

MAMMOGRAPHY SCREENING

A Decision Aid

Programme for the early detection
of breast cancer for women aged
between 50 and 69



Gemeinsamer
Bundesausschuss

You have the opportunity to take part in a mammography screening for the early detection of breast cancer. The screening is free of charge. You can decide for yourself whether you would like to take up the offer or not.

The aim of this brochure is to help you decide. It will assist you in weighing up the advantages and disadvantages and in coming to a decision that is right for you.

The brochure has four main sections:

- Information on what the screening involves, and on breast cancer
- Possible results of the early-detection screening
- Advantages and disadvantages of taking part
- Help for you to decide

WHY AM I BEING OFFERED MAMMOGRAPHY?

If you are aged between 50 and 69, you are entitled to have a mammography screening every two years in order to enable any breast cancer to be detected at an early stage. The aim is to detect any cancer as early as possible so that it can be treated better, thus increasing the chances of curing it. However, early-detection mammography does have some disadvantages – for example, it can result in unnecessary treatment.

The costs are borne by the statutory health insurance funds. If you have private medical insurance, please clarify the issue of costs with your medical insurance provider in advance.

The examination is also known as mammography screening. ‘Screening’ means that everyone in, for example, a certain age group is offered a certain type of examination.

In mammography, the breast is X-rayed. In order to ensure that the test is of a high quality, it is only carried out at special facilities which are part of the German mammography screening programme.

One important thing you should know is that mammography cannot prevent breast cancer developing.

You have the right to speak to a doctor working in the mammography programme in order to get more detailed information. In this case, please arrange an appointment through the Invitation Centre before the examination is due to take place. Contact details can be found in the written invitation sent out to you. As a rule, there is no doctor present during the mammography itself.



Photo: PantherMedia/Monkeybusiness Images

WHAT HAPPENS IF I DON'T TAKE PART?

If you do not wish to have the examination now, you will receive another invitation to do so in two years' time – unless you say that you do not wish to receive any further invitations. There will be no consequences as far as your health insurance is concerned. If you should get breast cancer sometime in the future, your health insurance will of course pay for the costs of any treatment.

WHAT HAPPENS DURING MAMMOGRAPHY?

The examination will be offered and carried out in dedicated rooms at a doctor's surgery or a clinic in the region where you live – or sometimes also in specially equipped vehicles. All of these facilities are called “screening units”.

The examination is carried out by a radiographer. She will take two X-rays of each breast, from different angles, with the breast being compressed between two plates. This can be unpleasant or painful, but it does no damage to the breast. The more the breast is compressed, the less X-ray radiation is necessary, and the more detailed the information provided.

Over the next few days the mammography images are given a detailed analysis, with two doctors, working independently, closely examining the images to look for any changes.

Any abnormal findings are assessed by another specialist.

A letter containing the results will generally be sent out within seven working days of the examination. The information which the majority of women receive is that there were no suspicious findings.

It is important that you should know that even if the results of the examination are in some way abnormal, this certainly need not mean that breast cancer was detected.

WHAT HAPPENS IF AN ABNORMALITY IS DETECTED?

Just looking at the X-ray images (mammograms), specialists cannot always say with certainty whether an abnormality is benign or malignant. In such cases the results need to be examined further.

Therefore, the doctor responsible will invite the woman concerned to come back again for another test in which the breast is examined using ultrasound or is again X-rayed. In many cases, any suspicion of cancer can then be ruled out.

If not, it is recommended that a tissue sample is taken from the breast (biopsy). This is done under a local anaesthetic, using a hollow needle, and the tissue is then examined under the microscope. Afterwards, the findings from the tests are discussed by a group of doctors. As a rule, the results are sent out within a week. In around half of the cases, it turns out that there is no breast cancer present.

WHAT DOES IT MEAN IF BREAST CANCER IS DETECTED?

Having breast cancer diagnosed is, first of all, a shock. However, the chances of treating it successfully can be very good and they depend, especially, on how far the cancer has progressed.

Most women are recommended to have an operation, in which, in most cases, the tumour and the surrounding tissue are removed. It is less common for the complete breast to be removed. Other possible forms of treatment are radiation, hormone and chemical therapies. Choosing the most suitable treatment depends on the precise diagnosis.

WHAT IS BREAST CANCER?

Breast cancer can develop when cells undergo a pathological change and begin to divide uncontrollably. Cancer cells can penetrate healthy tissue and form metastases.

