This notice is provided in compliance with the General Data Protection Regulation 2018. It relates to the use of personally identifiable information in the study **“NCRI RCT into annual mammographic screening – Age 40 Trial”** 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 for the study titled *“NCRI RCT into annual mammographic screening”*, 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**

The NHS Breast Screening Programme invites all women aged between 50 and 70 every 3 years to have a test called a mammogram (a breast x-ray) to look for cancer that may be too small to see or feel. In England, breast screening saves around 1,300 lives every year by detecting cancer at an early stage. Early stage breast cancers are usually easier to treat, may need less treatment, and are more likely to be cured.

The ‘Age 40’ Trial was designed to study the effect of routine mammographic screening starting at ages 40-41, on breast cancer mortality. The trial started in 1991 and collected information on 160,000 women which was provided by NHS Digital. The women were regularly followed-up until February 2017. Since then there has been no further data collected and the trial results are now being written up for publication.

**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](https://www.eugdpr.org/) (EU GDPR), QMUL’s legal basis for processing this information is for the performance of a task carried out in the public interest as set out in Article 6, paragraph 1 (e). QMUL also processes sensitive health information for the purposes of scientific research with appropriate safeguards in place to protect personal information, as set out in Article 9, paragraph 2 (j) of the EU GDPR.

Furthermore, 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](https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/why-confidential-patient-information-used/) of the NHS Act 2006 and is based on the advice of the [Health Research Authority’s Confidentiality and Advisory Group](https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/confidentiality-advisory-group/) (CAG).

**Personal data we collect about individuals**

When this study was initiated it was necessary to collect individuals’ *name*, *NHS number* and *postcode* for linkage purposes. These data items remain in the dataset in their original format, however, they were **not** used for any analysis and were not shared with those carrying out the analysis.

We also collected *date of birth* and *date of death.* Date of birth and date of death were used to calculate the participant’s age at various time points, and a number of time intervals between dates, after which they were removed from the analysis dataset.

When carrying out this work the information was only used for particular purposes and importantly, this information was 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 carried out the data analysis were 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 to 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 result published in 2019 stated that ‘standards were met’.

**Sharing identifiable data**

Personal identifiable data which is collected and managed by the PRU will not be shared with anyone else. 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/>.

The data collected for this trial has not been used in any automated decision-making, including profiling.

**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)