

Privacy Notice for research Using NHS England Data

This privacy notice is to provide you with details of the ways in which personal data received from NHS England is processed by the Centre for Health Economics at 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 UK GDPR. The University of York is registered with the Information Commissioner's Office:

[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 (CHE) will use NHS England data to conduct research to inform health and social care policy and practice by identifying the effectiveness, efficiency, distribution, and quality of a wide range of services provided to the population.

CHE's research is organised into the following six priority areas ([research themes](#)):

1. Economic Evaluation and Health Technology Assessment
2. Health Policy
3. Equity in health and health care
4. Health and social care
5. Mental Health
6. Public Health

Further information on CHE's use of NHS England data is available on our Data Sharing Agreement: Purpose Statement. Information about our department and the research we undertake can be found on the [CHE website](#).

Where do we get data from?

The data are provided to the Centre for Health Economics at the University of York by NHS England, under a data sharing agreement (ref. DARS-NIC-667040-B5T1X). The data originates from users of health and social care 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 data do we have?

CHE's research uses data provided by patients and collected by the NHS. All the data we receive from NHS England are pseudonymised which means that we have no means of identifying an individual. We have patient record data, including special category data on health, race and ethnic origin, as per the Information Commissioner's Office (ICO) definitions (ICO: [What is special category data?](#)). We have data from:

1. *Hospital Episode Statistics*. These data relate to all people who attended hospital as inpatients, outpatients and/or received critical care and who have attended Accident & Emergency departments.
2. *Emergency Care Data Set*. These data relate to people who attended emergency departments, and provides information on the treatment they received. ECDS replaced

HES Accident & Emergency (see 1. above); we retain access to historic HES A&E data, and now receive ECDS.

3. *Mental Health Services Dataset* (previously known by other names). These data relate to people who have been in contact with mental health services. 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.
4. *Patient Reported Outcomes Measures*. These data provide 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 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.
5. *Civil Registrations of Death - Secondary Care Cut*. These data provide details of all registered deaths in England and Wales, as provided by the Office for National Statistics, including details of the registration and basic demographics of the deceased person.
6. *Improving Access to Psychological Therapies*. These data provide information on patients with depression and anxiety disorders that are offered NICE approved evidence-based psychological therapies.
7. *Community Services Data Set*. This is a secondary uses dataset that re-uses clinical and operational data for purposes other than direct patient care. These data provide information on patients who are in contact with NHS-funded Community Health Services.

What is our legal basis for processing your data?

Under the UK GDPR, the University must 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 UK 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, to conduct research to inform health and social care policy, with the aim of improving population health. For detailed information on our use of NHS England data, please see our Data Sharing Agreement: Purpose Statement [LINK]. Your personal information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care.

The CHE Data Access Request Group (DARG) manages and reviews procedures for accessing NHS England data and is responsible for the assessment and decision making on requests to access

these data by University of York researchers. The DARG Terms of Reference, meeting minutes, and a public register of approved data access requests, is available on the CHE website: [insert link to page we create].

Will we share your data with third parties?

No. Only authorised employees, including students and associates 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 NHS England data is restricted to approved research projects, 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 England, they are documented and audited periodically.

Will we transfer your data internationally?

No. We will not transfer your data outside of 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?

NHS England data will be retained for the duration of a Data Sharing Agreement. The University has rules on how long research data can be kept when a project has finished (see [Research Data Management Policy](#)); additionally, our funders have policies with minimum retention periods for research data.

On expiry of a Data Sharing Agreement, NHS England data will be deleted in line with agreed secure data deletion methods. Datasets generated/extracted during research analysis (derived data) will be subject to University and funder retention policies, which typically require data to be stored for a minimum of 10 years after the end of a project - for transparency, to support open science and reproducibility.

What rights do you have in relation to your data?

Under the UK GDPR, 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: [Individuals Rights](#). However, as the identity of the individuals in the pseudonymised data is not known, national opt-outs from the processing or use of this data received from NHS England do not apply.

Questions or concerns

If you have any questions about this privacy notice or concerns about how your data are being processed, please contact the CHE Data Governance Group via che-enquiries@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 wish to complain about our use of personal data, please send an email with the details of your complaint to dataprotection@york.ac.uk so that we can investigate the issue and respond to you.

If you are unhappy with the way in which your personal data has been handled by the University of York, or with the response you received from us, you have a right to complain to the Information Commissioner's Office. Please refer to the ICO website for further guidance: [Make a complaint](#).

Changes to our privacy notice

This privacy notice was last updated in December 2023. We will place any updates to this privacy notice on the CHE website: [Privacy Notices](#).