

Breast cancer screening: It's your choice

New information to help women aged
about 50 to make a decision

This booklet was developed in 2013 at The University of Sydney as part of a study published as Hersch et al. *Lancet* 2015, and updated in 2017.



Introduction

Why is there a decision to make about having breast cancer screening?

Many people think screening for early signs of **breast cancer** is always a good thing. But **breast screening** has advantages and disadvantages. This booklet is designed to help you make an informed choice about whether you would prefer to have screening or not.

Remember, there is no right or wrong answer about whether to have breast screening. It is a matter of what you believe is the right choice for you.

What is the purpose of this booklet?

You may have seen the BreastScreen leaflet which gives a basic introduction to breast screening. The booklet you are now reading contains extra information★ you can consider to help you decide whether or not you want to start screening. It was developed at The University of Sydney by gathering together the best available scientific evidence.

Whenever you see a word in **this colour**, you can find its meaning on page 11.

What is breast cancer screening?

Cancer screening is testing people who are well and do not have any **symptoms**, to look for early signs of cancer. Screening cannot stop people from getting cancer, but aims to find those people who have cancer so they receive a diagnosis and can start treatment.

The best available method of screening women for breast cancer is using a test called a **screening mammogram**. This test uses x-rays to make images of the breasts.

Screening is for women without any breast symptoms (such as a lump, pain, or nipple discharge). **If you do have any unusual changes in your breasts, see your doctor.**

Making my choice about screening: Is this information relevant for me?

This booklet is for women who are 50 years old or will be 50 in the next few years, who have no symptoms and are thinking about whether to start breast screening.

If you have had breast cancer, or if you have been told that you are at very high risk for breast cancer or that you are likely to have a breast cancer **gene mutation**, this booklet is not for you. Ask your doctor about breast screening.

What can I consider to help me make my decision?

The next few pages of the booklet contain some diagrams showing different things that may happen to women who have breast screening. Each diagram shows 1000 women who have a screening mammogram every 2 years for a period of 25 years, starting when they are 50 years old.



There are 3 important things to know:

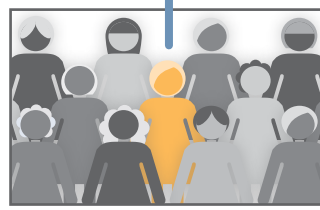
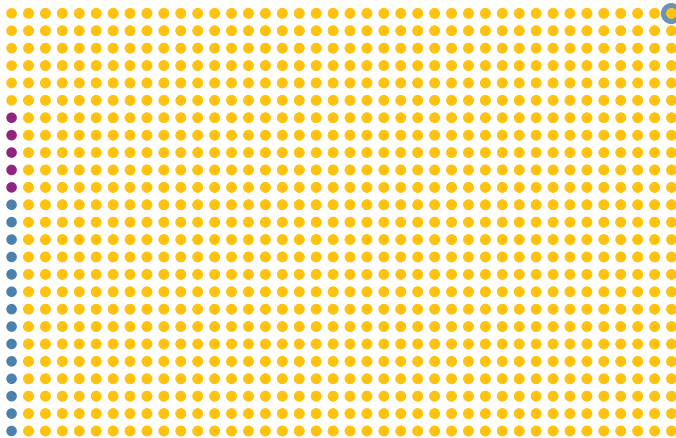
- (1) Screening leads to fewer women dying from breast cancer
- (2) Screening leads to finding some breast cancers that are not harmful (**over-detection**)
- (3) Screening leads to some **false positive** results and extra testing

The numbers presented are the best available estimates based on the latest research. They may need to be reviewed in the future when new information becomes available.

1. Screening leads to fewer women dying from breast cancer

The aim of breast screening is to lower the number of women who die of breast cancer.

Breast cancer deaths avoided due to 25 years of screening



1 dot = 1 woman

- woman who avoids dying from breast cancer because of screening
- woman who still dies from breast cancer, in spite of screening
- woman who would not die from breast cancer anyway

Out of 1000 women who have breast screening for 25 years,

- **5 women avoid dying from breast cancer** because of screening and
- **14 women still die** from breast cancer.

Note: Throughout this booklet, the number of deaths is added up over a total of 30 years because the benefit of screening continues after screening stops.

