



### **Privacy Notice for Project:**

Are travel times and distance to healthcare facilities associated with differences in outcomes for breast, lung, colorectal, prostate and oral cancer.

This notice relates to the data obtained from NHS England in the above project. Reference:

**NIC-675446-G2S5Q**

If you have any questions or concerns about how your data will be processed within this project please contact:

Dr Charlotte Kelly

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Email: [charlotte.kelly@hyms.ac.uk](mailto:charlotte.kelly@hyms.ac.uk)

Telephone: 01482 463107

If you are unhappy with the response, please contact the University of Hull Data Protection Officer

Email: [dataprotection@hull.ac.uk](mailto:dataprotection@hull.ac.uk)

Telephone: 01482466594

Address: University of Hull, Cottingham Road, Hull, HU6 7RX

### **Aim and Objectives**

The aim of this project is to use cancer registration data to explore whether people diagnosed with cancer living further from a healthcare provider (e.g. GP, hospital) have differences in their outcomes. We are exploring differences in survival rates, whether a person is diagnosed at a late or early stage of cancer and whether there are any differences in the treatment that they receive once they are diagnosed. We are also wanting to know whether this differs for people who are living in a coastal area compared to a non-coastal area.

### **What data are you using?**

Hospitals collect lots of data about any visit you make. When a person is diagnosed with cancer in England, information about them is automatically included in the national cancer registry. The cancer Registry is a list of people diagnosed with cancer, collected directly from hospitals and healthcare professionals.

The datasets that we will use in the project are:

- Cancer Registration data which records details of the cancer diagnosis such as type of cancer and date of diagnosis.
- Systemic anticancer therapy (SACT) dataset which records details about drug treatments used such as chemotherapy.
- Radiotherapy Dataset (RTDS) which records details about radiotherapy treatments.
- Hospital Episode Statistics (HES) which records information about when you visit the hospital.
- Cancer Patient Experience Survey (CPES) dataset which records patients' responses to the national cancer patient survey

Our research looks at selected information from these records for the period January 2013 – December 2020. Whilst these datasets contain many data items we have only selected the data items we need to answer our research questions.

Under GDPR we can confirm that the data we receive as part of this project cannot and will not be used for either automated decision making or profiling.

#### [Aim I in this dataset?](#)

If you were diagnosed with either lung, breast, colorectal, prostate or oral cancer, as an adult (over the age of 17 years old) between January 2013 and December 2020 whilst living in either the Yorkshire and Humberside Region or North East Government Regions then your data will be in this dataset. However, we have not requested any identifiable information so all researchers involved in this project do not know, and have no way of finding out, who is in the dataset.

The data is pseudonymised, which means that any information which would enable an individual to be directly identified have been removed and replaced by a unique identifier (a large number). In this project we link people in the different datasets using this unique identifier.

#### [How are you able to access the data?](#)

NHS England are very strict about who can have access to patient data. This is managed through a process called a Data Assess Request (DARS). This means we need to meet very detailed data governance standards and can demonstrate we are able to look after it appropriately.

#### [Where will you store the data?](#)

The data will be stored at the University of Hull which is registered under the NHS Information Governance Toolkit (Organisation code: EE133824-HHTU).

The University of Hull has a Data Safe Haven (DSH) where this data will be stored and analysed. This Data Safe Haven is disconnected from the internet and can only be accessed by approved researchers. The data

safe haven is managed by the Hull Health Trials Unit who hold a Data Security and Protection Toolkit, which provides assurance that they are practising good data security and that personal data is handled correctly.

We can confirm that data held for analysis will not be transferred outside of the HHTU to any third countries or organisations. More information about the Data security and protection toolkit can be found here:

<https://www.dsptoolkit.nhs.uk>

We will keep the data within the Data Safe Haven for a period of 3 years according to our data sharing agreement contract with NHS England. In line with the Data Protection Act, personal data will be held for no longer than is necessary to fulfil the purposes of the work outlined above. At the end of the contract all patient data must be deleted. We will retain summary data.

