

# BreastCheck

Important information to support women to access BreastCheck





#### Introduction

This document is intended to support the decision-making process for women who need extra support to avail of breast screening. It provides the information a woman needs to know to make an informed decision to participate in breast screening.

# What is breast screening?

Breast screening involves taking a mammogram (x-ray) of a woman's breasts, which is 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.

#### What is breast cancer?

Breast cancer is one of the most common cancers among women in Ireland.

- Women of any age can get breast cancer but the risk increases as you get 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 likely to be 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 69 a breast cancer test (a mammogram) every two years.

Women in this age range benefit most from a breast screening programme. Women, regardless of age, should contact their GP if they have concerns about their breast health.

### What is a 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 mammography examination uses a very low dose of radiation and the benefit significantly outweighs the risk. In fact, the actual radiation dose is equivalent to approximately two months exposure to naturally occurring background radiation in Ireland.

### 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. 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.

# **Helpful hints**

Wear a top with a skirt/trousers as it makes it easier to undress. Try to avoid using talcum powder or deodorant as this can show up on the mammogram.

# Where does the woman go for their BreastCheck appointment?

It depends on where they live. Their appointment could be in a BreastCheck unit beside a hospital or in a mobile screening unit.



# About a woman's BreastCheck appointment

- Please let us know in advance using the contact number on their appointment letter.
- A woman may need a longer appointment should she have additional support needs. If so, please let us know in advance using the contact number on their appointment letter.

# Requirements for a mammogram

Four good quality images are required to complete a mammogram. This requires 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.



### General requirements for a mammogram

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

# Physical Requirements for a mammogram

- Be able to hold up head and lift arms
- Have the flexibility to hold arms clear of the chest and the breast support table while the mammogram is taken
- Have sufficient muscle control to maintain the position required
- Be able to remain still for approximately 15 seconds at a time

Please contact the screening unit to discuss these requirements further.

#### 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 breast support table. 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 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.

If a women invited for BreastCheck is a wheelchair user it is important to contact the unit before the appointment to discuss her requirements.

### 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 should discuss this with her GP.

### What happens after the mammogram?

We aim to post a woman's result of their mammogram within three weeks. We will let a woman know if a follow-up visit is advisable. We will also send a copy of a woman's result to their GP (family doctor).

Around one in every 25 women (4%) will be called back for more tests (assessment) after screening. Women who are recalled are often very anxious, so BreastCheck tries to keep the recall rates as low as possible.

### Benefits of breast screening

#### **Breast screening:**

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

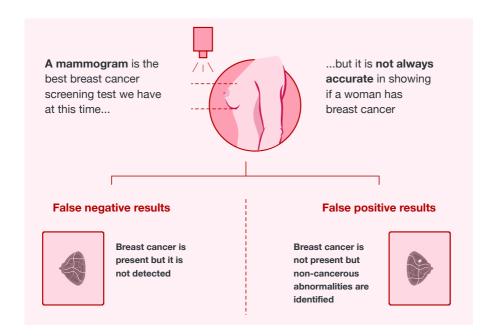
If breast cancer is found early through regular screening:

- it is easier to treat
- there may be more treatment options
- the woman's chances of surviving it are greater.

### Limitations of breast screening

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 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.

For more on the benefits and limitations of breast screening, see <a href="https://www.breastcheck.ie">www.breastcheck.ie</a> or Freephone 1800 45 45 55.



# What is non-invasive cancer (DCIS)?

Non-invasive cancer is known as 'ductal carcinoma in situ', or DCIS for short. DCIS is an early form of breast cancer. It can also be described as pre-cancerous, pre-invasive or intraductal.

When a woman has DCIS, some of the milk ducts (channels in a woman's breast that carry milk to the nipple) are cancerous. This means the cancer cells are inside the milk ducts ('in situ') and have not spread within or outside the woman's breast.

To confirm a diagnosis of DCIS, a woman would need to have a biopsy, where a piece of breast tissue is taken from the woman's breast for examination.

# Are there different types of DCIS?

Yes, they can be divided into high-, intermediate- and low-grade DCIS. This grading is based on what the cells look like under the microscope.

If DCIS is not treated, the cells may spread from the ducts into the surrounding breast tissue and become an invasive cancer (one that can spread to other parts of the body). Low-grade DCIS is less likely to become an invasive cancer than high-grade DCIS.

Not every woman with DCIS will develop invasive cancer, even if it is not treated. But it is impossible to tell which DCIS will develop into invasive cancer and which will not. As a result, some women will get treatment for a DCIS that would never have become an invasive cancer.

### Consent for breast screening

As per HSE consent policy those who provide health and social care services must work on the presumption that every person has the capacity to make decisions about their care, and to decide whether to agree to, or refuse, an examination, investigation or treatment.