There are more forms of breast cancer than of almost any other type of cancer. Breast cancer can often be cured. It can develop slowly and not form any metastases. But it can also develop quickly and spread in the body.

HOW FREQUENTLY DOES BREAST CANCER OCCUR?

The frequency of breast cancer depends above all on age. The following table gives an overview of the risk, showing how many women per thousand will develop breast cancer at which age in the next 10 years, and how many will die of it:

Age	How many women will get breast cancer in the next 10 years?	How many women will die of breast cancer in the next 10 years?
Age 50	25 per 1000	4 per 1000
Age 60	36 per 1000	7 per 1000
Age 70	34 per 1000	10 per 1000

Around 35 per thousand women die of breast cancer during their lives.

The risk of getting breast cancer depends on other factors too. Some women have a history of it in their family: if a woman's mother or sister has or had breast cancer, then her own risk is doubled. If a distant relative has it, however, then the woman is at scarcely any greater risk. High breast density may also play a role. Other risk factors such as childlessness or diet are of only minor significance.

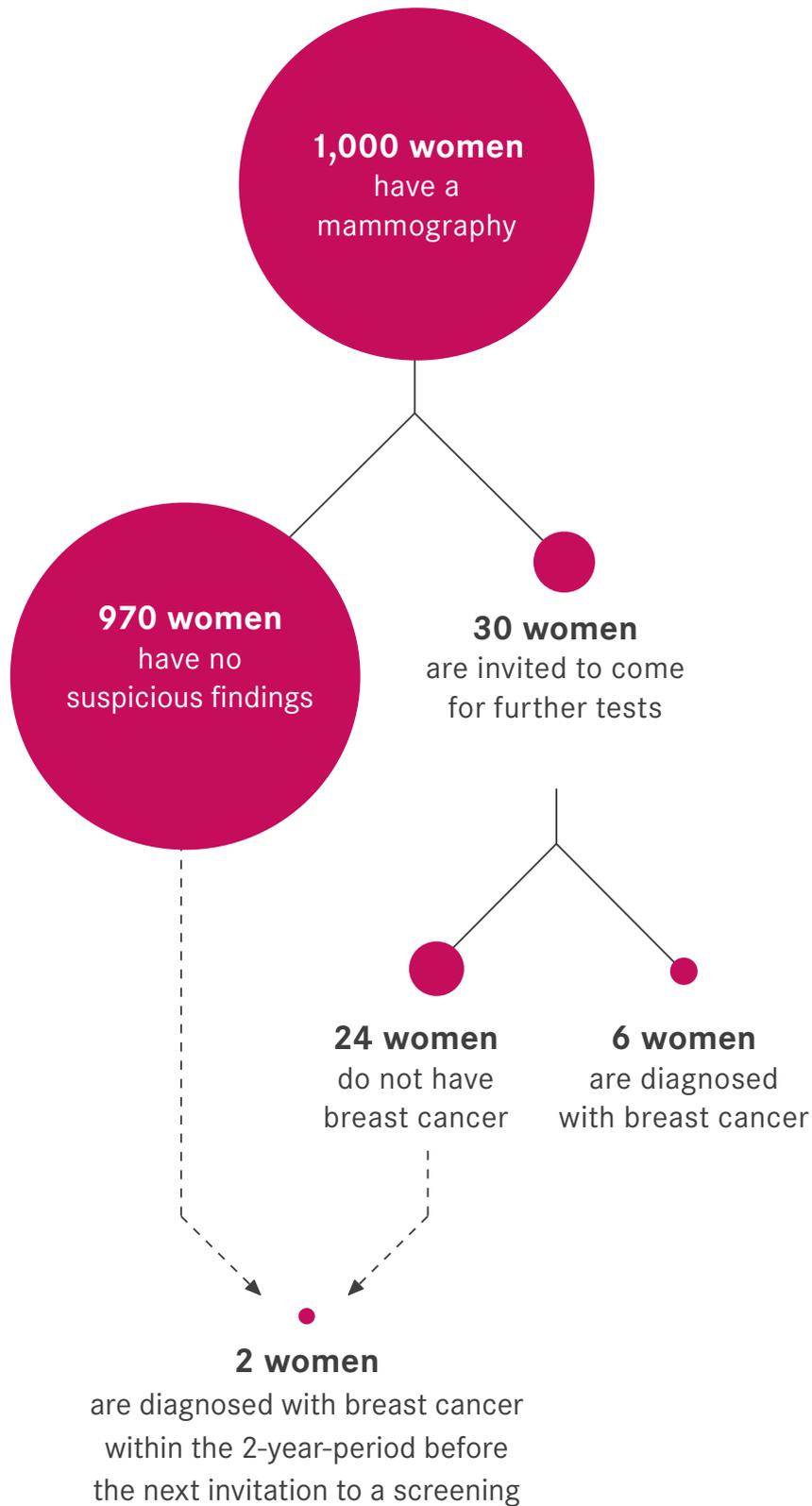
THE TEST IN FIGURES: WHAT RESULTS CAN BE EXPECTED?

