

MAMMOGRAPHY SCREENING

A Decision Aid

Programme for the early
detection of breast cancer
for women aged 50 to 75



MAMMOGRAPHIE
SCREENING
PROGRAMM



Gemeinsamer
Bundesausschuss

You have an opportunity to take part in mammography screening for the early detection of breast cancer. This is free of charge. It's your decision whether you wish to take up the offer or not.

This brochure is designed to help you to weigh up the advantages and disadvantages and then make a decision which is good for you.

There are four main points:

- Information on what happens in the screening and on breast cancer itself
 - Possible results of early detection in mammography
 - Advantages and disadvantages of taking part
 - Helping you to come to a decision
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WHY AM I BEING OFFERED A MAMMOGRAPHY?

If you are aged between 50 and 75, you are entitled to take part every two years in a mammography examination for the early detection of breast cancer. The aim is to detect any breast cancer as early as possible in order to improve the possibilities for treating it and thus increase the chances of curing it. However, the early detection examination does also have some disadvantages: it can, for example, result in treatment which is unnecessary. The costs of the screening are borne by the medical insurance funds. If you have private medical insurance, please clarify with your insurance fund in advance whether it will bear the costs.

The examination is also called mammography screening. "Screening" means for example that all people in any one age group are offered a certain examination. Mammography involves an X-ray of the breasts. In order to ensure a high level of quality in the examination, it is only carried out in special centres which belong to the German mammography screening programme. It is important to note that having a mammography cannot prevent breast cancer.

You have the right to talk things over in person with a physician from the mammography screening programme. If you wish to do so, you will have to make an appointment yourself, through the Invitation Centre, before the examination takes place. Contact details are included in the invitation you receive for the examination. As a rule, there are no physicians present at the mammography session itself.

WHAT HAPPENS IF I DON'T TAKE PART?

If you do not wish to have an examination, you will again receive an invitation to do so two years later – unless you do not wish to be invited again in the future. This will have no consequences for your medical insurance. If you should be diagnosed with cancer at some point in the future, your medical insurance will of course bear any costs for treatment.

WHEN IS IT POSSIBLE FOR A MAMMOGRAPHY TO BE CARRIED OUT?

An appointment for an examination is not possible until 22 months, at the earliest, after the last early detection mammography. Nor is a mammography possible if one has already been carried out within the last 12 months for reasons other than for early detection.

WHAT HAPPENS IN THE MAMMOGRAPHY?

Examinations are carried out in rooms set aside for them in a doctor's surgery or in a clinic in your region, sometimes also in specially equipped vehicles. These locations are called "screening units".

The examination is supervised by a radiology specialist, who takes two X-rays of each breast from different angles. For this purpose, the breast is pressed between two plates. This can be uncomfortable, or even painful, but it does not harm the breast. The flatter the breast is pressed, the less radiation is needed for the X-ray, and the image made also provides more information.

The mammography images are carefully assessed in the days afterwards. Independently from each other, two specialist physicians study the images to look for any changes.

Any suspicious findings are assessed by another specialist.

A letter containing the result is usually sent out within seven working days of the examination. Most women are notified that there were no adverse findings.

It is important to note that even if the findings turn out to be suspicious, that does not by any means suggest that breast cancer has been detected.

WHAT HAPPENS IF THERE ARE SUSPICIOUS FINDINGS?

Just by looking at the X-rays, even specialists cannot always decide with any certainty whether what has been detected is benign or malignant. This means that the findings need to be examined some more.

For this purpose, the physician responsible invites the woman concerned to come back again. In the next session, the breast is examined using ultrasound, or it is X-rayed again. Any suspicion of cancer can often be ruled out in this way.

If this is not possible, it is recommended that a tissue sample (biopsy) is taken from the breast. This is carried out using a cannula and under a local anaesthetic. The tissue is studied under the microscope, and the findings are then discussed by a team of specialist physicians. As a rule, the patient is notified of the result within a week. In around half of the cases, it turns out that there is no breast cancer.

WHAT DOES IT MEAN IF BREAST CANCER IS DETECTED?

When breast cancer is diagnosed, this is first of all a shock. However, the chances of the cancer being cured can be very good, and they depend above all on how far the cancer has progressed.

