



Privacy Notice for project:

Socioeconomic Inequalities in the Diagnosis and Treatment of Colon and Ovarian Cancer in England Between 2016-2017: A Data Linkage Study Linking National Cancer Registration and Analysis Service, Hospital Episode Statistics and NHS Digital Datasets

This notice relates only to personal data obtained from the Office for Data Release (ODR), Public Health England (PHE) in the above project. The project has the following ODR reference: ODR2021_179

A table of abbreviations is available in Appendix 2 of this document.

[I have questions or want further information. Who do I talk to?](#)

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

Dr Benjamin Pickwell-Smith, MBChB MRCP
Yorkshire Cancer Research funded PhD Student,
Institute for Clinical and Applied Health Research, Faculty of Health Sciences.

Professor Una Macleod and Professor Mike Lind, Hull York Medical School, are supervising this project.

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

Email: dataprotection@hull.ac.uk

Telephone: 01482 466594

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

What is this project about?

The aim of this project is to use cancer registration data to explore whether patients living in more deprived areas either:

- Experience delays in the diagnosis of colon or ovarian cancer, compared with patients living in more affluent areas, or
- Receive different treatments for colon or ovarian cancer, compared with patients living in more affluent areas.

During the 1990's cancer survival improved significantly for almost all the common cancers, however for many cancers survival improved more for patients living in more affluent areas compared to those living in more deprived areas (Rachet et al, 2010). Unfortunately this means that survival after a cancer diagnosis in England for most cancers is markedly different across socioeconomic groups, with those living in the least affluent areas experiencing lower rates of survival. It is estimated that there are about 19,000 extra deaths each year because of these differences in survival, known as the 'deprivation gap' (Public Health England, 2014).

There has been a steady decline in this deprivation gap over the past few decades for some cancers in particular, for example a narrowing of the 5-year survival gap has been observed for women with ovarian cancer. However despite this, there remains a 5-7% deprivation gap in 1-year survival affecting women with ovarian cancer living in the most deprived compared with the most affluent areas. (Exarchakou et al, 2018) With regards to bowel cancer, there remains a significant 3-year deprivation gap affecting both sexes. (Kajiwara et al, 2021)

Various reasons for the deprivation gap have been explored and are the focus of multiple studies across different health care systems, often using different study designs. It is therefore difficult to draw firm conclusions for the principal reason behind the deprivation gap. It is likely to be caused by several factors.

Differences in the stage (how advanced a cancer is) is a commonly cited reason for survival differences between socioeconomic groups. Large reviews have concluded that although stage may explain some of the socioeconomic differences in survival observed in some studies, it does not explain them all - there are many other contributing factors. (Afshar et al, 2021) For example, variations in the presence of other medical conditions is an important consideration, but even after accounting for these, socioeconomic differences in survival still affect patients with ovarian cancer. (Ibfelt et al, 2015) Inequalities (differences) in the diagnostic and treatment pathway are also likely important contributing factors for the deprivation gap.

Cancers typically grow progressively, with a 'doubling time' - a recognised period of time that it takes for a cancer to double in size. Reducing diagnostic and treatment delay is therefore of paramount importance. Delays may occur at any stage of the diagnostic or treatment cancer journey, it is therefore important to evaluate the whole of a person's

pathway (journey) to diagnosis and treatment. Evidence suggests a negative effect of prolonged diagnostic and treatment times and so it is important to reduce delays to diagnosis and treatment.

There is some evidence for socioeconomic inequalities in the length of time to diagnosis and treatment of bowel and ovarian cancer in England. However previous research did not account for the combined effects of key factors such as general health and the journey a patient has taken to receive cancer diagnosis. We aim to study if there are inequalities after accounting for these important factors, and why they might arise within the diagnostic and treatment pathways of bowel and ovarian cancer.