If you imagine 1,000 women taking part in the mammography programme next week, then these are the test results which can by and large be expected:

- Around **970** of the **1,000** women will be informed that there were no **suspicious findings**. This is a relief for many women.
- Around **30 of the 1,000** women will receive notification of **abnormal findings**, as well as an appointment for some further tests.
- For **24 of these 30 women with abnormal findings**, further tests will show that they do not have **breast cancer**. Being informed that an abnormality has been found in a mammography is often a cause of anxiety. For most women, waiting for a final result is a very stressful experience. Even if the suspected cancer is not confirmed, the experience can still have a lasting effect.
- For **6 of the 30 women** with abnormal findings, the suspected cancer will be confirmed. **Breast cancer will have been diagnosed**. These women will receive their own appointment with a doctor from the mammography screening unit to discuss the next steps. Of course, a woman can also consult her own gynaecologist.

After the test: breast cancer will be diagnosed in about **2 of the 1,000** women within the 2-year-period before the next invitation to a screening. In most cases, the cancer in question will only have developed after the last test. Also, and in spite of all the care taken, it is possible to miss tumours in the mammography. This is a very rare occurrence, though.

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



WHICH FORMS OF BREAST CANCER ARE DIAGNOSED?

In **5 out of 6 women** diagnosed with breast cancer, an invasive tumour is found. If untreated, such a cancer often spreads in the body.

In about **1 out of 6 women** diagnosed with breast cancer, a mammography detects a change in the breast, known as **ductal carcinoma in situ (DCIS)**. In such a diagnosis, the cells in the milk ducts have changed. These cells are only located inside the milk ducts and have not spread to other tissue. For some women, this DCIS remains harmless, but for others it develops into an invasive tumour. As it cannot be predicted for any individual woman whether the DCIS will remain harmless, it is generally recommended that it be treated.

WHAT ARE OVERDIAGNOSES?

In some women, breast cancer is diagnosed which would never have been noticed without an early detection test. The reason for this is that there are small tumours which grow only slowly or not at all. Some women die of other causes before a tumour can make its presence felt. The diagnoses of such tumours are called 'overdiagnoses', because they would not have caused any problems throughout a woman's life. Whether a tumour, once discovered, will grow any further is something that doctors cannot predict with any certainty, and they generally advise that treatment be undertaken.

This is why overdiagnoses lead to unnecessary operations or radiation treatment. Overdiagnoses are different from abnormalities seen in the X-ray image which, after further tests, turn out to be harmless (see page 8). Overdiagnoses can occur in all early-detection tests.

GOING REGULARLY TO SCREENINGS: WHAT ARE THE ADVANTAGES AND DISADVANTAGES FOR ME?

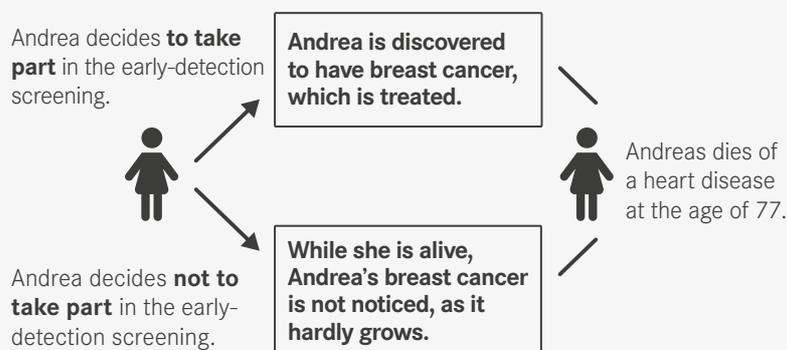
Several studies have looked at the question of what women can expect if they regularly go to mammography screenings. These studies make it possible to assess the important advantages and disadvantages.