Most women are advised to have an operation. In such an operation, as a rule, the tumour and the surrounding tissue are removed: it is rarer for the entire breast to be removed. Further options for treatment are radiation, hormone therapy and chemotherapy. Which option is chosen also depends on the exact diagnosis.

WHAT IS BREAST CANCER?

Breast cancer can arise when cells undergo a pathological change and begin to divide in an uncontrolled way. Cancer cells can invade healthy tissue and form so-called metastases.

Breast cancer is more diverse than almost any other type of cancer. Often it can be cured. It can develop slowly and not form any metastases. But it can also grow rapidly and spread throughout the body.

HOW FREQUENTLY DOES BREAST CANCER OCCUR?

The frequency of breast cancer depends above all on women's ages. Overall, around 35 women out of 1,000 die from breast cancer. The following table makes the risk clear: it shows how many women, out of every 1,000 at the respective age indicated, will get breast cancer in the next 10 years and how many will die from it.

Age	How many women will get breast cancer in the next 10 years?	How many women will die from breast cancer in the next 10 years?
50 years	25 out of every 1,000	4 out of every 1,000
60 years	36 out of every 1,000	7 out of every 1,000
70 years	34 out of every 1,000	10 out of every 1,000

The risk of getting breast cancer also depends on other factors. With some women, there is a predisposition in the family. If a woman's mother or sister has, or had, breast cancer, then her own risk is twice as high. If a distant relative has it, then her own risk is hardly any higher. A high breast density may also play a role. Other risk factors such as childlessness or diet have only a slight importance.

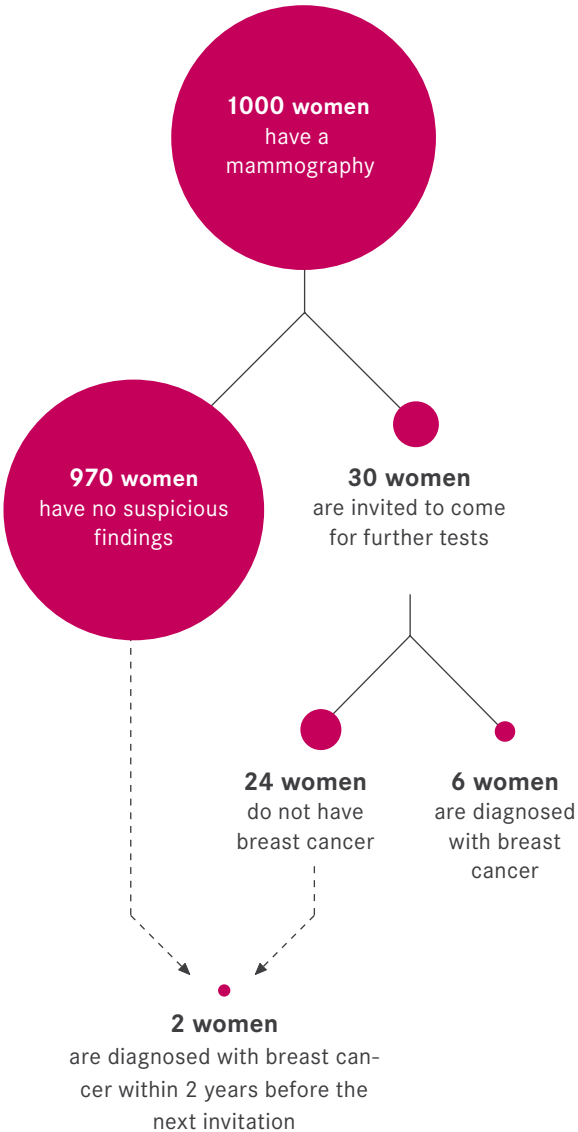
THE EXAMINATION IN FIGURES: WHAT RESULTS CAN BE EXPECTED?

Imagine 1,000 women who will be taking part in the mammography screening programme next week. The following results can be expected from the examinations:

- Around **970 of the 1,000 women** are notified that the results showed nothing. This is a great relief for many women.
- Around **30 of the 1,000 women** are notified that the **findings are suspicious**; they are offered an appointment for further tests.
- Of these 30 women with suspicious findings, further tests show that **24 of them do not have breast cancer**. Being told that a mammography has produced suspicious findings is often a cause for fear. The time which elapses until the conclusive result is known is very stressful for most women. Even if the suspicion is not confirmed, the experience can still continue to leave its mark.
- For **6 out of the 30 women**, the suspicious findings are confirmed, and they are told that **breast cancer has been diagnosed**. The physician from the mammography screening unit then gives these women an appointment to discuss the next steps to be taken. The woman can also, of course, contact her own gynaecologist.

