



BreastCheck

Breast Screening for Women who have a Disability



An tSeirbhís Náisiúnta Scagthástála
National Screening Service


BreastCheck
An Clár Náisiúnta Scagthástála Cioch
The National Breast Screening Programme

Breast Screening for women who have physical or intellectual disabilities, or both

This document is intended for use by:

- carers and other staff at care homes
- GPs and medical guardians of women who have physical or intellectual disabilities, or both
- families of women who have disabilities
- others who have an interest in breast screening and disabilities.

Staff supporting women who have extra requirements need to consider the needs of their clients on a case-by-case basis. They should have in place a collaborative process (involving their clients, family, carers, nurses and doctors) to decide whether the client would benefit from breast screening, and if she is able to participate in the mammogram process. This document is intended to support this collaborative process.

What is breast screening?

Breast screening involves taking mammograms (x-rays) of a woman's breasts, which are used to help find breast cancer when it is too small to see or feel.

When breast cancer is found early, it is easier to treat and there is a better chance of recovery. Breast screening is for women who do not have symptoms of breast cancer.

What is breast cancer?

Breast cancer occurs when normal breast cells begin to grow in an abnormal way.

- Breast cancer is the second most common cancer for women in Ireland, with around 3,215 cases identified each year.
- Women of any age can get breast cancer but the risk increases as a woman gets older.
- Research shows that women aged 50 and over are at a higher risk of getting breast cancer.
- If breast cancer is found early, it is usually easier to treat.

What is BreastCheck?

BreastCheck – The National Breast Screening Programme is part of the National Screening Service. It is a health service funded by the Government. This means there is no charge for this service.

The programme offers all women between the ages of 50 and 68 a breast cancer test (a mammogram) every two years.

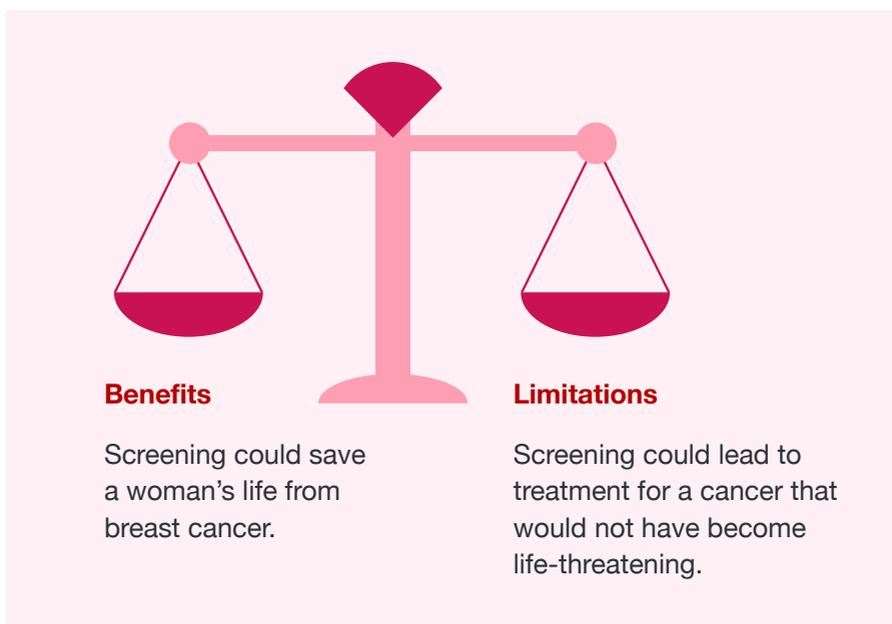
BreastCheck is expanding and by the end of 2021 will be available to women aged 50-69. Women in this age range benefit most from a breast screening programme.

Women, regardless of age, should contact their GP if they or their carer have concerns about their breast health.

Benefits and limitations of breast screening

It is the woman's choice whether or not to have a BreastCheck screening. She has the right to accept or decline the invitation from BreastCheck. She may also accept an invitation, but later change her mind.

All screening aims to find a balance between potential benefits and potential limitations. The woman, or her carer, must decide which is the most suitable decision for her.



Benefits of breast screening (mammography)

A mammogram is able to identify small changes with the breast tissue and can identify early signs of breast cancer. Finding cancer early is important for women who will develop breast cancer. Breast screening and better treatments are helping to lower the rate of deaths from breast cancer.

Breast screening:

- saves lives
- can detect breast cancer early
- improves survival rates from breast cancer.

