

This notice is provided in compliance with the General Data Protection Regulation 2018. It relates to the use of personally identifiable information in the context of research conducted by the Policy Research Unit in Cancer Awareness, Screening and Early Diagnosis (PRU)

### **What is the purpose of this document?**

The Policy Research Unit in Cancer Awareness, Screening and Early Diagnosis (PRU) (a research department in Queen Mary, University of London (QMUL)) is committed to protecting the privacy and security of your personal information. This privacy notice describes how the PRU collect and use personal information, in accordance with the applicable data protection legislation (the Data Protection Act 2018, the General Data Protection Regulations (the “GDPR”) and the University’s Data Protection Policy (<http://www.arcs.qmul.ac.uk/media/arcs/policyzone/Data-Protection-Policy-v03.0.pdf>).

### **Background**

Colorectal cancer is the second most common cancer in England: in men, it is the third most common cause of cancer death after prostate and lung cancer, and in women, the third after breast and lung cancer. A national bowel cancer screening programme began in July 2006 and rolled out incrementally across the country, achieving national coverage in 2010. In the post-randomised controlled trials epoch, assessment of the impact of the programme using observational studies is needed.

To help people make an informed choice about attending a screening check, and to inform the implementation of the National Bowel Cancer Screening Programme, the PRU has been appointed by the National Institute for Health Research (NIHR) to carry out this research. The PRU collect and analyse information about people who are invited to participate in the NHS Bowel Screening Programme. This information is generated and collected by Public Health England as part of delivering national cancer screening programmes and the cancer registry. Further information on these can be found at <https://www.gov.uk/topic/population-screening-programmes> and <https://www.ndrs.nhs.uk/>.

This type of study is called a “retrospective case-control study”. A study like this does not require contact with the participants themselves or anyone involved in their direct care.

The NIHR commissions this work on behalf of the Department of Health and the PRU is led from the Wolfson Institute of Preventive Medicine at Queen Mary, University of London.

### **Who is responsible for the data we process?**

For the purposes of any applicable data protection laws in England, Wales and Scotland, including the EU General Data Protection Regulation 2016/679 (GDPR), QMUL is the Data Controller of personal information once data has been made available to us for this research study. QMUL is registered with the Information Commissioner’s Office under registration number Z5507327.

## **Legal basis for processing your personal information**

All of the personal information QMUL collect is used solely for the purposes of carrying out our research. Personal information collected for research will not be used for any other purpose.

Under the [EU General Data Protection Regulation](#), QMUL's legal basis for processing this information is for the performance of a task carried out in the public interest. QMUL processes sensitive health information for the purposes of scientific research with appropriate safeguards in place to protect personal information, as required by the EU General Data Protection Regulation.

QMUL only use personal information when the law allows us to and we have sought special permission from the Secretary of State for Health to use confidential patient information when it is necessary for our research, without seeking individual consent. This approval is given under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 – also known as [Section 251](#) of the NHS Act 2006 and is based on the advice of the [Health Research Authority's Confidentiality and Advisory Group](#) (CAG).

## **Personal data we collect about individuals**

We collect and analyses personal information about individuals who have been diagnosed with bowel cancer. This includes their date of birth and date of death. We also collect health information about these individuals including their date of bowel cancer diagnosis, dates of bowel cancer treatments and attendance to cancer screening programmes (bowel (and breast and cervix for women). This information is regarded as a special category of information. We do not collect data such as names, address, postcode or NHS number. All the information for this research study comes from Public Health England who are the data controllers for the cancer registration databases and the national cancer screening databases.

When we are carrying out this work this information is only used for particular purposes and importantly, this information is only made available to specified individuals in the PRU team on a 'need to know' basis. For example the members of the research team who carry out the data analysis are not given access to the identifying data.

## **How we use personal data**

As a research unit within the university we use personally-identifiable information to conduct research to improve health, health care and health services. We have to ensure that it is in the public interest when we use personally-identifiable information in our research. Health and care research should serve the public interest, which means that before we are able to access the personal identifiable information which is listed above we have to demonstrate that our research serves the interests of society as a whole.

To ensure we carry out our research to the highest standards we comply with the UK Policy Framework for Health and Social Care Research and other regulatory requirements. For example, we have approval from the Confidentiality Advisory Committee for section 251 approval under the NHS Act 2006 (England and Wales).

## **How long we keep personal data for**

QMUL must only retain your personal data for as long as necessary to fulfil the purposes for which it was collected and to satisfy any legal, regulatory, accounting or reporting requirements.

### **How we protect data**

We ensure that we protect personal identifiable data against unauthorised access, unlawful use, accidental loss, corruption or destruction. To do this we use ‘technical measures’ such as encryption and passwords to protect the individual datasets as well as the systems the datasets are held in. We also use ‘operational measures’ to protect the data, for example, by limiting the number of people who have access to the databases in which identifiable data is held.

Queen Mary, University of London completes The Data Security and Protection Toolkit (previously known as IG Toolkit) every year. It is an online self-assessment tool that allows organisations to measure their performance against the National Data Guardian’s 10 data security standards. All organisations that have access to NHS patient data and systems must use this toolkit to provide assurance that they are practising good data security and that personal information is handled correctly. Our last assessment was published in June 2021 and we achieved a status of “standards met”.

### **Sharing identifiable data**

Personal identifiable data which is collected and managed by the PRU will not be shared with anyone else. The information we receive for this research is only used for the purposes agreed with legally binding data sharing contracts issued by Public Health England. We do not share your personal information with any third parties. We do not transfer your personal information outside our secure information systems.

Anonymous data (from which individuals cannot be identified) may be shared with other research groups who are doing similar research. The data which is shared in these circumstances will not include any information to enable individuals to be identified and the data will not be combined with any other information in a way that could lead to individuals being identified. Any information shared will only be used for the purpose of health and care research, and will not be used to contact individuals or to affect their care.

Decisions about who has access to data managed by the PRU for this study are made by the PRU Chief Investigator, Professor Stephen Duffy. Your data will not be shared with any persons or organisations outside of the EU.

### **The rights of individuals**

The rights of individuals to access, change or move their information are limited, as we need to manage information in specific ways in order for the research we carry out to be reliable and accurate. Individuals can however, choose whether their confidential patient information is used for research and planning. To find out more visit <https://www.nhs.uk/your-nhs-data-matters/>. If this happens we will keep the information that we have already obtained.

### **Complaints**

The individuals whose data we hold have the right to complain. If you wish to complain about any aspect of QMUL's handling of your data, you can contact our Data Protection Officer by email at [data-protection@qmul.ac.uk](mailto:data-protection@qmul.ac.uk).

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). Please see <https://ico.org.uk/> for details.

#### **Contact us**

If you would like to contact us directly for more information about how we use and protect data collected for research conducted at the PRU, please email Professor Stephen Duffy, [s.w.duffy@qmul.ac.uk](mailto:s.w.duffy@qmul.ac.uk)