How long will you keep it?

Will we identify you in any research outputs?

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

#### Data Protection Laws

1. Data protection law, including the Data Protection Act 2018, or any act which replaces it, and the General Data Protection Regulation (GDPR), sets out how personal data (personal information identifying someone) may lawfully be processed (collected, used and shared).

2. The University of Hull (UoH) is registered with the Information Commissioner's Office (ICO) which is the body that ensures that data protection law, including the Data Protection Act 1998, or any Act which replaces it, and GDPR, is complied with by all those processing personal data. The ICO notification sets out the types of personal data the UoH processes and for what purposes. The UoH registration can be viewed at:

<https://ico.org.uk/ESDWebPages/Entry/Z5907252>

3. Details about your rights in relation to your data are set out on the UoH website page "EU General Data Protection Regulations. Data Protection at the University of Hull" available here: <https://www.hull.ac.uk/choose-hull/university-and-region/keydocuments/data-protection>. This also explains how to ask any questions you may have about how your personal data is used, exercise any of your rights or complain about the way your data is being handled.

4. Under the terms of our contract with NHS England we (the University of Hull) are the data controller for the time that we hold it. As a data controller we have the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called "GPDR") and a new UK law, the Data Protection Act 2018. In particular the University must:

- Take steps to ensure that the data it processes is accurate and up to date;
- Give you clear information about its processing of your data, in one or more privacy notices like this one
- Only process your data for specific purposes described to you in a Privacy Notice, and only share your data with third parties as provided for in a Privacy Notice; and
- Keep your data secure.

The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. As we are processing your special category data we also must meet one of the conditions in Article 9 GDPR. Special category data includes personal data which relates to your ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership. Under the data protection legislation we need to explain the legal basis for holding your data, i.e. which of these conditions apply. For our research project the following conditions apply:

- Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that UoH performs in the public interest, as part of our core function as a university;
- Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purpose in accordance with Article 89(1). This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests. Further details can be found at: <https://ico.org.uk/media/fororganisations/documents/2614158/ico-introduction-to-the-data-protection-bill.pdf>

### Your rights as a data subject

Under the data protection laws you have a number of rights in relation to the processing of your data. These are however limited by the lawful basis under which we hold your data. Your rights are:

- Right to request access to your data as processed by UoH and information about that processing
- Right to rectify any inaccuracies in your data
- Right to place restrictions on our processing of your data

If you would like to exercise any of your rights as outlined above, you can contact the DPO as above or visit the Data Protection page on our website.

<https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection>

You can choose to 'opt out' if you do not want your data to be held on the National Disease Registration Service (cancer register). More information on this can be found at the following webpage.

[www.digital.nhs.uk/ndrs/patients/opting-out](http://www.digital.nhs.uk/ndrs/patients/opting-out)

Please note that the data from NHS England will be shared with the University of Hull as de-personalised data (with only a pseudonymised ID and direct patient identifiers removed). This makes the possibility, at the University of Hull, of linking the data back to an individual highly unlikely. We at the University of Hull cannot identify and contact the individual members of the cohort. Under Article 17 of the GDPR individuals have a right to have personal data erased. However, removing information will limit our ability to conduct research. We are performing a task carried out in the public interest and processing is necessary for achieving purposes in the public interest, scientific or historical research purposes where erasure is likely to render impossible or seriously impair the achievement of that processing. Also we are not relying on consent as the lawful basis for holding the data. Please see for further details: <https://ico.org.uk/your-data-matters/your-right-to-get-yourdata-deleted/>

We will always aim to respond clearly and fully to any concerns you have about our processing and requests to exercise the rights set out above. However, as a data subject, if you have concerns about our data processing or consider that we have failed to comply with the data protection legislation, then you have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: <https://ico.org.uk/make-a-complaint/>

Email: [casework@ico.org.uk](mailto:casework@ico.org.uk)

Tel: 0303 123 1113

Post: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5A