

Privacy Notice for the Place Based Longitudinal Research Resource, University of Liverpool.

This privacy notice is to provide you with details of the ways in which personal data is processed by the Place Based Longitudinal Research Resource at the University of Liverpool, 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 Liverpool is a Data Controller, as defined in 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 Liverpool ('Liverpool') is registered with the Information Commissioner's Office and its entry can be found here:

<https://ico.org.uk/ESDWebPages/Entry/Z6390975> Registration number: Z6390975. We have an appointed Data Protection Officer who can be contacted as follows: Vicki Heath, University of Liverpool, The Foundation Building, 765 Brownlow Hill, Liverpool L69 7ZX

LegalServices@liverpool.ac.uk

What is the purpose of the research?

The Place-Based Longitudinal Data Resource (PLDR) uses data on the use of services by the public in order to understand the causes of ill health and to evaluate the health impact of *health, social care, public health and government services*. The aim is to study the way in which public services can more effectively improve health and reduce health inequalities. Specifically data is used by the PLDR to:

1. Investigate the impact of socioeconomic changes, national health and welfare policy changes, environmental changes and disease trends on healthcare utilisation and whether there are neighbourhood level characteristics that modify these effects. Analysis investigate inequalities between neighbourhoods in the consequences of these adverse trends and events.
2. Evaluate the impact of area based local authority and NHS economic, environmental, social, governance and service redesign activities on health outcomes and demand for health and social care services.
3. To develop predictive models of the factors driving adverse health trends and increases in demand for health services at the neighbourhood level, that can then be used by local agencies to better target resources at the root causes of ill-health and health service demand and the neighbourhoods most affected.
4. To develop new approaches for monitoring progress on health inequalities at the neighbourhood level and involving the public in using data to influence local services and policies - supporting Open Data initiatives to promote transparency and accountability.

Further information about the research we undertake can be found here [<https://www.clahrc-nwc.nihr.ac.uk/index.php>] or by contacting benbarr@liverpool.ac.uk

What data do we have?

We receive *Hospital Episode Statistics (HES)* data from NHS Digital that is pseudonymised which means that we have no means of identifying an individual. 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 information on each person's age, gender, ethnicity, their GP practice and an indicator of the neighbourhood in which they live called a Lower Super Output Area (LSOA). Each LSOA is a geographical area that contains a population of approximately 1500 people. The data also includes "diagnostic codes" that tells us what medical condition each person was treated for and what procedures they received, indicators about duration of stay and place of discharge and which hospital was attended.

The HES data is used to derive aggregate LSOA and GP practice level indicators for particular categories of patients. For example the number of admissions for Coronary Heart Disease in each LSOA each year. This aggregate data is then used by researchers to investigate the causes of health problems and to evaluate services. Not all the data are used for every research 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 HES data are provided to the Place-based Longitudinal Research Resource at the University of Liverpool 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 improve our understanding of the causes of ill health and to evaluate the health impact of *health, social care, public health and government services*. This research is used to develop public services that more effectively improve health and reduce health inequalities.

Will we share your data with third parties?

No record level HES data is shared with any third parties. Only authorised employees, including students and visitors, who have the same contractual obligations as employees, of the PLDR at the University of Liverpool use this data.

Aggregate indicator data derived from the record level data are only shared after a risk assessment has been completed and any small numbers suppressed in line with NHS digital's Anonymisation Standard for Publishing Health and Social Care Data Specification. This aggregate indicator data is only shared with research groups that are part of the National Institute for Health

research Collaboration for Health Research and Care (see <https://www.clahrc-nwc.nihr.ac.uk/index.php> for details) or the National Institute for Health Research School of Public Health Research (see <https://sphr.nihr.ac.uk/> for details). Data is only released for research that falls under the purposes outlined above and only the minimum aggregate data required to answer each projects research questions is released.

How will we keep your data secure?

The Place-based Longitudinal Data Resource at the University of Liverpool 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 Place-based Longitudinal Data Resource at 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.liverpool.ac.uk/legal/data_protection/

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 Dr Ben Barr in the first instance (benbarr@liverpool.ac.uk). Queries can also be directed to the University of Liverpool's Data Protection Officer at legalservices@liverpool.ac.uk

Right to complain

If you are unhappy with the way in which your personal data have been handled by the University of Liverpool 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.