If breast cancer is found early through regular screening:

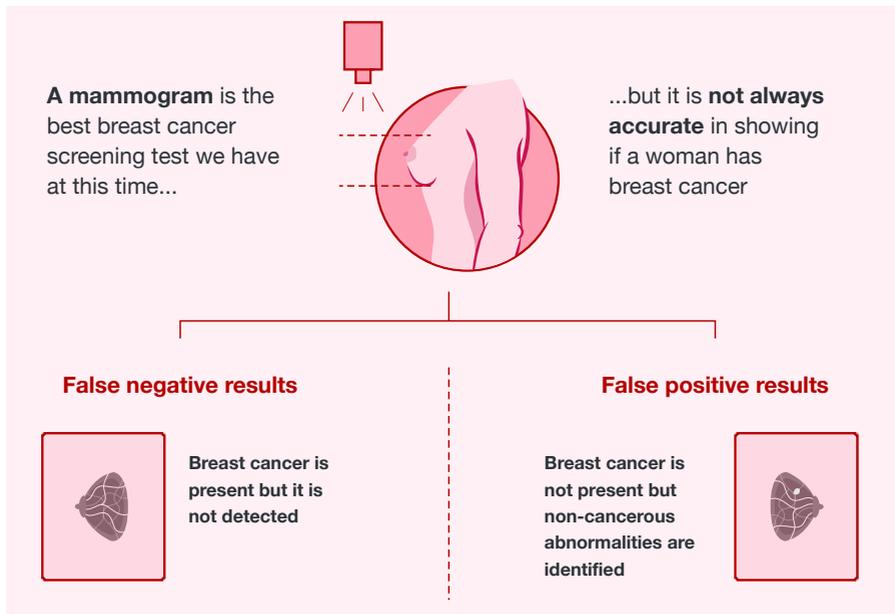
- it is easier to treat
- there may be more treatment options
- it is less likely to have spread to other parts of the body
- the woman's chances of surviving it are greater.

Limitations of breast screening

No screening tool is 100% effective. The limitations of breast screening should be made known to women. Breast screening does not prevent breast cancer. A normal result means that there is no cancer visible at that time.

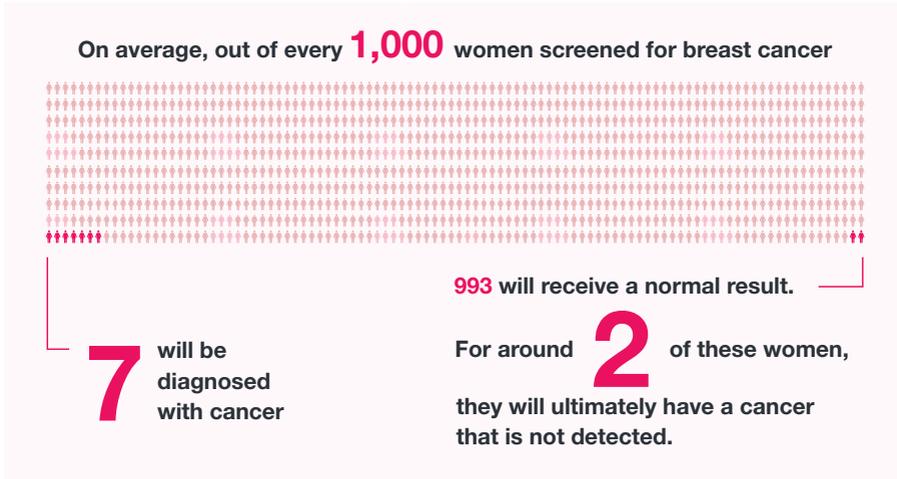
A radiologist cannot tell a woman with absolute confidence that they have detected all possible abnormalities. There will be cases when the examination will not identify an abnormality that could be cancerous. There will also be cases when abnormalities are identified that are harmless.

This happens in all screening programmes that meet international best practice standards, including BreastCheck. For this reason, we advise women to remain breast aware and consult their GP if they have any concerns.



Missed diagnosis – There is a small chance a woman will receive a negative (all clear) mammogram result when cancer is present. This is known as a false negative result, and can happen in any screening programme.

Around two out of every 1,000 women screened will receive a false negative result. Around three in every 100 women screened will receive a false positive result.



Overdiagnosis – Screening may lead to overdiagnosis. This is when issues are identified that are harmless, leading to unnecessary treatment and stress.

Sometimes breast cancers are visible but are at an early stage. It's not always possible to tell which cancers will become life-threatening.

All screening programmes are assessed against international criteria and must be judged on balance to provide more benefit than harms to the populations they screen.

For more on the benefits and limitations of breast screening, see www.breastcheck.ie or Freephone 1800 45 45 55.

