could be used to accurately identify individuals. We have similar data as in HES but with added information on the scores given by patients to indicate aspects of their health status and quality of life, before and after surgery.

Not all the data are used for every project and we maintain a register of which individual needs access for each project and we restrict researchers' access to the data strictly on the grounds of the data required for their individual project.

Where do we get data from?

The data are provided to the Centre for Health Economics at the University of York by NHS Digital, under a data sharing agreement. The data originates from users of healthcare services and are provided in pseudonymised format which means that individuals are not identified in the data nor are they identifiable by the researchers who analyse the data.

What is our legal basis for processing your data?

Under the General Data Protection Regulation (GDPR), the University has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data. Some of the data we process (ethnicity and data concerning health) is in the category of special data.

In line with our charter which states that we advance learning and knowledge by teaching and research, the University 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 will we use your data?

Data will be processed for the purposes outlined in this privacy notice, in order to conduct research involving the economic analysis of health and social care.

Will we share your data with third parties?

No. Only authorised employees, including students and visitors, who have the same contractual obligations as employees, of the Centre for Health Economics at the University of York will use the data.

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 and special category 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 NHS Digital, they are documented and audited periodically.

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?

Data will be retained for the duration of the funding of the projects and until outputs from the research have been published. Data will be destroyed safely, in accordance with the Data Protection Laws and in line with our agreement with NHS Digital governing secure data deletion methods.

What rights do you have in relation to your data?

Under the Data Protection Laws, you have a general right of access to your data, a right to rectification, erasure, restriction, objection or portability. You also have a right to withdraw. Please note not all rights apply where data are processed purely for research purposes. For further information see: <https://www.york.ac.uk/records-management/generaldataprotectionregulation/individualsrights/>.

However, as we do not know the identity of the individuals in the pseudonymised data we receive from NHS Digital, 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 NHS data used for research of this kind, please contact NHS Digital: enquiries@nhsdigital.nhs.uk. Information about opting out can be obtained on their website: <https://digital.nhs.uk/services/national-data-opt-out-programme>

Questions or concerns

If you have any questions about this privacy notice or concerns about how your data are being processed, please contact Adriana Castelli or Maria Goddard in the first instance (adriana.castelli@york.ac.uk; maria.goddard@york.ac.uk). Queries can also be directed to 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 have been handled by the University of York 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.

We will place any updates to this privacy notice on this webpage.