

BREAKTHROUGH UK WOMEN'S COHORT STUDY (Breast Cancer NOW GENERATIONS STUDY)

With appropriate ethics committee and Health Research Authority approval, since 2003 individually identifiable information from medical health records and on cancer and mortality in women in the UK who joined the Breast Cancer Now Generations Study (previously known as the Breakthrough Generations Study) have been sent to The Institute of Cancer Research by NHS-Digital and National Records of Scotland (Public Health England ceased to exist from 1st October 2021 and the information PHE previously provided is now supplied by NHS-Digital). The information originates from medical records and national cancer and death registrations, and is necessary to enable the analyses described to participants when they joined, including finding factors affecting risk of breast cancer, other cancers and causes of death. As stated to women when they joined, the study will continue for at least 40 years, and individually identifiable data from these organisations will not be shared outside The ICR.

The women who have joined the study are volunteers, and are free to withdraw if they wish to do so at any time. Appropriate ethics and data protection approval is carried out at all levels in the process.

The ICR is the data controller for this study. The ICR collect special category data (health information) for the purposes of this study. The lawful basis for processing this information is for the performance of a task carried out in the public interest. The ICR processes sensitive health and genetic information for the purposes of scientific research with appropriate safeguards in place to protect personal information, as required by the UK General Data Protection Regulation.

Individuals have the right to request from the controller access to and rectification or erasure of the personal data, or restriction of processing of personal data, or to object to the processing of such personal data, as well as data portability.

If you are a member of this study and want further information or wish to opt out of future supply of the above data by these NHS organisations, please do not hesitate to contact us via email at DataProtectionOfficer@icr.ac.uk or by post:

ICR Data Protection Officer,
123 Old Brompton Road,
London,
SW7 3RP

If you feel we have breached your rights under UK GDPR you have the right to lodge a complaint with the [Information Commissioners Office](#).