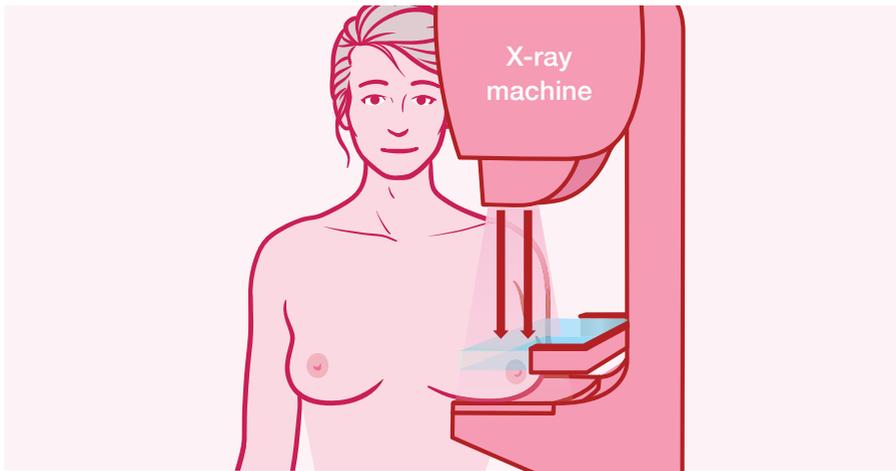
What happens during the mammogram?

When a woman has a mammogram, a special x-ray machine is used to produce an image of her breasts. One at a time, her breasts are compressed between two flat plastic plates to take the x-ray. There has to be pressure to make sure that the mammogram is of a high quality. This pressure spreads out the breast tissue so that it can be seen more clearly. The dose of radiation used is very small and is within recommended limits, so the risk to the woman's health is very low.

Does a mammogram hurt?

A mammogram may hurt. The procedure takes a few minutes and during this time pressure is applied to each breast. Some women find this uncomfortable or painful, but there is no evidence that the pressure harms the breasts.

If the woman finds the procedure excessively painful, she should tell the radiographer immediately and they will stop.



Requirements for a mammogram

Four good quality images are required to complete a mammogram. This requires a complex set of skills and a good partnership between the radiographer and the woman. The woman is carefully positioned by the radiographer at the machine to ensure as much breast as possible is seen. The woman must be able to hold the position (usually 10-15 seconds) until each picture is taken.

There are certain requirements that need to be met for the mammogram to be completed. If the answer is 'no' to any of the following questions, please contact the screening unit.

General requirements for a mammogram

- Is the woman able to cope in unfamiliar situations and environments (with support if required)?
- Is the woman able to comprehend and cooperate with simple requests?
- Will the woman allow handling of the breast to facilitate positioning?
- Is the woman able to tolerate possible discomfort resulting from compression of her breasts?

Physical Requirements for a mammogram

- Is the woman able to hold up her head and lift her arms?
- Does she have the flexibility to hold her arms clear of her chest and the breast support table while the mammogram is taken?
- Has the woman sufficient muscle control to maintain the position required?
- Is the woman able to remain still for a few minutes?
- If the answer is 'No' then please contact the screening unit to discuss the woman's suitability for a mammogram.

Wheelchair Users

Mammograms can be taken while a woman sits in her wheelchair. However, women need enough upper body balance to allow the breast to be put on the plate. Also, some wheelchairs cannot get close to the machine, particularly if the footplates or armrests cannot be removed.

Some women in a wheelchair whose sides do not come off will have to transfer to a special screening chair for their mammogram. This chair has a weight limit of 128Kg (20 Stone and 2lbs).

Due to the limited space on the mobile units a motorised chair may not be suitable for a mobile unit but may be facilitated in a static unit building.

All mobile units do have lifts for a wheelchair to access the unit (weight limit of 300kg/47 stone). They also have a bell on the lifts to indicate to staff that assistance is required.

It is important to contact the unit before the appointment to discuss what help or information is needed.

Ultrasound instead of mammogram?

Ultrasound is not suitable as a screening test. Ultrasound is a useful test for investigating abnormalities which may be seen on the mammogram. It is often used as a follow-up test for telling the difference between benign cysts and malignant masses. If a mammogram is not achievable, a woman or her carer should discuss this with her GP.

Consent for breast screening

As per HSE consent policy, capacity to give informed consent is necessary for breast screening and depends on whether the woman is able to understand and retain information to make an informed choice.

For the consent to be valid, the woman must:

- have received sufficient information in a comprehensible manner about the nature, purpose, benefits and risks of the test
- not be acting under duress
- be acting voluntarily
- have the capacity to make the particular decision.

If a woman cannot provide her own consent, prior to her appointment a collaborative decision should be made in good faith on whether she will participate in breast screening.