2. Screening leads to finding some breast cancers that are not harmful (over-detection)[★]

The cancers found by screening are treated to try and prevent problems later. But some cancers found by screening would never cause problems anyway. Cancers like this may grow very slowly or just stay the same. Without screening, they would never be noticed or cause any trouble. **Finding these cancers through screening is called over-detection (or over-diagnosis).**

Even after further checks and examination, doctors cannot be sure which cancers will be harmless. Therefore, treatment is recommended. So, across all the women who have screening, some end up having treatment they do not need.

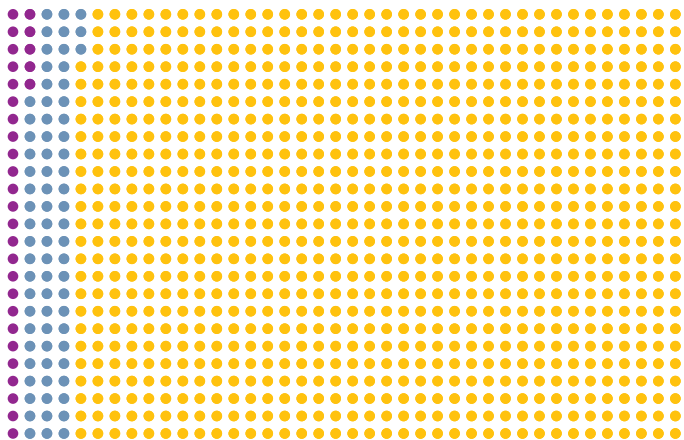
Breast cancer treatments include **surgery, radiotherapy, hormone therapy,** and **chemotherapy.** There are important side effects to these treatments which are described on page 8.

Over-detection due to 25 years of screening

Out of 1000 women who have breast screening for 25 years, **103** women are diagnosed with breast cancer.

Of these,

- **30 women experience over-detection:** they are diagnosed and treated for a cancer that would not have caused any trouble and
- **73** women are diagnosed with breast cancer that is not over-detection.

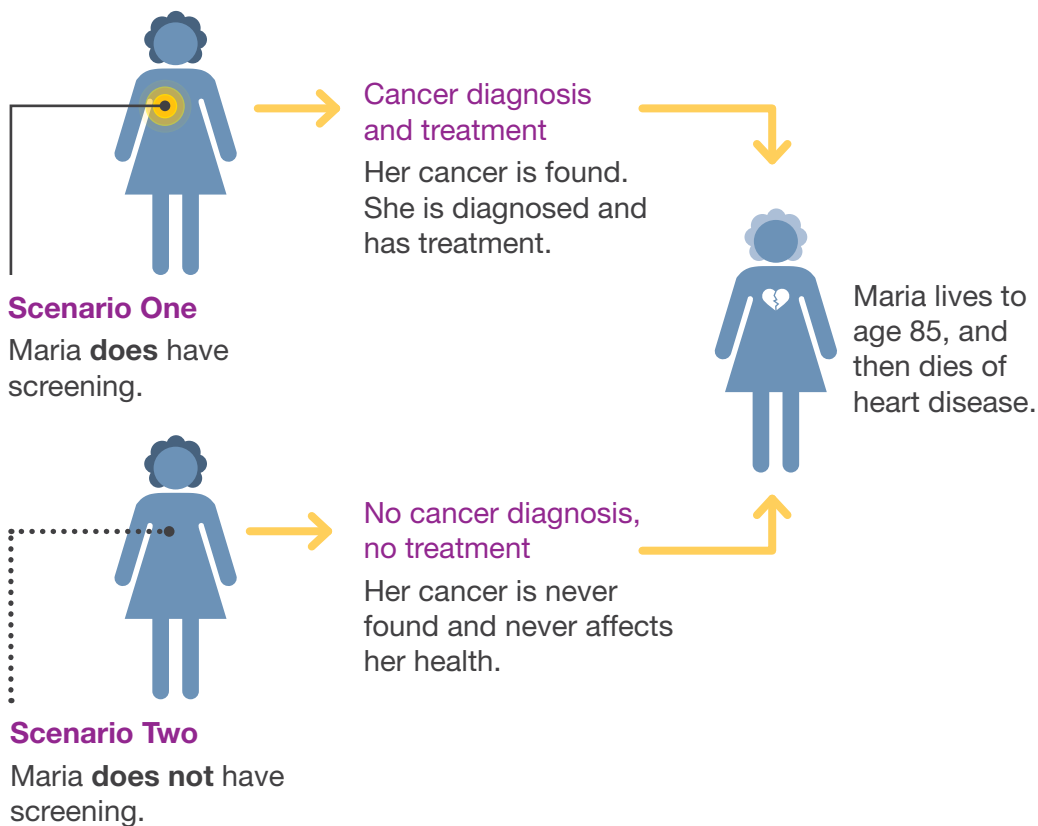


- extra woman diagnosed with breast cancer due to over-detection
- woman diagnosed with breast cancer that is not over-detection
- woman not diagnosed with breast cancer

As this information is new, there is an example of over-detection on the next page.

