IRAS project ID: 134352

Mammographic surveillance in breast cancer patients aged 50 years or older
MAMMO-50

DATA TRANSPARENCY STATEMENT

If you are taking part in the Mammo-50 study, this statement describes how your data is being used and are being stored. We would like to take this opportunity to thank you for your involvement in the study.

The purpose of the Mammo-50 study is to investigate the most effective and safest way of monitoring women of 50 years or over who have had breast cancer surgery. It will also consider acceptability to patients and value for money. The results of the study will inform national guidelines about the best way to follow up women who have had surgery for breast cancer.

University Hospitals Coventry and Warwickshire NHS Trust and The University of Warwick are the sponsors for this study based in the United Kingdom. The University of Warwick will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The sponsors will keep identifiable information about you at least five years after completion of the trial.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information here:
https://warwick.ac.uk/services/legalandcomplianceservices/dataprotection/privacynotices/research/

Everyone that took part in the Mammo-50 study was asked to sign a Consent Form. As a reminder, you provided signed, written consent for your personal data to be held on a secure database at the University of Warwick. Your NHS hospital will collect information from you and your medical records for this research study in accordance with our instructions, and pass this information on to the study team at the University of Warwick. The people who analyse

This study is funded by the National Institute for Health Research (NIHR) Health Technology Assessment Programme (project number: 11/25/03).
ISRCTN48534559

the information will not be able to identify you and will not be able to find out your name, NHS number, hospital number or contact details.

Your NHS hospital will use your NHS number, hospital number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from University Hospitals Coventry and Warwickshire NHS Trust, The University of Warwick and regulatory organisations may look at your medical and research records to check the accuracy of the research study.

The University of Warwick will have access to information that identifies you only if you have given your permission to take part in the telephone interview-based qualitative sub-study and only to enable us to contact you to perform the telephone interviews. Following the interviews, your contact details will be removed from our system.

The University of Warwick will collect information about you for research purposes from NHS England (formerly known as NHS Digital), Office of National Statistics (ONS) and other relevant bodies to provide information about your health status. NHS England is an organisation that collects health and care data from NHS hospitals in England and Wales. The study team will provide NHS England with your NHS number, date of birth and unique trial ID number to allow us to link to the data held by NHS England. NHS England will transfer data back to the University of Warwick regarding any hospital admissions and appointments over the study period, plus information about any further cancer diagnoses and survival. The data transferred back to the University of Warwick will be identified by your trial ID number only. Data transfer will be using a secure, encrypted procedure. We will use this information to inform future mammographic surveillance regimes for patients over 50 years of age treated surgically with curative intent for invasive and non-invasive breast cancer.

Your NHS hospital will keep identifiable information about you from this study at least five years after completion of the trial. When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research**.** Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government. Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance. Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

This study is funded by the National Institute for Health Research (NIHR) Health Technology Assessment Programme (project number: 11/25/03).
ISRCTN48534559