If a woman who lacks capacity to consent attends for her mammogram, no other person who attends with her – such as family member, friend or carer – can give or refuse consent on her behalf, unless they have formal legal authority to do so. The decision to screen may be made in good faith by the BreastCheck radiographer.

It is important to be aware that a woman may withhold her consent. Examples of how she might indicate this include:

- refusal to attend the appointment
- refusal to enter the unit
- refusal to undress
- becoming unduly distressed or agitated either before or during the examination
- shying away from staff or equipment.

Even if consent is obtained for a mammogram, it is important to recognise that consent can be withdrawn either verbally or behaviourally at any point during the examination.

The radiographer will check throughout the process for signs that the woman has withdrawn consent. This means considering if the woman:

- cooperates with the radiographer
- responds to simple requests
- becomes agitated or upset
- becomes unduly anxious
- pulls away from/out from equipment.

Communication between the radiographer, carer and woman should be ongoing throughout the examination

Prior to the appointment:

- Ensure clear guidelines for obtaining consent are considered.
- Carers/staff (or screening lead) should liaise with screening units prior to attending. The staff will allow extra time to facilitate getting into and out of the unit, assistance with undressing, and other elements of the visit.
- Use appropriate information materials. BreastCheck's *A Guide to Breast Screening* developed for women with intellectual disabilities may help to support women to participate in breast screening. It is available to download from the BreastCheck website (www.breastcheck.ie).
- Another useful document is our *Important information about your breast screening* booklet, and is also available from the BreastCheck website (www.breastcheck.ie).

- Ensure women are made aware of the benefits and limitations of breast screening.
- Provide accurate and accessible information about the mammogram, the breast screening appointment, and follow-up.
- The woman may need a visit to the screening unit before the test.
- Answer all questions honestly to avoid the unexpected.
- Allow sufficient time to explain the process to the woman prior to appointment.
- Respect the woman's privacy and dignity.
- Check with the screening unit if breast screening is physically possible for the woman concerned.
- Encourage breast awareness and encourage the woman to tell someone if she notices changes.

At the screening appointment

A woman can choose to have a family member, friend or carer present at her appointment. Because the mammogram uses ionising radiation, carers are not permitted to hold the woman in position during the test.

- It is important that the staff member who accompanies the woman is familiar to the woman, and is themselves familiar with the screening process.
- Allow for extra time in case the appointment takes longer than expected.
- Our radiographers aim to make the appointment as positive as possible but there may be situations where a complete mammogram is not achievable on the day, and the woman may become distressed.

Be breast aware

It is important that women of any age are always breast aware. A woman should, where possible, know what is normal for her body. She and her carer should be aware of what changes may require examination by her GP:

- any lumps or unusual thickening in her breast
- dimpling, puckering or redness of the skin
- a nipple that appears to be pulled-in or flattened
- a rash, or flaky or crusted skin around the nipple
- a change in the size or shape of her breast
- swelling in her armpit or around her collarbone.

Important: There are many reasons for changes in a woman's breast. Most changes are harmless, but any changes should be checked by a GP, even if the woman has had a recent mammogram.

BreastCheck Commitment to Accessibility

BreastCheck has outlined its commitment to accessibility detailing what it provides for women with disabilities. This is shown on our website www.breastcheck.ie or can be requested on 1850 45 45 55.

A health promotion team is available nationwide to provide support or training to organisations on breast screening. Pictorial and other materials are also available on request. The access officer in BreastCheck can be contacted on access@breastcheck.ie for more details or support.

BreastCheck Register

BreastCheck puts together a register (list) of women eligible for screening from details supplied by the Department of Employment Affairs and Social Protection, the medical card scheme, long-term illness schemes, and private health insurers. Eligible women also register themselves.

BreastCheck women's details and health records are kept safe and confidential. If a woman does not want to take part in BreastCheck, she or her carer should write to us, and we will not contact her again.

Some women may not be on the register, or we may have incorrect details for them. All details can be checked and updated online at www.breastcheck.ie, or on the Freephone number 1800 45 45 55.

How we use personal information

BreastCheck takes and stores the woman's personal information (name, address, phone number, date of birth, PPSN) and breast screening history. We will use this information to contact the woman when her next screening appointment is due, or to send her results.

We also exchange her information with those who deliver the programme, her GP, and the National Cancer Registry of Ireland. This is to make sure we have an accurate history of the woman.

It is the policy of BreastCheck that personal data is processed lawfully, fairly and in a transparent manner and is stored, in agreement, with the General Data Protection Regulation (GDPR), the Data Protection Acts 1988 to 2018, and in accordance with the HSE Data Protection Policy

Please let BreastCheck know if the woman's contact details change.



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