Previous studies of colorectal cancers have also suggested that patients living in more deprived areas were less likely to receive optimal treatments compared with more affluent socioeconomic groups in England. (Lejeune et al, 2010) However, data from such studies are now a decade old, or only looked at specific situations such as surgery for secondary cancer within the liver, use of adjuvant chemotherapy in stage 3 bowel cancer, or were limited to specific regions of England. We plan to update previous analyses of all bowel and ovarian cancer diagnoses in England over a two-year period, accounting for regional variations and route to diagnosis. Including adjustment for regional variation is crucial, as treatments have been shown to vary between regions, though the reasons underlying this are not well understood. (Chamberlain et al, 2015)

The results from this study will help us discover inequalities in the time it takes to diagnosis and treatment, and discover inequalities in the treatments received, for all patients diagnosed with bowel or ovarian cancer. We may be able to suggest explanations as to why this occurs and what can be done to reduce this variation. With a better understanding of the factors that lead to differences in diagnosis and treatment times, and differences in treatments received, this research will contribute to published evidence to help inform, develop and provide evidence for proposals and policies. This research may ensure cancer services are developed to allow all patients to benefit from improvements in cancer diagnosis and treatment, decreasing the differences in survival between different socioeconomic groups currently observed in England.

Who is working on the project?

Only permitted colleagues within the Institute for Clinical and Applied Health Research (ICAHR) and Data Safe Haven, University of Hull with experience in epidemiology, clinical information systems and early cancer diagnosis will access the data. Information will be treated as confidential and access granted to researchers within the institution on a need-to-know basis only. Data will not be shared with any third parties. The University of Hull may need to disclose the data to a regulator or to otherwise comply with the law.

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. In England data collection is performed by the National Cancer Registration and Analysis Service (NCRAS). NCRAS also links this information to other health information routinely collected by the NHS such as information managed by NHS Digital which includes details on attendances in hospital or details about diagnostic imaging tests carried out on NHS patients.

The datasets that we will use in this project are:

- Cancer registration data which records details personal details and 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
- Hospital Episode Statistics (HES data) which records information about when you visit hospital
- Diagnostic Imaging Dataset (DIDS) which records details about diagnostic imaging tests performed
- Cancer Waiting Times (CWT) which records details of dates a patient has been referred on an urgent diagnostic pathway

The data collected is at cancer and patient level data consisting of data from NCRAS and NHS Digital from the aforementioned datasets. The data for this study from NHS Digital is sent to NCRAS and linked.

This data is used for many purposes within the NHS but is also made available for research. More information on NCRAS can be found here:

<https://www.gov.uk/guidance/national-cancer-registration-and-analysis-service-ncras>

More information on NHS Digital can be found here:

<https://digital.nhs.uk/data>

Our research project looks at selected information from these records for the period 2016-2017. Whilst these datasets contain many data items we have only selected the data items we need to answer our research questions. These items are listed in Appendix 1 at the end of this notice.

Under GDPR we need to confirm to you if the data we receive will be used to inform automated decision making or profiling. We confirm that the data we receive as part of this project cannot and will not be used for either automated decision making or profiling.

[Am I in this dataset?](#)

If you were diagnosed with bowel or ovarian cancer between January 1st 2016 and December 31st 2017 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 has been removed and replaced by a unique identifier (a large number). In the project we link people in the different records using this unique identifier generated for us by NCRAS. This means we can match a person who received a diagnosis of bowel cancer and the treatment they received. The identifier we use is specific to this dataset so we cannot use it to link to any other record provided by NCRAS or NHS Digital or other data provider to identify you.

NCRAS holds both the identifier and the full data. This means they can identify you from the data we hold. We would work with them to meet any request you might make using your rights under GDPR as described below.

How are you able to access this data?

NCRAS and NHS Digital are very strict about who can have access to patient data. This is managed via a department called the Office for Data Release (ODR) or via a process called a Data Access Request (DARS). This means we need to meet very detailed data governance standards and can demonstrate we are able to look after it appropriately. More information about requesting data from the ODR can be found here:

<https://www.gov.uk/government/publications/accessing-public-health-england-data/about-the-phe-odr-and-accessing-data>

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 DSH is disconnected from the internet and can only be accessed by approved researchers at specific computers within specially secured rooms. The DSH is managed by the Hull Health Trials Unit who hold a Data Security and Protection Toolkit (DSP), which provides assurance that they are practising good data security and that personal data is handled correctly.

