

Breast surveillance

screening for women with a
very high risk of breast cancer



Breast  *Screening*

Women at very high risk of breast cancer are offered breast screening annually and at an earlier age than women from the general population. We call this surveillance screening.

What does 'very high risk' mean?

You have been assessed by a specialist in genetics or oncology as being at greater risk of developing breast cancer than women in the general population. This is because you have one of the following genetic mutations: BRCA1, BRCA2, TP53, A-T homozygotes, PALB2, PTEN, STK11, CDH1, or another genetic mutation with a similar level of risk; or because you have had radiotherapy treatment to an area involving breast tissue.

How often will I be offered surveillance screening?

Most women will be offered surveillance screening annually. A small number of women will require less frequent screening than this.

You will be offered mammography, MRI, or both; depending on your age and the reason for your very high risk of breast cancer. Your specialist may already have let you know what type of screening you can expect to have and how often you need to be screened.

Where will my screening be done?

Surveillance screening for women with very high risk of breast cancer is carried out at a Specialist Imaging Unit in Antrim Area Hospital.

If you only require mammography screening, it may be possible to arrange this at your local screening unit. You can discuss this with the Very High Risk Breast Screening Unit.

Making a decision about surveillance screening

Current guidelines recommend that women at very high risk of breast cancer attend annual surveillance screening. It is up to you whether you wish to participate in breast surveillance screening. If you do not wish to participate, you will be asked to confirm this in writing.



How will my screening be done?

There are two types of screening technology used for women at higher risk.

Digital mammography – x-rays of the breasts

You will have to undress from the waist up for your mammogram, so it is a good idea to wear a separate top instead of a dress. The radiographer will position you so that each breast, in turn, is placed on the x-ray machine and gently



compressed against a plastic plate. Two mammograms are usually taken of each breast from different angles.

Mammography uses x-rays to examine the breast. X-rays can very rarely cause cancer. Having mammograms every year very slightly increases the chance of getting cancer over a woman's lifetime. Information about the risks and benefits of screening for women invited to the routine Breast Screening Programme is available in the information leaflet *Northern Ireland breast screening: helping you decide* (available at pha.site/helping-you-decide). You may wish to contact the Very High Risk Breast Screening Unit if you would like to discuss this further.

MRI – magnetic resonance imaging

The MRI scanner is a large tube surrounded by a strong magnetic field, with a platform bed that slides into it. You will have to change into a gown and all metal objects must be removed from your person before you enter the scan room. You will be asked to lie face down on the bed. There are cushioned holes for your breasts, and a special rest for your head. MRI involves taking many different images of the breast, which may take a while. The whole imaging session usually lasts between 30 minutes and an hour.



A 'call-bell' will be given to you so that you can contact the radiographer at any time. The MRI scanner makes a loud banging noise when taking the images. Earplugs or headphones are provided to minimize this. If you have any questions about your scan you can speak to the doctor.

Before MRI is carried out, you will be asked some standard questions to ensure your safety. MRI is not suitable for everyone. The questions you are asked will allow screening staff to decide if it is right for you. MRI for breast screening is carried out at the Very High Risk Breast Screening Unit, as both the equipment and screening staff must meet special specific screening standards.

For best results, breast MRI examinations should be performed between 6 and 16 days from the beginning of your last menstrual period.

During the process, you will be given a small injection in your arm. This contains a liquid (called a 'contrast agent') which helps different areas of breast tissue to show up on the scans. The liquid used with your MRI contains gadolinium. We know that small amounts of gadolinium may remain in the brain afterwards. However there is currently no evidence that these small amounts cause any harm. Gadolinium is essential for diagnosing a wide range of life-threatening diseases including breast cancer. If you need a scan using gadolinium, the doctor will use the lowest dose required for a clear image.

Please phone the Very High Risk Breast Screening Unit before coming for your appointment if:

- you have a physical disability or find climbing steps difficult, so that your screening unit can make any necessary arrangements for you
- you have breast implants - you will usually be able to have a mammogram but please let the screening staff know beforehand
- you have had a mammogram recently, or are pregnant or breastfeeding, as you may be advised to delay breast screening, or
- you need an interpreter

What if I am considering or awaiting risk-reducing surgery?

It is recommended that women considering or awaiting risk-reducing surgery attend for surveillance screening until surgery has been performed.

When will I get my results?

You should receive your results by letter within two weeks.

A small number of women will be asked to attend an assessment clinic for further tests because of an abnormality on their mammogram and/or MRI. Most of these abnormalities are caused by harmless changes within the breast and do not mean that you have breast cancer.

If you attend a Family History Clinic the specialist clinician you attend will be informed about your screening results. If you do require further treatment you can choose to be referred to your local specialist Breast Surgery Unit.

What happens when I reach the normal screening age?

For the general population, women get their first routine screening invitation between their 49th and 53rd birthdays and are invited for screening every three years up to the age of 70.

Most women at very high risk continue to require annual surveillance screening after the age of 50. If you were previously screened using MRI before the age of 50, you may change to being screened using only mammography. This is because mammography is better at detecting breast cancers in the over 50s. Some women will have MRI as well as mammography. This will be decided by the radiologist.

When will I stop receiving screening invitations?

Currently, most women with a very high risk of breast cancer are invited for screening on an annual basis up to their 71st birthday. Once you no longer receive invitations, you can still request an annual screening appointment by contacting the Very High Risk Breast Screening Unit.

What if I notice any changes in my breasts?

No screening method can detect every cancer; and cancer can develop in between screening appointments. If you notice any unusual changes in your breasts, please speak to your GP as soon as possible. Do not wait for your next screening appointment, even if it is soon.

Check for change



Turned in nipples



Skin changes like dimpling



Lumps



Crusted nipples

Be Breast Aware

- You should know what is normal for you
- Know what changes to look for
- Look at and feel your breasts (in any way that is best for you)
- Tell your GP about any changes as soon as possible
- Go for breast screening when invited (if you decide you want to be screened)

You can read or download our leaflet *Breast awareness: looking out for changes* at:

pha.site/looking-for-changes



What happens to my mammograms after screening?

The Northern Ireland Very High Risk Breast Surveillance Screening Programme will keep your mammograms and MRIs for at least 8 years. These are saved securely. The programme regularly checks records to make sure the service is as good as possible. Staff in other parts of the health service may need to see your records for this, but your records will only be shared with people who need to see them.

We will review your previous screening results if you are diagnosed with breast cancer between screening appointments. You can see the results of this review if you wish.

More information

Very High Risk Breast Screening Unit, Antrim Hospital:
VeryHighRiskBreastScreening@northerntrust.hscni.net
028 9442 4426

Genetic Medicine, A Floor, Belfast City Hospital:
bso.nigeneticcounsellors@nhs.net

The Northern Ireland Very High Risk Breast Surveillance Screening Programme:
www.nidirect.gov.uk/breast-screening

BRCA LINK NI:
www.brcani.co.uk, info@brcani.co.uk

For more information on breast cancer genetics, including a support telephone line, please visit:
www.breastcancergenetics.co.uk

Be Cancer Aware website:
www.becancerawareni.info/resources/links



Public Health Agency

12–22 Linenhall Street, Belfast BT2 8BS.

Tel: 0300 555 0114 (local rate).

www.publichealth.hscni.net

www.nidirect.gov.uk/breast-screening

www.becancerawareni.info/breast-cancer



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