Over-detection: an example

Imagine a woman called Maria who develops a small, slow-growing breast cancer in her 50s or 60s. The picture below shows two possible scenarios that could happen to Maria: Scenario 1 (top) is with screening, and Scenario 2 (bottom) is without screening.



Maria's life span is the same, whether or not she has screening. So if she has screening, she experiences over-detection (a diagnosis and treatment she does not need).

Putting it together ★

For women in Australia who have breast screening over 25 years:

5 out of 1000 women avoid dying from breast cancer, and 30 out of 1000 women experience over-detection.

So that means **more women experience over-detection than avoid dying** from breast cancer.

3. Screening leads to some false positive results and extra testing

Like any other screening test, a mammogram is not perfect. Sometimes the result looks **abnormal** and the woman is recalled for extra tests, but it turns out that there is **no cancer** so it was a false alarm. **These false alarms from screening are called false positive results.**

Women often feel anxious while they are having the extra tests and waiting for their results, and then feel relieved when they are told there is no cancer after all. However, some women find that they keep worrying about breast cancer for a while afterwards.

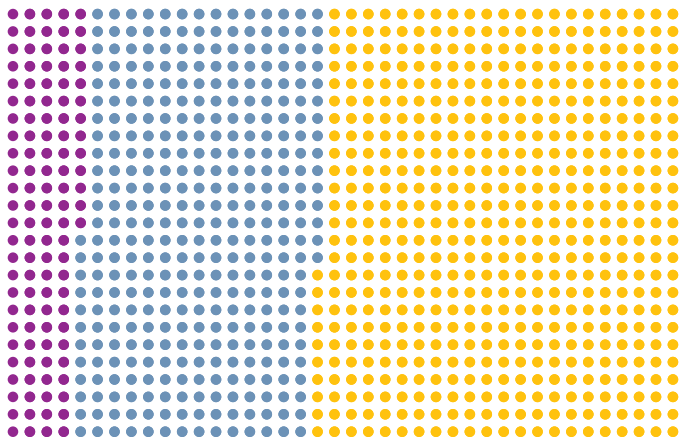
False positives due to 25 years of screening

Out of 1000 women who have breast screening for 25 years,

465 women experience a false positive result: they have an abnormal mammogram followed by extra tests but they do not have cancer.

Of these,

- **113** women have a **biopsy** and
- **352** women have other extra tests but no biopsy.



- woman who has a false positive with a biopsy
- woman who has a false positive with other tests
- woman who does not have a false positive

Some questions you may have



1. What happens after an abnormal screening result?

If her screening mammogram result is abnormal, the woman is called to a clinic for extra tests to check whether she has cancer or not. The extra tests may include more mammograms, **ultrasound scans**, **clinical examination**, and a biopsy (taking a sample of breast **cells**, usually with a needle).

2. How is over-detection different from false positives?

False positives occur in women who do not have breast cancer. These women have an abnormal screening result, but then extra tests (see above) show they **do not** have cancer. By contrast, in cases of over-detection the women **do** have breast cancer confirmed by further tests, so they get a cancer diagnosis and treatment (see below).

3. How is breast cancer treated?

As part of their treatment, nearly all women with breast cancer have surgery. Most also have radiotherapy or hormone therapy, and some have chemotherapy. For more information on breast cancer treatments, see below.



Nearly all breast cancer patients have **surgery** to either remove the cancer and a bit of surrounding tissue or to remove the whole breast. In addition, one or more of the other treatments described here may be recommended.



Hormone therapy blocks certain hormones in the body that may be contributing to tumour growth. Common side effects include hot flushes, vaginal dryness, and reduced libido (sex drive).



Radiotherapy uses X-rays to destroy cancer cells in the breast or stop them from growing. Common side effects include tiredness, and the skin of the breast becoming dry and red or darker in colour.