We also confirm that the data held for analysis will not be transferred outside of the HHTU to any third countries or organisations.

More information about the DSP can be found here:

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

How long will you keep it?

We will keep the data within the Data Safe Haven for a period of 5 years according to our data sharing agreement contract with the ODR. 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 but this will not be individual data.

Will we identify you in any research outputs?

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

The legal stuff – 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/key-documents/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 the ODR 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 "GDPR") 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.

More legal stuff – Lawful basis

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/for-organisations/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>

Please note that the data from NCRAS and NHS Digital 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-your-data-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

Tel: 0303 123 1113

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

Table 1: AT_Patient_England data will be provided to the Data Recipient in accordance with the cohort definition and event restrictions listed above.

PATIENTID (project specific pseudonymised)
SEX

Table 2: AT_Tumour_England data will be provided to the Data Recipient in accordance with the cohort definition and event restrictions listed above.

ETHNICITY
ETHNICITYNAME
PATIENTID (project specific pseudonymised)
TUMOURID (project specific pseudonymised)
AGE
BASISOFDIAGNOSIS
SITE_ICD10_O2
SITE_CODED
SITE_CODED_DESC
SITE_CODED_3CHAR
CODING_SYSTEM
CODING_SYSTEM_DESC
MORPH_CODED
BEHAVIOUR_CODED
BEHAVIOUR_CODED_DESC
HISTOLOGY_CODED
HISTOLOGY_CODED_DESC
GRADE
ROUTE_CODE
FINAL_ROUTE
STAGE_BEST
STAGE_BEST_SYSTEM
CHRL_TOT_78_06
HES_LINKED
SCREENDETECTED
DCO
CANALLIANCE_CODE
CANALLIANCE_NAME
QUINTILE_2015

Table 3: AT_Treatment_England data will be provided to the Data Recipient in accordance with the cohort definition and event restrictions listed above.

PATIENTID (project specific pseudonymised)
TUMOURID (project specific pseudonymised)
EVENTID (project specific pseudonymised)

CT_FLAG
SG_FLAG
EVENTCODE
EVENTDESC
EVENTDATE
OPCS4_CODE
OPCS4_NAME
IMAGINGCODE
IMAGINGDESC

Table 4: HES Admitted Care data will be provided to the Data Recipient in accordance with the cohort definition and event restrictions listed above.

PATIENTID (project specific pseudonymised)
diag_4n
opertn_nn
opdate_nn

Table 5: Diagnostic Imaging Data will be provided to the Data Recipient in accordance with the cohort definition and event restrictions listed above.

PATIENTID (Project specific pseudonymised)
DIAG_TEST_REQ_DATE
DIAG_TEST_REQ_REC_DATE

Table 6: AT_Pathway_Englad data will be provided to the Data Recipient in accordance with the cohort definition and event restrictions listed above.

TUMOURID (project specific pseudonymised)
PATIENTID (project specific pseudonymised)
EVENT_TYPE
EVENT_PROPERTY_1
EVENT_PROPERTY_2
EVENT_PROPERTY_3
EVENT_DATE

Appendix 2 Abbreviations

Abbreviation	Full Description
CWT	Cancer Waiting Times
DARS	Data Access Request Service – Online system hosted by NHS Digital
DIDS	Diagnostic Imaging Dataset
DPO	Data Protection Officer
DSH	Data Safe Haven
DSP	Data Security and Protection Toolkit
GDPR	General Data Protection Regulation
HES	Hospital Episode Statistics
HHTU	Hull Health Trials Unit
ICAHR	Institute for Clinical and Applied Health Research, University of Hull
ICO	Information Commissioner’s Office
NCRAS	National Cancer Registration and Analysis Service
ODR	Office for Data Release
PHE	Public Health England
SACT	Systemic Anticancer Therapy
UoH	University of Hull