

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 “**BRCOH - Evaluation of the NHS Breast Screening Programme**” 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 “*BRCOH - Evaluation of the NHS Breast Screening Programme*”, 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 PRU collect and analyse information about women who are invited to participate in the NHS Breast Screening Programme and/or have died from breast cancer. 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/>.

The study which began in 2002 aimed to evaluate the impact of the NHS Breast Screening Programme on breast cancer mortality in England and Wales. The study was initially carried out by the Cancer Screening Evaluation Unit and was transferred to the Queen Mary University of London in 2014. The study population comprises over 2 million women aged 49–64 in 1988.

QMUL will continue the research and carry out a one-off flagging exercise in order to obtain up-to-date cancer incidence and mortality follow-up to conduct analysis on a longer-term basis. The objectives of this follow-up phase are to further assess the effectiveness of the screening programme by comparing risk of death from breast cancer in woman who were invited for screening with those who were not invited in the same period for follow-up over a 25-year period and wider objectives related to the impact of the screening programme on diagnosis of breast cancer.

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 Health Research Authority (HRA) to use confidential patient information when it is necessary for our research, without seeking individual consent. This support 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 Advisory Group](#) (CAG).

Personal data we collect about individuals

We collect and analyse personal information about women who have been diagnosed and/or died from breast cancer. When this study was initiated it was necessary to collect individuals' *NHS number* for linkage purposes. The NHS Number remains in the dataset in its original format, however, it is **not** used for any analysis and is not shared with those carrying out the analysis.

We also collect *date of birth*, *date of death* and *postcode*. Date of birth and date of death are used to calculate the participant's age at various time points, after which they are removed from the analysis dataset. Postcode is converted into a 'deprivation index' and then removed from the analysis dataset.

When we are carrying out this work the 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 most recent Data Security and Protection Toolkit (Version 1) was published on 28/03/2019 and all mandatory assertions were **fully 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

Individuals can 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 you do not wish for your individual data to be used for this research please email Professor Stephen Duffy, s.w.duffy@qmul.ac.uk

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.

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