Should I Continue Having Mammograms to Screen for Breast Cancer?

A decision aid for women aged 70 and older at their next screening mammogram.

AUSTRALIAN SCREENING MAMMOGRAPHY DECISION AID TRIAL
Why is there a decision to make about having mammograms to screen for breast cancer?

A mammogram every two years to screen for breast cancer reduces the chance of dying from breast cancer among women aged 50 to 69 years. It is unclear if women aged 70 years and older get the same benefits.\(^1\) Continuing to have screening mammograms once you reach 70 is seen as an “option” about which there is a decision to make.

Acknowledgement

This decision aid was developed by members of the Screening and Test Evaluation Program (STEP) at the University of Sydney using the decision support format of the Ottawa Health Decision Centre, Canada (http://www.ohri.ca/decisionaid). ©2003
What is the purpose of this booklet?

This booklet helps you think about whether you want to continue or stop having mammograms to screen for breast cancer. It has information about the issues you may want to consider in making your decision.

The booklet also contains a worksheet to help you make your decision and examples of how other people have made their decision.

Throughout the booklet you will notice numbers following certain statements (eg. “It is unclear if women aged 70 years and older get the same benefit.”). The number refers to information in the appendix (see page 22).

Is this booklet for me?

This booklet is for you if you:

- will be aged 70 years or older at your next mammogram;
- have previously had a screening mammogram;
- do not have a current breast symptom such as a breast lump, lumpiness, nipple discharge, itchiness, redness or any other breast change; and
- are thinking about whether to continue or stop having mammograms to screen for breast cancer.
Should I **continue** or **stop** having mammograms to screen for breast cancer?

Many people think mammograms are always a good thing. But there are reasons why you might choose not to have another screening mammogram if you are aged 70 or older. The following pages outline some issues you may want to consider in making your decision.

There is no right or wrong answer about whether to **continue** or **stop** having screening mammograms.

**It is your decision to make.**

Screening is for women with no breast symptoms.

If you have any breast symptoms, you should see your doctor.
What can I consider to make my decision?

What happens to women aged 70 who screen and don’t screen.

The next few pages (pages 8-11) provide a comparison of what happens to 1000 women who continue screening mammograms every 2 years for 10 years with 1000 women who stop having screening mammograms. These numbers are estimates from a mathematical model of breast cancer and breast cancer screening. They use data from the Australian female population aged 70-79 years, and data from BreastScreen Australia. ²
How many women aged 70 who stop having screening mammograms will die from breast cancer in the next 10 years?

Out of 1000 women aged 70 who stop screening mammograms, over the next 10 years:

- 8 women will die of breast cancer
How many women aged 70 who continue having screening mammograms every 2 years for the next 10 years will die from breast cancer?

Out of 1000 women aged 70 who continue screening mammograms, 204 will die from any cause of death (including breast cancer) over the next 10 years. Out of 1000 women who stop having screening mammograms, 206 will die from any cause of death (including breast cancer) over the next 10 years.
What else happens to 1000 women aged 70 who stop having screening mammograms?

- **26 women** develop symptoms and are diagnosed with breast cancer
- **974 women** continue with their daily activities without being affected by breast cancer or attending for screening for the next 10 years
What else happens to 1000 women aged 70 who continue having screening mammograms every 2 years for 10 years?

In summary, screening 1000 women aged 70 for the next 10 years results in:

- 2 less women who die from breast cancer – these deaths are prevented by screening.
- 15 more women diagnosed with breast cancer. Some of these cancers would never be found without screening (see page 19 for more information).
- 135 women have extra tests after an abnormal mammogram, but do not have breast cancer. They may worry from these “false alarms”.
- 824 women are correctly reassured they do not have breast cancer.
What else should I think about before I make my decision?

Risk factors are conditions that make women more likely to get breast cancer.\textsuperscript{6,7,8,9} Risk factors for getting breast cancer are:

- Getting older
- Having had breast cancer or DCIS (ductal carcinoma in situ)
- Having a family history of breast cancer
- A previous surgical breast biopsy (especially if showing abnormal breast cells)
- Never having had children
- First child after the age of 30
- Early age of first period (less than 12 years old)
- Current or recent use of HRT (Hormone Replacement Therapy)

Women who have a higher risk of breast cancer are more likely to benefit from regular screening than women at average risk. If you are concerned about your risk of breast cancer, see page 21 for more information.
What to do next.

We have included a personal worksheet to help you weigh up points you may want to consider in making a decision about whether to continue or stop having screening mammograms.

You may want to:
- continue having a screening mammogram every 2 years for the next 10 years;
- have your next screening mammogram and then think again about whether to continue or stop (the benefits and harms are smaller for one mammogram than the numbers we have given for 5 mammograms); or
- stop screening altogether.

How do you fill out the worksheet?

The worksheet has 3 steps. You should complete each step by following the instructions.

Pages 12-15 are examples of how other people have completed their worksheet.

If you are happy to fill out your own personal worksheet without reading these example worksheets, please skip to page 16.