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.

Best practice favour "supported decision-making" where possible. This requires that efforts must be made to support individuals in making decisions for themselves where this is possible. It is important to give those who may have difficulty making decisions the time and support they need to maximise their ability to make decisions for themselves.

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, and the woman will be ongoing throughout the examination.

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.

### Women who lack capacity to consent

There is currently no legislative framework to govern how a decision about treatment and care should be made for those who lack capacity to make that decision themselves. However, best practice suggest that in making decisions for those who lack capacity, the health and social care professional should determine what is in their best interests, which is decided by reference to their will and preferences if known.

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. This is aligned to the HSE consent policy.

#### **Resources Available**

BreastCheck have developed a collection of materials and videos to assist women with intellectual disabilities to make an informed decision to participate in BreastCheck.

These resources were developed with experts by experience – women with intellectual disabilities, and their support staff. These resources are available on www.breastcheck.ie

The BreastCheck access officer co-ordinates assistance for women with disabilities helping them to access the BreastCheck service.

Please contact <u>access@breastcheck.ie</u> if you have a query or require assistance.

# Prior to the appointment a woman can be supported by:

- Carers/staff (or screening lead) contacting 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 on www.breastcheck.ie
- Ensuring women are made aware of the benefits and limitations of breast screening.
- Providing accurate and accessible information about the mammogram, the breast screening appointment, and follow-up.
- Bringing the woman for a visit to the screening unit before the test if required.
- Answering all questions honestly to avoid the unexpected.
- Allowing sufficient time to explain the process to the woman prior to appointment.
- Respecting the woman's privacy and dignity.
- Encouraging breast awareness and encourage the woman to tell someone if she notices changes.

# At the screening appointment if the woman needs extra support

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 person 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. A new appointment for a different day can be made if this is decided.

# Does screening prevent breast cancer?

Screening does not prevent breast cancer. However, it helps to find breast cancer at an early stage.

A small number of cancers cannot be found by a mammogram, but if you go for regular screenings, any changes can be found as early as possible. At this stage, breast cancer is easier to treat and you have a higher chance of a good recovery.

Screening is for women who do not have symptoms of cancer. Speak with your GP (family doctor) as soon as possible if you have any concerns or symptoms.

#### Be breast aware

No matter what age you are, it is important to always be breast aware.

- Know what is normal for your body.
- Know what changes you should look for.

# What changes should I look and feel for?

- 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.

# Communicating with women

We will communicate with women in an open, honest, timely and transparent manner if:

- · something goes wrong with their care
- the women experiences harm as a result of your care
- we think that harm may have occurred.

This means that we will keep women fully informed of the facts and details about their involvement in the Breast Screening Programme.

### **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 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 <a href="https://www.breastcheck.ie">www.breastcheck.ie</a>, 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.

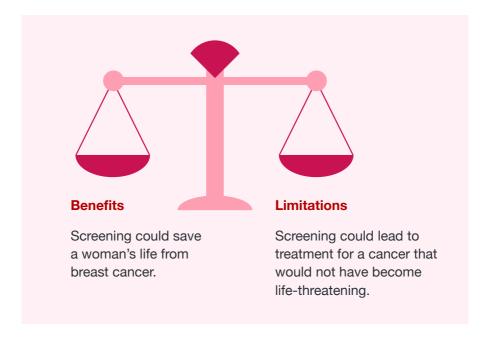
It is the policy of BreastCheck that personal data is processed lawfully, fairly and in a transparent manner and is stored, in agreement, with the General Data Protection Regulation (GDPR), the Data Protection Acts 1988 to 2018, and in accordance with the HSE Data Protection Policy

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

### Benefits and limitations of breast screening

It is the woman's choice whether or not to participate in BreastCheck. 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 must decide where that balance falls for her.



#### More information

For more information, to register or to check if you are on the register, visit <a href="https://www.breastcheck.ie">www.breastcheck.ie</a> or Freephone 1800 45 45 55.

#### **Central Office**

King's Inns House, 200 Parnell Street, Dublin 1

Tel: 01 865 9300

Freephone: 1800 45 45 55 Email: info@breastcheck.ie

#### **Eccles Unit**

36 Eccles Street, Dublin 7

Tel: 01 882 6200

Email: eccles@breastcheck.ie

#### **Merrion Unit**

Merrion Road, Dublin 4

Tel: 01 223 5800

Email: merrion@breastcheck.ie

#### **Southern Unit**

Infirmary Road, Cork

Tel: 021 464 9700

Email: southern@breastcheck.ie

#### **Western Unit**

Newcastle Road, Galway

Tel: 091 580 600

Email: western@breastcheck.ie

#### **More information**

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