After the examination: breast cancer will be diagnosed in around **2 of the 1,000 women** within the 2 years until the next invitation. In most cases, it is cancer which has only developed after the last examination. Also, and in spite of every care taken, tumours can be overlooked in the mammography. But this happens only very rarely.

AT A GLANCE: WHAT HAPPENS WHEN 1,000 WOMEN ARE EXAMINED?



WHAT FORMS OF BREAST CANCER ARE DETECTED?

In around **5 out of every 6 women** diagnosed with breast cancer, an invasive tumour is detected. If it is not treated, such a form of cancer often spreads throughout the body.

In around **1 out of every 6 women** diagnosed with breast cancer, the mammography shows up a change in the breast which is called **Ductal carcinoma in situ (DCIS)**. In the case of this diagnosis, cells in the breast's milk ducts have changed. These cells are only situated inside the milk ducts and have not spread to other tissue. In some women, the DCIS remains harmless; in others, it develops into an invasive tumour. As it cannot be predicted for any woman whether the DCIS will remain harmless, treatment is advised as a rule.

WHAT ARE OVERDIAGNOSES?

In some women, breast cancer is diagnosed which would never have been noticed without an early detection examination. One reason for this is that there are small tumours which grow only slowly – or not at all. For some women there are other causes of death which come before any tumour can make itself felt. The diagnoses of such tumours are called overdiagnoses because they would not have caused any problems as long as the woman was alive. Whether a tumour, once detected, will continue to grow is something which physicians cannot predict with any certainty and, as a rule, they therefore advise treatment.

Overdiagnoses therefore lead to unnecessary operations or radiation treatment. Overdiagnoses are something different from suspicious findings in an X-ray image which, in the course of further tests, turn out ultimately to be harmless (see page 8). Overdiagnoses can happen in all early detection examinations.

TAKING PART REGULARLY: WHAT ADVANTAGES AND DISADVANTAGES CAN I EXPECT?

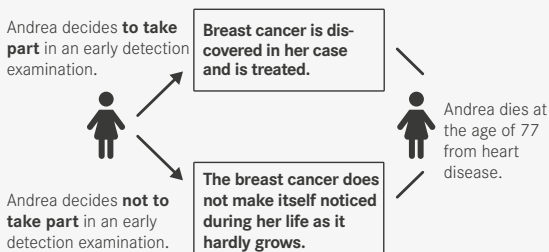
Several studies have examined what women can expect in the long term if they take part regularly in mammography screenings. These studies enable important advantages and disadvantages to be gauged.

One important advantage is that there are better chances of being cured. A mammography can discover breast cancer at an early stage, and, as a result, there is a lower risk of dying from breast cancer.

One important disadvantage is the risk of overdiagnoses. A mammography can result in breast cancer being diagnosed which would never have happened without an examination. Such diagnoses result in unnecessary treatment.

OVERDIAGNOSES: AN EXAMPLE

Let's take the example of a woman we're calling Andrea. She is 65 years old and has a small tumour in the breast growing very slowly. Without early detection she doesn't learn of it. She dies at the age of 77 - but not from breast cancer. An early detection examination would not have changed her life expectancy, but it would have led to unnecessary treatment.