Your worksheet is on pages 16-17.
Elizabeth is 71 years old. She is in good health and enjoys being out and about. This is how she filled in her worksheet

Your Personal Worksheet

Step 1: Think if the points listed below make you feel that you want to continue or stop screening mammograms. On the next page, write each one where you think it should go.

For 1000 women aged 70 who continue screening:

- 2 deaths from breast cancer are avoided, because of screening
- 15 more women are diagnosed with breast cancer, because of screening
- 135 women will have extra tests, because of screening
- 824 women are reassured they do not have breast cancer, because of screening

Things that might increase my breast cancer risk:

- Having had breast cancer or DCIS (ductal carcinoma in situ)
- Having a family history of breast cancer
- A previous surgical breast biopsy (especially if showing abnormal breast cells)
- Never having had children
- First child after the age of 30
- Early age of first period (less than 12 years old)
- Current or recent use of HRT (Hormone Replacement Therapy)

Others: __________________________________________

Elizabeth feels that the breast cancer deaths avoided, the 824 women reassured and the things that increase her risk of breast cancer make her want to continue screening. She feels that 135 women having extra tests make her want to stop screening. The other points are not important to her decision. She writes these on the next page.

Elizabeth’s daughter has had breast cancer, she currently uses hormone replacement therapy and was 33 when she had her first child.
These points make me feel like I want to continue having screening mammograms

- 2 deaths from breast cancer avoided **
- 824 women reassured ***
- My risk of breast cancer *

These points are not important to my decision

- 15 more women diagnosed with breast cancer

These points make me feel that I want to stop having screening mammograms

- 135 women having extra tests ***

Elizabeth writes each of the points on this page. She now places *** next to the points that are most important to her decision, ** next to points that are fairly important to her and * next to points that are the least important to her decision. The points that are not important to her decision are left blank.

Step 2: For each point above put *** next to the issues that are most important for your decision, ** next to fairly important issues, and * next to the least important issues.

Step 3: Weigh up the points from above and how important they are to your decision. Now tick the box that best shows what you have decided.

☐ Continue having a mammogram every 2 years for the next 10 years
☐ Have my next mammogram and after that decide about future ones
☐ Undecided
☐ Not have my next mammogram but I may reconsider later
☐ Not have another mammogram

Elizabeth now weighs up the points above. Although she has strong feelings about the 135 women having extra tests, she feels that the other points that make her want to continue screening - especially the women reassured - outweigh the extra tests that she may have. She decides to have her next mammogram, and will decide about the next one in 2 years time.

Before you make your final decision, you may want to discuss your decision with your doctor.
Amelia is 70 years old, she helps out her children by minding her grandchildren. This is how she filled in her worksheet.

**Your Personal Worksheet**

**Step 1: Think if the points listed below make you feel that you want to continue or stop screening mammograms. On the next page, write each one where you think it should go.**

For 1000 women aged 70 who continue screening:
- 2 deaths from breast cancer are avoided, because of screening
- 15 more women are diagnosed with breast cancer, because of screening
- 135 women will have extra tests, because of screening
- 824 women are reassured they do not have breast cancer, because of screening

Things that might increase my breast cancer risk:
- Having had breast cancer or DCIS (ductal carcinoma in situ)
- Having a family history of breast cancer
- A previous surgical breast biopsy (especially if showing abnormal breast cells)
- Never having had children
- First child after the age of 30
- Early age of first period (less than 12 years old)
- Current or recent use of HRT (Hormone Replacement Therapy)

Amelia feels the women reassured make her want to continue screening. She feels that the extra tests, the extra women diagnosed, and the fact that some of the cancers found by screening are slow growing and may never affect her health, but you have treatment anyway make her want to stop screening. Although they are painful, this is not important to her decision.

Others: **Mammograms are painful**

**Unnecessary treatment of some cancers.**
These points make me feel like I want to continue having screening mammograms

- Women reassured *
- Deaths avoided
- Pain of mammograms

These points are not important to my decision

These points make me feel that I want to stop having screening mammograms

- Extra women diagnosed*
- Extra tests**
- Detection of cancers which may never affect my health and undergoing unnecessary treatment***

Step 2: For each point above put *** next to the issues that are most important for your decision, ** next to fairly important issues, and * next to the least important issues.

Step 3: Weigh up the points from above and how important they are to your decision. Now tick the box that best shows what you have decided.

- Continue having a mammogram every 2 years for the next 10 years
- Have my next mammogram and after that decide about future ones
- Undecided
- Not have my next mammogram but I may reconsider later
- Not have another mammogram

Amelia writes each of the points on this page. She now places *** next to the points that are most important to her decision, she places ** next to points that are fairly important to her and * next to points that are the least important to her decision. The points that are not important to her decision are left blank.

Before you make your final decision, you may want to discuss your decision with your doctor.

Amelia now weighs up the points above. She feels that women reassured and the extra women diagnosed balance each other out. She feels very strongly about the possibility of undergoing extra tests and unnecessary treatment for a cancer which may never affect her health. For these reasons, she decides that she is not going to have any more mammograms.
Now it is time for you to fill out your personal worksheet.