Some breast cancer patients have **chemotherapy**, which uses drugs to destroy cancer cells. Common side effects include nausea and vomiting, tiredness, hair loss, and diarrhoea or constipation.

4. If I am diagnosed with breast cancer, can I just wait and see if it is growing fast or not before I decide about treatment, or maybe try alternative therapies instead?

Once a breast cancer is found, doctors cannot be sure whether it can safely be left alone. This is why they recommend treatment.

5. Can I screen using ultrasound or some other test instead, or combine multiple tests?

Mammograms are the only tool scientifically shown to work for breast cancer screening in the general population. Having other tests instead of mammograms, or as well, cannot avoid over-detection and has not been shown to have any health benefits.

6. How do we know that over-detection exists?

Over-detection research compares groups (populations) with and without screening. For example, there have been big studies that randomly allocated women to be invited to screening or not. This made two groups that were the same in every way; the only difference between them was whether or not they were offered screening. When researchers followed these groups over many years, they found that more women in the screened group were diagnosed with breast cancer. The reason is that some of the cancers found by screening would never cause symptoms; otherwise the unscreened group of women would have just as many cancers diagnosed.

Making a choice: summary over 25 years with and without screening

Key questions	Screening (for 25 years, from age 50)	No screening (for 25 years, from age 50)
1. What are the chances of dying from breast cancer?	14 out of 1000 women die from breast cancer.	19 out of 1000 women die from breast cancer.
2. What are the chances of being diagnosed and treated for a breast cancer that is not harmful?	30 out of 1000 women are diagnosed and treated for a breast cancer that is not harmful (over-detection).	Women who do not have screening will not experience over-detection caused by screening.
3. What are the chances of having a false positive screening result that leads to extra testing?	465 out of 1000 women have a false positive result and extra testing, when they do not have cancer.	Women who do not have screening will not experience a false positive screening result.
4. What would I need to do?	<p>If you decide to start screening, you will be invited to have another mammogram every 2 years.</p> <p>If you have any breast symptoms, see your doctor.</p>	<p>If you decide not to start screening now, you can always reconsider in the future.</p> <p>If you have any breast symptoms, see your doctor.</p>

Key scientific articles: (1) Barratt A, Howard K, Irwig L, Salkeld G, Houssami N. Model of outcomes of screening mammography: information to support informed choices. *British Medical Journal* 2005; 330: 936. (2) Independent UK Panel on Breast Cancer Screening. The benefits and harms of breast cancer screening: an independent review. *Lancet* 2012; 380: 1778.

List of medical terms and what they mean

abnormal not normal

biopsy taking a small sample of tissue or cells from the body, mostly with a needle

breast cancer collection of cells in the breast that grow and multiply abnormally, which in some cases can spread (metastasise) to other areas of the body

breast screening having mammograms to look for early signs of breast cancer

cells the basic units of living things such as plants, animals and people

chemotherapy drug treatment to kill cancer cells or stop them growing so fast

clinical examination examination by a doctor to look and feel for signs of illness

false positive abnormal test result in a person who does not have the illness

gene mutation problem in a gene that may increase the risk of certain diseases

hormone therapy drug treatment to stop cancer responding to certain hormones

over-detection / over-diagnosis finding a hidden illness through screening that would otherwise never cause any symptoms or health problems in the person's life

radiotherapy treatment using strong x-rays to kill cancer cells or stop their growth

screening mammogram test using x-rays to make images of the breasts to look for early signs of cancer in women who have not noticed any breast symptoms

surgery operation, for example to remove a part of the body affected by illness

symptoms changes in the body, like pain or a lump, that may be due to illness

ultrasound scan test using sound waves to make images of a part of the body

For more information talk to your doctor or the Cancer Council Helpline 13 11 20.

Useful websites: www.cancercouncil.com.au, www.canceraustralia.gov.au or www.cancerresearchuk.org/about-cancer/type/breast-cancer/about/screening/breast-screening-review-2012

If you want to know more about breast cancer risk, you may find this website useful: breastcancerrisk.canceraustralia.gov.au

This booklet was developed in 2013 by members of the Screening and Test Evaluation Program at The University of Sydney, Australia.

It was developed and evaluated as part of a research study which has been published in the following article: Hersch J, et al. Use of a decision aid including information on over-detection to support informed choice about breast cancer screening: a randomised controlled trial. *Lancet* 2015; 385: 1642.

The booklet was updated in 2017 to reflect the extended age range for screening.



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