

## The Age at First Breast Screening Study: Privacy Notice

### 1. What are we trying to do?

The aim of the Age at First Breast Screening Study is to establish whether the age women are when first invited for routine breast screening affects their subsequent mortality from breast cancer.

### 2. Why are we doing this?

Regular mammography between the ages of 50 and 70 years has been shown to reduce breast cancer mortality. In England and Wales, the National Health Service first invites women for breast screening between the ages of 50 and 53. It is not known whether this three-year range makes a difference to subsequent mortality from breast cancer.

### 3. How will we do this?

We will use your data if you were born in 1945-1948 and were on the administrative system used to invite women to routine breast screening in England and Wales at the beginning of the calendar year in which you turned 50.

In 2008-2010 NHS Connecting for Health (now part of NHS Digital) provided The Age at First Breast Screening Study with information on your first invitation to routine breast screening including personal identifiers such as name, postcode, NHS number and date of birth. The Health and Social Care Information Centre (now known as NHS Digital) then provided linked information on cancer registrations and death records that occurred up to December 31<sup>st</sup> 2012. To do this we supplied the Health and Information Centre with your personal identifiers. We have not retained any personal identifiers, except date of death for those women who have passed away. We retain date of death as it is needed for analysis purposes.

We will now extend follow-up by obtaining linked information from NHS Digital on cancer registrations and death records that occurred up to December 31<sup>st</sup> 2019. This data will not include and personal identifiers, except date of death for those women who have passed away. We will use a unique participant code to link this information with that which we have already obtained. The unique participant code is a series of numbers and letters that cannot be used to identify any woman.

We have ethical approval and special permission to use your data (see Section 5 below). Your data is held securely by the University of Oxford and used solely for academic research purposes. Importantly, whilst the information received is specific to each study participant, no individual person will be identifiable in any publication arising from this work. Your personal data has not and will not be shared with any 3<sup>rd</sup> parties or used for any automated decision making or profiling.

### 4. Who is responsible for the data we collect?

The University of Oxford, as sponsor, is the data controller. This means that we, as University of Oxford researchers, are responsible for looking after your information and using it responsibly.

### 5. What approvals/permissions do we have to conduct this study?

Initially the Age at First Breast Screening Study was classed as an audit of the NHS Breast Screening Programme and did not require ethical approval. In 2018, the screening programme changed its routine practices and the study can no longer be classed as an audit. Hence, we have obtained approval to complete analyses of the information already obtained and to extend follow-up until

December 31<sup>st</sup> 2019 from the Leicester Central Research Ethics Committee (REC reference: 21/EM/0035).

We have special permission to conduct the Age at First Breast Screening study without your consent or knowledge (i.e. to link, transfer, process and analyse the data). The permission was initially given in 2008 under Section 60 of the Health and Social Care Act 2001 by the Patient Information Advisory Group (PIAG reference number: PIAG 3-05(1)/2007). We have updated this permission and it is now given under Section 251 of the National Health Service Act 2006 and its current regulations, the Health Service (Control of Patient Information Regulations 2002) and is granted by the Confidential Advisory Group (CAG reference number: 21/CAG/0020).

The legal basis for the permission to process and store personal data for the Age at First Breast Screening Study is that it is 'a task in the public interest' (GDPR Article 6(1)(e)) and that sensitive (termed 'special category') personal data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes (GDPR Article 9(2)(j), based on Article 89 (1)). This is particularly pertinent to the use of personal identifiers and we will use the minimum personally-identifiable information possible.

## **6. Can I opt out of the Age at First Breast Screening Study?**

If you think that your personal information has been included in this study and wish to opt out, please write, email or phone giving your name and NHS number using the contact details given in Section 10. You can find your NHS number on any letter you receive from the NHS. However, if you do not have any letters you can use the online service at <https://www.nhs.uk/nhs-services/online-services/find-nhs-number/>. We will pass your details on to NHS Digital and instruct them to stop providing us with follow-up information. We cannot delete any information we have already obtained as we do not retain personal identifiers other than date of death.

We will not retain your request to opt out and it will in no way affect your current medical care.

## **7. How long will personal data be stored?**

The data will be retained in accordance with the funder's requirements for at least 25 years from the completion of the study. After this time, data will be retained if it is used solely for the purposes of scientific or historical research, statistical purposes, or archiving in the public interest, in accordance with GDPR Article 5(1)(e). We may also need to retain data for longer if it is necessary to fulfil our purposes, including any relating to legal, accounting, or reporting requirements.

## **8. Your rights**

Data protection regulation provides you with control over your personal data and how it is used. When your information is being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at <https://compliance.admin.ox.ac.uk/individual-rights>.

## **9. Complaints**

If you want to exercise any of the rights described above or are dissatisfied with the way we have used your information, please contact the University's Information Compliance Team at [data.protection@admin.ox.ac.uk](mailto:data.protection@admin.ox.ac.uk). The same address can be used to contact the University's Data Protection Officer. If you remain dissatisfied, you have the right to lodge a complaint with a supervisory authority. In the UK, this is the Information Commissioner's Office (ICO). A complaint to the ICO can be made by visiting their website <https://ico.org.uk/make-a-complaint/> or by calling their helpline on 0303 123 1113.

**10. Who can I contact for more information?**

For more information, please see the Age at First Breast Screening Study website (<https://www.ceu.ox.ac.uk/research/the-age-at-first-breast-screening-study>) or write, email or phone using the contact details below.

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