

FAQs for breast screening very high risk surveillance issue

Background information

Some women are at higher risk of breast cancer because they have received radiotherapy above the waist to treat Hodgkin lymphoma when aged between 10 and 35 years old. These women should be referred to annual breast cancer MRI screening, starting 8 to 15 years after their treatment depending on their age. This is because the increased risk does not emerge until approximately 10 years later.

This advice came from the Chief Medical Officer in 2003, who also advised that all women who had this type of radiotherapy between 1962 and 2003 should be invited for an annual MRI. Depending on their age they should also have been offered a mammogram.

Last year, NHS England was alerted that some women were not receiving the level of screening that they need. After a thorough review of each patient record, the NHS is now contacting everyone affected to let them know, and to offer appropriate follow up care and support.

Why has this happened?

In 2003, some women were identified as being at increased risk of breast cancer, so were contacted by their local Trust to discuss their risks and were offered appropriate screening. A recent review by NHS clinicians showed that some of the women eligible for very high risk annual screening were not invited.

When did you find out there was a problem?

Last year, NHS England was alerted to the issue and carried out detailed investigations into each patient record to identify what action is needed.

Why am I being informed now?

Last year, NHS England was alerted to the issue and a detailed investigation had to be carried out into each person's record to understand their circumstances. This review found that some people were already on the right screening pathway, some were not eligible and some needed to be invited onto the very high risk screening pathway. Now the review is complete, patients are being quickly contacted.

How quickly will I get my screening?

If you are one of those who needs very high risk screening, the NHS will contact you and your local breast screening service will offer you an appointment for an MRI scan within three months. We will also check if you need a mammogram and if so, you will be offered that on the same day as your MRI.

Why do I need an MRI and not just a mammogram?

For women who are considered at very high risk of breast cancer or for those with very dense breast tissue, an MRI is a more sensitive test as it can provide a very detailed image of your breast. Because you are considered at high risk of getting breast cancer, you are being offered MRI. You may also be offered a mammography at the same appointment, depending on your age and when you had your last one.

I've had a mammogram within the past 6 months. Can that mammogram be read alongside the new screening MRI or does another one need to be taken on the same day as my MRI?

A mammogram taken within the past 6 months, regardless of its setting (screening, symptomatic or private), does not need to be repeated and should be available to review alongside the MRI.

I have a relative who died of breast cancer who I think should have been on the very high risk programme

As part of the detailed review, while it can't be determined with certainty whether it would have changed outcomes, NHS Trusts are committed to trying to contact families of patients that died of breast cancer to offer an apology and full discussion about not being on the very high risk pathway.

What happens if you find a tumour?

If cancer is found as part of the screening, your clinician will talk you through the options available and begin the treatment process.

Will I get any compensation for this?

If you would like to seek legal advice, you may wish to review the information available from NHS Resolution in the first instance [Advice for claimants - NHS Resolution](#)

I've heard about some women needing more regular breast screening and think I might be affected but I haven't received a letter yet, what shall I do?

Letters have been sent by the NHS to women affected by this issue. If you think you may have been affected, please wait for a couple of days to see if you get a letter. If not, there is a dedicated helpline.

This will initially operate 7 days a week - Monday to Friday, 9.30am to 5pm and Weekends 10am to 4pm (local call charges apply).

I've received a letter saying I need more regular breast screening – what happens now?

You should be contacted by your local service to arrange an appointment within the next few weeks. If you have any questions in the meantime, or if you don't receive an appointment letter, please contact the dedicated helpline on Tel 0345 8778962. This will initially operate 7 days a week - Monday to Friday, 9.30am to 5pm and Weekends 10am to 4pm (local call charges apply).

I haven't received a letter yet inviting me for breast screening, but I am worried about some possible symptoms. What shall I do?

Please make an appointment at your GP practice.

Radiotherapy Q&As

What sort of radiotherapy puts someone at risk?

Radiotherapy is a very effective treatment for many cancers but like all treatments has some unwanted side effects, including second cancers. Girls and young women (aged 10-35 years) who receive radiotherapy to the chest involving breast tissue are at increased risk of developing breast cancer later in life. Breast screening with

mammography and/or MRI (magnetic resonance imaging) is effective at detecting breast cancers when small and potentially curable which is why it is recommended, starting between 8-15 years after radiotherapy. Screening doesn't start immediately after completion of radiotherapy because the increased risk doesn't emerge until approximately 10 years later. Screening for other second cancers isn't currently recommended but work is underway to see if there is sufficient evidence to introduce this in some circumstances.

What is Mantle radiotherapy?

This refers to the type of radiotherapy that was used during this time window to treat patients with Hodgkin lymphoma. This technique delivered the radiotherapy to a large area of the neck, chest and upper body. However, it has since become much less frequently used.

Is it just women who have had Hodgkin's lymphoma who have this sort of radiotherapy?

No, radiotherapy is used to treat Hodgkin lymphoma in both males and females. The risk of a man developing a breast cancer following radiotherapy to their chest area when aged <35 years is low. This means that you do not need to have annual screening.

Also, breast screening has not been shown to be beneficial, even in men at high risk such as due to inherited genes, and so is not recommended by international guidelines.

Q&As to support staff:

What should we advise women over 71?

Women are being invited to attend for a baseline MRI regardless of age. In all women over 50 years the images taken at this screen will inform the optimal screening tests needed going forward

A woman rings and tells me she has a letter and had breast cancer – what do I advise her to do?

As with routine screening, women diagnosed with cancer and under care should continue to be invited for VHR screening. This is regardless of whether the woman was diagnosed via screening or symptomatically. This is a failsafe mechanism to make sure that all women are invited. Depending on where she is in her treatment the woman can decide to either attend or opt-out of this screening episode. If she opts-out, the NBSS episode should be closed as under care temporarily and her next test due date moved forward 12 months.

Will some women be finding out for the first time they are at higher risk of breast cancer?

No, all women identified in the Patient Notification exercise (PNE) were told in writing that they were at increased risk and were invited for a personal consultation to discuss their risks

Is this a similar risk to a BRCA carrier?

Very high risk is defined by the NHS breast screening programme as:

- women with a lifetime risk of 40% or greater due to a specific genetic abnormality in the woman or her family

- those receiving radiotherapy to breast tissue during treatment for Hodgkin and non-Hodgkin lymphoma between the ages of 10 and 35 years
- a small number of women who received radiotherapy to breast tissue during treatment for cancers other than lymphoma