One important advantage is the better chances of being cured. A mammography can detect breast cancer at an early stage, and this means that there is less risk of dying of breast cancer.

One important disadvantage is the risk of overdiagnoses. A mammography can lead to unnecessary diagnoses of breast cancer which can result in unnecessary operations and radiation treatment.

OVERDIAGNOSES: AN EXAMPLE

Imagine a woman called Andrea. She's 65 years old and has a small tumour in her breast which is growing at a very slow rate. She has no early-detection test and doesn't find out about the tumour. She dies at 77 - but not from breast cancer. Early detection would have made no difference to her life expectancy, but it would have led to unnecessary treatment.

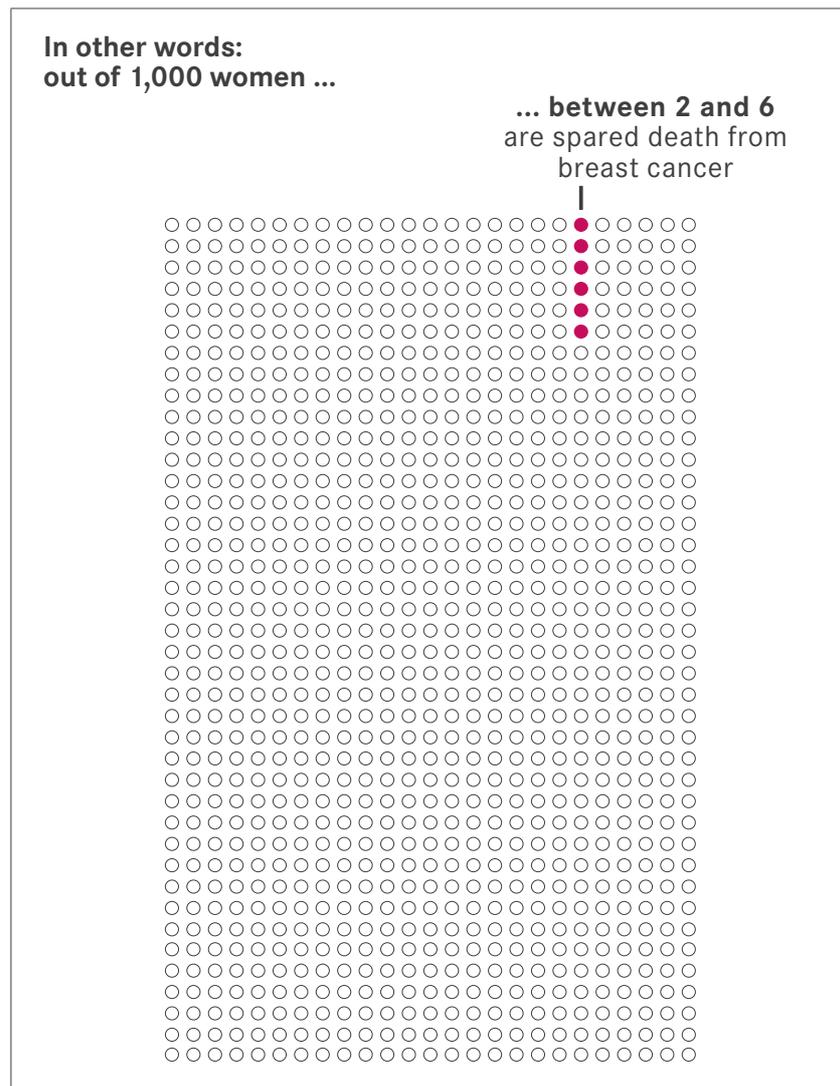


IN FIGURES: THE CHANCES OF RECOVERY

This page summarizes the approximate chances of recovery that women can expect if they regularly take part in the mammography screening programme between **the ages of 50 and 69**.

