

Breast Screening for Women with a Family History of Breast Cancer (FH 01)

An evaluation funded by the NHS Research and Development Programme

INFORMATION SHEET

You are being invited to take part in a project to evaluate the effectiveness of mammographic screening in women with a family history of breast cancer. Before you decide to take part in the project, it is important for you to understand why the evaluation is being done and what it will involve. Please take time to think about the following information on breast screening and discuss it with others if you wish. If you require further information on breast screening, or on the evaluation project, please ask us. Take time to decide whether or not you wish to take part.

What's the purpose of screening?

The purpose of breast screening is to detect breast cancer as early as possible by picking up changes to the breast that often cannot be seen or felt. In the UK, around one in every 9 women will develop breast cancer at some point in their life-time. Women with a family history of the disease have a higher risk. Early diagnosis of breast cancer offers the best chance of a successful recovery, however it is not known whether or not breast screening is effective in women under 50 with a family history of breast cancer.

What's the purpose of the evaluation?

The purpose of this evaluation is to look at the effectiveness of providing annual mammographic screening in women under 50 with a family history of breast cancer. The evaluation will involve collecting data from 10,000 women aged 40-44 with a significant family history of breast cancer, who are offered regular mammographic surveillance over 5 years.

How does screening work?

X-ray pictures called mammograms are taken of the breast. Two views of each breast are taken at every screening appointment. Women having a mammogram are asked to undress to the waist, so wearing a separate top rather than a dress may be preferable. The actual X-ray only takes a few minutes and the level of radiation is very low.

Who can have screening?

In the UK women aged between 50 and 64 are routinely invited for breast screening every three years by the National Breast Screening Programme. Work is being carried out to extend the programme to all women up to and including the age of 70. Continued three yearly screening from the age of 64 is available in those areas where

the programme has not been extended if requested by the woman and for those over 70 where the programme has been extended.

Why does screening not start until the age of 50?

Research studies have shown that screening significantly reduces deaths from breast cancer in women aged 50-64 who attend for screening. For women under 50 the effectiveness of screening is controversial. Experts in the UK currently believe the disadvantages of screening outweigh the advantages for women in the general population under 50, hence it is not routinely offered.

Why am I being offered screening before I am 50?

For younger women who have an increased risk of developing breast cancer on account of their family history, the collective view of experts in the UK is currently that the benefits of screening are likely to outweigh the harms. However, it is important to realise that, as yet, there is no strong evidence to prove whether or not breast screening in younger women with a family history is effective and will reduce deaths from breast cancer.

Is there anything else I need to know?

For the purposes of this evaluation we need to hold personal information on you to issue regular invitations and to check on the performance of the programme. We take great care to keep your personal details confidential and only share information with people who have a statutory or medical requirement for it, for example your General Practitioner.

We are centralising personal data from everyone involved in this evaluation. The data will be held in a database on behalf of the NHS by Breast Test Wales, the Welsh equivalent of the NHS Breast Screening Programme, which is based in Cardiff. These personal details will remain confidential to Breast Test Wales. Only anonymised details will be released to the research teams involved in the evaluation.

If this evaluation provides evidence to the NHS that regular mammography is not beneficial then this will be formally reported to the National Screening Committee who reserve the right to advise that regular mammography will not be available to women under 50.

How reliable is screening?

Mammography is currently the best way of detecting breast cancer early. However, like other screening tests it is not perfect:

- Some cancers are very difficult to see on the X-ray
- Some cancers, even though they are there, cannot be seen on the X-ray at all
- The person reading the X-ray may miss the cancer (this will happen occasionally, no matter how experienced the reader is)

Does screening hurt?

Each breast needs to be held firmly in position and compressed as the X-ray is taken, in order to obtain a clear picture. Some women describe a mammogram as uncomfortable, while others describe it as painful. Any discomfort only lasts for a brief period of time.

At what age does screening start for women with a family history?

In women with a family history screening usually starts at age 40, although in some women with a strong family history, regular mammography will be offered from a younger age.

How often would I have a mammogram?

Screening is currently recommended every year for younger women with a family history. This is because breast cancer in younger women may appear more quickly than in older women.

How would I get my results?

When you have had the mammogram, a member of the screening team will tell you how and approximately when you will get your result.

What does it mean if I am called back for more tests?

Some women (about 1 in every 20 who goes for screening) are asked to come back for a further appointment because the appearance of the X-ray is not completely normal. It may be necessary to perform further mammographic views, or other investigations such as ultrasound or a biopsy may be needed. In the majority of cases, these further tests will show there is nothing to worry about.

What should I do if I notice any breast symptoms?

As breast cancer can occur between screens it is important you see your doctor immediately if you notice any unusual changes in your breasts, even if you have just had a normal screen or are due for a screen in a month or so.

So should I go for screening or not?

To help you decide whether or not **you** want to attend for breast screening, the main advantages and disadvantages of regular mammography in women under 50 with a family history of breast cancer are outlined below:

- Screening is currently believed to provide the best chance of detecting cancers at an early stage when treatment can offer the best chance of a successful recovery. However there is no good evidence that this is the case.
- Around seventy per cent of the cancers found at screening are still small enough to be removed from the breast. This means that the whole breast does not have to be removed.
- Screening will **not** detect all breast cancers, so some cancers will be missed at screening and some women may be falsely reassured.
- Screening will **not** prevent breast cancer from developing.
- Approximately one in every 20 women who go for screening will be called back for further investigations. Most of the women who have further tests will turn out not to have cancer. However, women who are called back often find this a very anxious time.
- Each mammogram gives a small dose of radiation. The expert view is that the dose is so small it is unlikely to cause any harm. However, it is theoretically possible that regular mammography in younger women could actually promote the development of a breast cancer.
- Many women find mammography uncomfortable or painful.

What if I may be/am pregnant?

The radiation dose to the abdomen during mammography is extremely low, so you could still be screened. However, you may prefer to wait until you know you are not pregnant.

What do I do now?

If you would like to be part of the evaluation including regular mammography, please sign the consent form and return it to the person named on the form

What if I do not want regular mammography?

You do not have to choose screening now. You will be invited automatically for screening after the age of 50 by the NHS Breast Screening Programme. If you change your mind before then and decide that you do wish to have screening please contact the person named on the consent form.

How will the evaluation affect me?

Your treatment will not be affected in any way if you participate in the evaluation. You will receive exactly the same mammographic screening if you participate in the evaluation as you would outside the evaluation. You may withdraw from the evaluation at any time if you wish, without this affecting your treatment. Your mammograms and the results of any further tests, which you may have, may be reviewed by a panel of national experts.