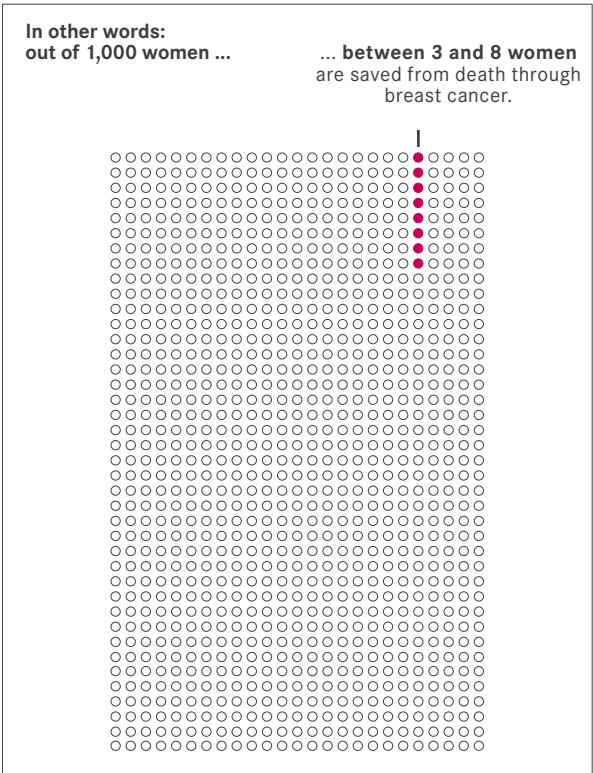


IN FIGURES: CHANCES OF BEING CURED

This page summarises the chances which women can expect, roughly, of being cured if they take part regularly in the mammography screening programme **for 25 years**.

THE MAMMOGRAPHY PROGRAMME: OF 1,000 WOMEN WHO...

	How many women die of breast cancer?
... Don't take part	24
... Take part	16 to 21

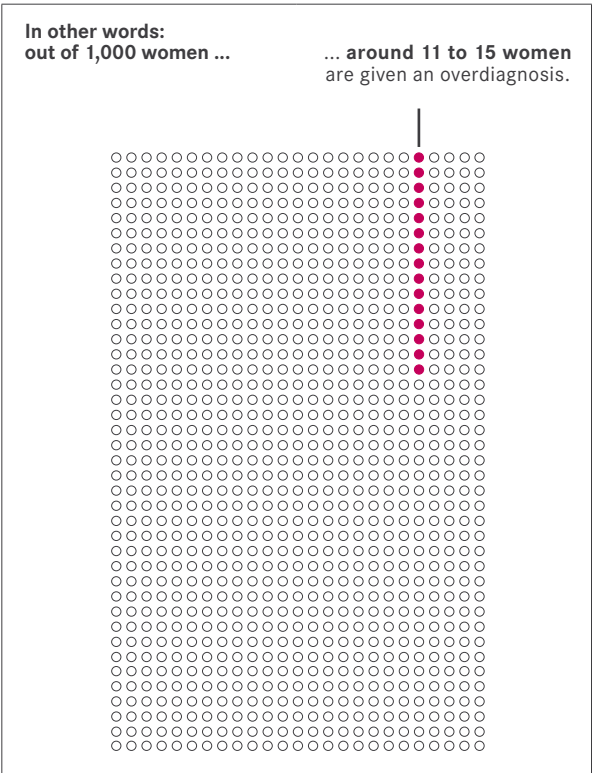


IN FIGURES: RISK OF OVERDIAGNOSES

This page summarises how many women are given an overdiagnosis if they take part regularly in the mammography screening programme for 25 years.

THE MAMMOGRAPHY PROGRAMME: OF 1,000 WOMEN WHO...

	How many women are given an overdiagnosis?
... Don't take part	59 to 63
... Take part	74



HOW HIGH IS THE RADIATION DOSE?

X-rays are used in mammography. The radiation dose is so low that it does not ordinarily have any consequences. Nevertheless, it cannot be ruled out that, over a period of 25 years, regular X-ray examinations might contribute to the occurrence of breast cancer – but in fewer than 1 in 1,000 women.

ARE THERE ALTERNATIVES TO THE MAMMOGRAPHY EARLY DETECTION PROGRAMME?

Some women are offered other means of the early detection of breast cancer, such as ultrasonic examinations of the breast or magnetic resonance imaging (MRI). It is not, however, clear whether these examinations reduce the risk of dying from breast cancer – which mammography, on the other hand, does. Such examinations can more frequently lead to overdiagnoses than mammography does and can result in suspicious findings which turn out to be harmless.

Mammography is only permitted to be used for early detection purposes as part of the German programme, for which there are strict regulations for quality assurance. Outside this programme, mammographies are used to examine changes in the breast discovered in other ways. These mammographies are not subject to the same quality standards. For example, the X-ray images do not have to be assessed by two specialist physicians.