Your Personal Worksheet

Step 1: Think if the points listed below make you feel that you want to continue or stop screening mammograms. On the next page, write each one where you think it should go.

For 1000 women aged 70 who continue screening:

- 2 deaths from breast cancer are avoided, because of screening
- 15 more women are diagnosed with breast cancer, because of screening
- 135 women will have extra tests, because of screening
- 824 women are reassured they do not have breast cancer, because of screening

Things that might increase my breast cancer risk:

- □ Having had breast cancer or DCIS (ductal carcinoma in situ)
- □ Having a family history of breast cancer
- □ A previous surgical breast biopsy (especially if showing abnormal breast cells)
- □ Never having had children
- □ First child after the age of 30
- □ Early age of first period (less than 12 years old)
- □ Current or recent use of HRT (Hormone Replacement Therapy)

- Others: ________________________________________________________________
These points make me feel like I want to **continue having** screening mammograms

These points are **not important to** my decision

These points make me feel that I want to **stop having** screening mammograms

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**Step 2:** For each point above put *** next to the issues that are most important for your decision, ** next to fairly important issues, and * next to the least important issues.

**Step 3:** Weigh up the points from above and how important they are to your decision. Now tick the box that best shows what you have decided.

- [ ] Continue having a mammogram every 2 years for the next 10 years
- [ ] Have my next mammogram and after that decide about future ones
- [ ] Undecided
- [ ] Not have my next mammogram but I may reconsider later
- [ ] Not have another mammogram

Before you make your final decision, you may want to discuss your decision with your doctor.
Appendix

You do not have to read this to make your decision.

Pages 19-21 provides you with more information about the issues that you might like to consider in making your decision to continue or stop screening mammograms.

Pages 22-23 tells you where our data came from and what assumptions and calculations we used. These are the best estimates based on available data and will need to be reviewed as new information becomes available.
Cancers which may never affect your health

You may have noticed that more breast cancers are found in women who are screened than in women who are not screened. Some breast cancers found by screening never cause any problems because women die of something else first. These breast cancers may be slow growing cancers, for example DCIS (ductal carcinoma in situ).

So, if women with these slow growing cancers had not had screening, they might never have known they had cancer and would not have had treatment. The diagram below tries to illustrate this.

Maria is 70 years old. She needs to decide whether to continue or stop having mammograms

If Maria stops, this may happen:

Age 70
She actually has a breast cancer, but it causes no symptoms and because she stops having screening mammograms, it is never found

Age 75:
Dies of heart attack

If Maria continues, this may happen:

Age 70
Her breast cancer is found by screening. She has surgery (lumpectomy + radiotherapy) and tamoxifen. She has no symptoms of breast cancer and her breast cancer does not recur.

Age 75:
Dies of heart attack
Effects of radiation from mammograms

A mammogram is an x-ray of your breast. Although mammograms use a low dose of radiation, there is a very small chance that breast cancer is caused by this radiation.

The United Kingdom National Health Service Breast Screening Program has recently reviewed evidence on the radiation risk in breast screening. From this review we estimate that if 1000 women aged 70 have 5 screening mammograms over the next ten years, the radiation may lead to the development of 0.1 breast cancers over the rest of these women’s lifetimes. This is the same as saying 1 breast cancer may be caused by the radiation from mammograms if 10,000 women aged 70 have 5 screening mammograms over the next 10 years.

The review also found that in women aged around 70 years the chance of screening mammograms detecting a breast cancer is about 400 times greater than the chance of the radiation causing a breast cancer.
Personal risk of breast cancer

As mentioned earlier, women who are at a higher risk of breast cancer are more likely to benefit from regular screening than women at average risk.

If you are concerned about your personal risk of breast cancer, you can use the Breast Cancer Risk Assessment Tool which is available on the internet. http://bcra.nci.nih.gov/brc/

Other internet sites with information are:
http://www.yourdiseaserisk.harvard.edu/english/
References


2. Outcomes of screening: The estimates of outcomes of screening in this decision aid come from a mathematical model of mammography screening among women aged 40-84 years, based on Australian breast cancer incidence and mortality data.

   Number of cancers detected, number of recalls for further tests, false reassurance, missed cancers: These data were obtained from statistical reports from BreastScreen Australia services

   Breast cancer deaths: The model assumes that mammography screening reduces the risk of death from breast cancer by 37% in women aged over 50 years. These estimates come from data from randomized trials of screening and are adjusted to reflect the likely benefit among women who regularly participate in screening\(^{(1, 7, 8)}\). In this decision aid, the number of breast cancer deaths is the number occurring over 10 years.

   The model has been developed by staff at the Screening and Test Evaluation Program, School of Public Health, University of Sydney. It has been published in the British Medical Journal and is available free online - Barratt A, Howard K, Irwig L, Salked G, Houssami N. Model of outcomes of screening mammography: information to support informed choices. *BMJ*. April 2005; 330: 936. (Available from www.bmj.com)