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

	How many die of breast cancer?
... don't take part:	19
... do take part	13 - 17

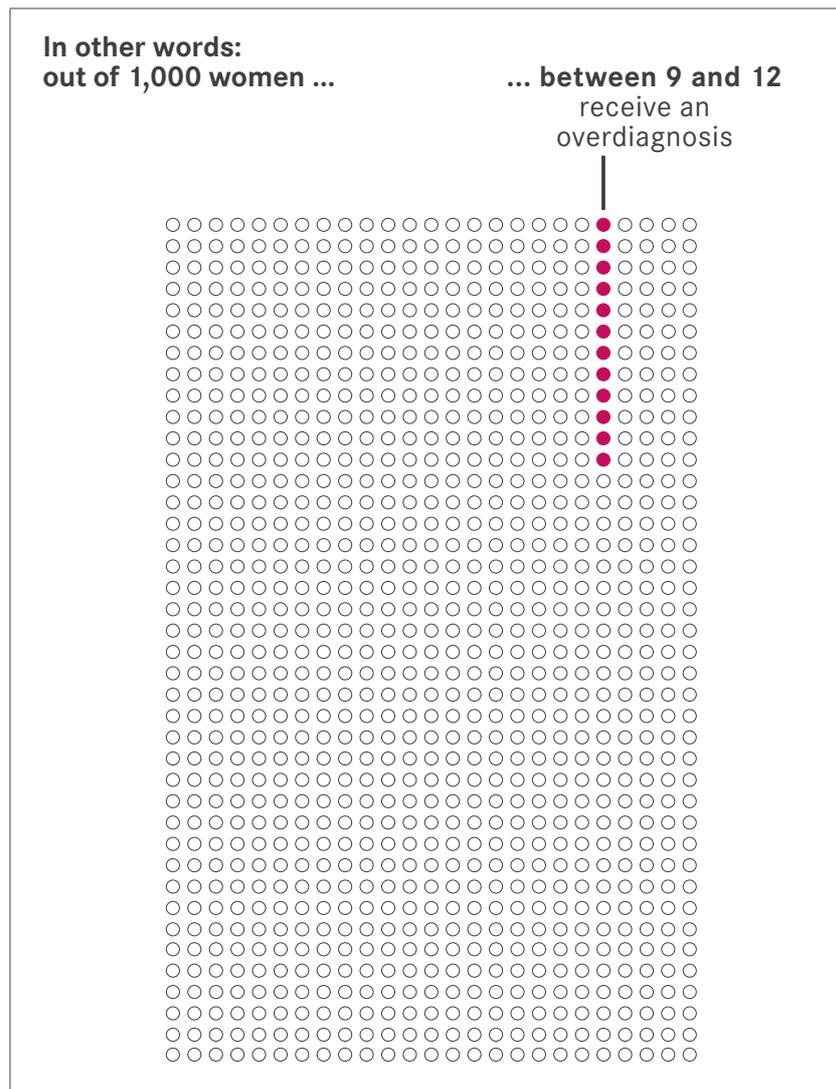


IN FIGURES: RISK OF OVERDIAGNOSES

This page summarizes the approximate number of women who receive an overdiagnosis when they regularly take part in the mammography programme between **the ages of 50 and 69**.

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

	How many are diagnosed with breast cancer?
... don't take part:	47 to 50
... do take part	59



HOW HIGH IS THE RADIATION DOSE?

X-rays are used in mammography. The denser the breast tissue is, the higher the radiation dose needs to be in order for an accurate image to be obtained. Even then, the radiation dose is so low that, as a rule, it has no consequences. Nevertheless, it cannot be ruled out that regular X-ray examinations over a period of 20 years may contribute to the development of breast cancer in a maximum of 1 in 1,000 women.

ARE THERE ALTERNATIVES TO THE EARLY-DETECTION MAMMOGRAPHY PROGRAMME?

Other methods for the early detection of breast cancer are sometimes offered to women, including ultrasound tests on the breast or magnetic resonance imaging (MRI). It is not clear, however, whether these tests reduce the risk of dying of breast cancer, as mammography does. These tests can lead to overdiagnoses more often than mammography does, as well as to abnormal findings which subsequently turn out to be harmless.

Mammography for the purpose of early detection may only be used as part of the German programme – for which there are strict quality assurance regulations in place. Outside the scope of this programme, mammographies serve to examine changes in the breast discovered through other methods. Such mammographies are not subject to the same quality standards: for example, the X-ray images are not examined by two specialist doctors.

THE LIMITS OF EARLY DETECTION

Taking part regularly in mammography screening cannot prevent breast cancer from developing. But the aim is to find any cancer early enough.