THE LIMITS OF EARLY DETECTION

Taking part regularly in mammography screening cannot prevent breast cancer from occurring. The aim of the mammography, however, is to detect it earlier.

Mammography cannot discover all tumours. Some develop a few months after an examination has been carried out. It is therefore important to contact a physician directly if any changes are noticed in the breast in the time before the next mammography, for example

- palpable lumps, dimpling or hardening of the skin,
- any visible changes of shape or of the skin, or any pulling inwards of the nipple,
- bleeding or other discharges from the nipple.

WHAT HAPPENS WITH MY PERSONAL DATA?

Handling personal data is subject to the stipulations contained in the German data protection legislation. All data from the mammography screening programme is treated just as confidentially as in a normal doctor's surgery. The physicians and all members of staff are bound by confidentiality regulations.

The results of examinations are regularly assessed centrally. This is important for supervising the quality of the programme. Personal data such as names or addresses are not needed for these assessments and are not passed on. The assessments cannot therefore be traced to individual women.

The Invitation Centre is responsible for handling personal data. Contact details are included in the invitation you receive for the examination.

WOULD I LIKE TO TAKE PART IN THE MAMMOGRAPHY SCREENING PROGRAMME? HELPING YOU TO COME TO A DECISION

All women assess the advantages and disadvantages of mammography for themselves differently. Some would like to use the possibility of early detection because for them the advantages are greater. Others decide against it because for them the disadvantages outweigh.

The following table again summarises the most important facts relating to the mammography screening programme. If you wish, you can use it to weigh up the pros and cons of taking part – or perhaps see what is not so important for you. You can discuss the table with a doctor.

IF I TAKE PART IN THE NEXT EXAMINATION: WHAT CAN I EXPECT?

	For me, this argues <u>for</u> taking part	For me, this argues <u>against</u> taking part	I'm unsure	Irrelevant to my decision
Relief at the absence of any suspicious findings: of 1,000 women who go to a mammography, 970 are told that nothing suspicious was found.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stress as a result of suspicious findings: of 1,000 women who go to a mammography, about 24 are notified of suspicious findings – which then turn out to be harmless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain: the mammography examination can be uncomfortable and can hurt.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

IF I TAKE PART REGULARLY FOR 25 YEARS: WHAT CAN I EXPECT?

Chances of being cured: Of 1,000 women who take part regularly in a mammography for 25 years, between 3 and 8 people are saved from death through breast cancer.

Risk of overdiagnoses: Of 1,000 women who take part regularly in a mammography for 25 years, between 11 and 15 are given an overdiagnosis and unnecessary treatment.

Radiation dose: The X-ray dose in a mammography is low. Nevertheless, it cannot be ruled out that, over a period of 25 years, regular X-ray examinations might contribute to the occurrence of breast cancer – but in fewer than 1 in 1,000 women.

WHAT ELSE IS IMPORTANT FOR ME? WHAT IS OF PRIME IMPORTANCE FOR MY DECISION?

WHICH WAY AM I LEANING?

I'll take part **every two years.**

I'll take **part this time.**
In 2 years I'll decide again.

I'm still **unsure.**

I won't take part this time.
In 2 years I'll decide again.

I'm not taking part at all.

HELP FOR WHEN YOU TALK TO A DOCTOR

Do you have any more questions?

You have the right to talk things over in person with a physician from the mammography screening programme before any examination. If you wish to do so, please contact your Invitation Centre. Contact details are included in the invitation you receive for the examination.

Write down any questions and any thoughts you have and take this brochure with you. You can discuss with the physician anything to do with the early detection procedure and anything that you may be worried about.

You can also discuss any questions you have with your gynaecologist or your GP.

You can write down your questions here:

SOURCES

Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (Institute of Quality and Efficiency in Health Care) (IQWiG). Einladungsschreiben und Entscheidungshilfe zum Mammographie-Screening: Abschlussbericht; Auftrag P14-03. 16.09.2016.

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Gemeinsamer Bundesausschuss

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This decision aid is an annex to the Guidelines for the Early Detection of Cancer issued by the Federal Joint Committee (G-BA).

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Federal Joint Committee

The G-BA is a joint self-governing body for physicians, dentists, psychotherapists, hospitals and medical insurance funds in Germany. Since 2004 patients' representatives have also been involved in it.

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