Mammography cannot discover all tumours – some develop just a few months after a test has been undertaken. This is why it is important to go and see a doctor straight away if, during the interval between mammography screenings, any changes in the breast are noticed, such as

- any palpable lumps, indentations or hardenings of the skin,
- any visible deformations, changes to the skin or retractions of the nipple,
- any bleeding or other secretions from the nipple.

WHAT HAPPENS TO MY PERSONAL DATA?

Handling personal data is subject to German data protection legislation. All data collected during the mammography programme will be treated just as confidentially as in any doctor's surgery. All the doctors and staff working on the programme are obliged to observe patient confidentiality.

The results of the tests are regularly evaluated centrally. This is important for supervising the quality of the programme. Personal details such as a woman's name or address are not needed for these evaluations and are not passed on to anyone else. This means that the evaluations cannot be linked to any individual woman.

The Invitation Centre is responsible for handling personal data. Details of how to contact the Office can be found in the invitation sent out to you.

DO I WANT TO TAKE PART IN THE MAMMOGRAPHY PROGRAMME? HELPING YOU TO DECIDE

Every woman has her own individual opinions on the advantages and disadvantages of mammography. Some want to use the opportunity of early detection as they see more advantages. Others, on the other hand, decide against it because for them the disadvantages outweigh the advantages.

The table below summarizes the most important statements regarding the mammography programme. You can use it to weigh up the arguments for and against taking part – or even see what may not be particularly important for you. If you like, you can discuss the table with a doctor.

IF I TAKE PART IN THE NEXT TEST, WHAT CAN I EXPECT?

Relief at no suspicious findings: of 1,000 women who go to a mammography, around 970 are notified that there were no abnormal findings.

Stress as a result of abnormal findings: of 1,000 women who go to a mammography, about 24 are notified that there are suspicious findings – which subsequently turn out to be harmless.

Pain: the mammography test may be unpleasant and may hurt.

Argument for me to take part	Argument for me not to take part	I'm not sure	Irrelevant for my decision
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

IF I TAKE PART REGULARLY FOR 20 YEARS, WHAT CAN I EXPECT?

Chances of being cured: of 1,000 women who regularly go to a mammography for 20 years, between 2 and 6 are spared death from breast cancer.

Risk of overdiagnoses: of 1,000 women who regularly go to a mammography for 20 years, between 9 and 12 receive an overdiagnosis leading to unnecessary forms of treatment.

Irradiation dose: the radiation dose from a mammography is low. Nevertheless, it cannot be ruled out that regular tests over a period of 20 years may contribute to breast cancer developing in a maximum of 1 out of 1,000 women.

WHAT ELSE IS IMPORTANT FOR ME? WHAT IS DECISIVE IN HELPING ME TO MAKE UP MY MIND?

WHAT DO I TEND TO THINK?

I'll take part every two years.

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

I'm still not sure.

I won't take part this time. In 2 Jahren entscheide ich neu.

I won't take part at all.

HELP IN SPEAKING TO A DOCTOR

Do you have any other questions? Before the test, you have a right to be informed in a personal discussion with a doctor from the mammography programme. For this purpose, please contact the Invitation Centre. Details can be found in the invitation sent out to you.

Before you go to see the doctor, make a note of the questions you have, as well as your own thoughts, and take these with you to help you make a decision. With the doctor, you can talk about anything that is on your mind or that worries you about the mammography screening programme.

Equally, you can discuss any questions you may still have with your gynaecologist or GP.

You can note 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.

Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (Institute of Quality and Efficiency in Health Care) (IQWiG).

Einladungsschreiben und Merkblatt zum Mammographie-Screening: Rapid Report; Auftrag P14-02. 20.03.2015 (the studies used for the decision aid are shown in Table 7, page 48)

Kooperationsgemeinschaft Mammographie (Mammography Screening Office). Ergebnisse des Mammographie-Screening-Programms in Deutschland: Evaluationsbericht 2013. Berlin, Juni 2016.

Robert Koch Institute (RKI). Beiträge zur Gesundheitsberichterstattung des Bundes: Krebs in Deutschland 2011/2012. 10. Ausgabe. Berlin, 2015.



Gemeinsamer Bundesausschuss

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

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Federal Joint Health Committee

G-BA is a body within the self-administrative organisation of doctors, dentists, psychotherapists, hospitals and health insurance funds in Germany. Since 2004, patients' representatives have also been actively involved in G-BA's work.

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