

Patient decision aid

Taking a medicine to reduce the chance of developing breast cancer

Decision aid for postmenopausal women at high risk

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About this decision aid

This decision aid can help you to decide whether or not to take a medicine to reduce your chance of developing breast cancer. It is not intended for women who have had breast cancer in the past. Your decision depends on several things that this information will help to explain. Different women will feel that some of these things are more important to them than others, so it is important that you make a decision that is right for you. **This decision aid is designed for you to work through with your healthcare professional.** You might also find it helpful if you want to talk things over with your family or friends.

What is my risk of breast cancer?

You have been assessed as having a high lifetime risk of developing breast cancer compared with most women. **Being at high risk does not mean that you will definitely develop breast cancer.** Depending on your age, your estimated risk of cancer and whether you have a faulty gene or a high chance of a faulty gene you may be offered regular scans to check for breast cancer. Most women who do develop breast cancer can be successfully treated. Your healthcare professional can explain more about what being at high risk means for you.

What is my choice?

You can choose to take a medicine every day for 5 years to reduce your risk of developing breast cancer. But you do not have to take it: there are pros and cons. **The medicine NICE recommends for most women who have been through the menopause is called anastrozole.** However, this may not be suitable for all women; for example, women who have severe osteoporosis. NICE recommends that, if anastrozole is not suitable or they prefer not to take it, women could think about taking one of two other medicines, called tamoxifen and raloxifene.

Anastrozole, raloxifene and tamoxifen are recommended by NICE as options for postmenopausal women at high risk of breast cancer, based on NICE's assessment of the scientific evidence. However, the manufacturers of raloxifene have not applied for a marketing authorisation to cover its use for this purpose, so this would be an 'off-label' use. There is more information about [licensing of medicines on the NHS website](#).

The key points to think about are as follows:

- No one can say for certain what will happen to an individual woman.
- Being at high risk does not mean that you will definitely develop breast cancer.
- If you take one of the medicines you will be less likely to develop breast cancer than if you do not take it. However, some women who take one of the medicines will still develop breast cancer. Each medicine reduces your risk of breast cancer by a different amount.

- Taking any of the medicines has not been shown to make a difference to your chance of dying from breast cancer compared with women similar to you who do not take one of the medicines.
- Taking any of the medicines might give you side effects, although not every woman gets these. Each medicine has a different pattern of possible side effects.
- If you start taking a medicine to reduce your risk of breast cancer you can stop at any time.

There is more information about these things in the rest of this decision aid. For some women at particularly high risk of developing breast cancer, risk-reducing surgery might be an option. This decision aid does not cover this option but your healthcare professional will explain it to you.

Using this decision aid to help you make your choice

There is a lot of information that you will need to think about before you decide what to do. **You do not have to make a decision immediately.** Once you have made a choice, you can change your mind later if you wish or if your situation changes.

The information in the table below and on the following pages considers many of the questions that women want to think about and discuss with healthcare professionals when making this decision. It is based on the [scientific evidence assessed by NICE when it produced its guideline on familial breast cancer](#). There are also diagrams that show some of the information in a visual way. You can use the table on page 8 to make a note about how important the different issues are to you. A [user guide](#), written primarily for healthcare professionals, is also available. It explains how this decision aid was produced and the sources of information used.

Table 1 How do the options compare?

-	No medicine	Anastrozole	Raloxifene	Tamoxifen
<p>1. What does this option involve?</p>	<p>Taking no medicine. Depending on things such as your age and your estimated risk of cancer you may be offered regular scans to check for breast cancer</p>	<p>Taking one tablet every day for 5 years. Depending on things such as your age and your estimated risk of cancer you may be offered regular scans to check for breast cancer</p>	<p>Taking one tablet every day for 5 years. Depending on things such as your age and your estimated risk of cancer you may be offered regular scans to check for breast cancer</p>	<p>Taking one tablet every day for 5 years. Depending on things such as your age and your estimated risk of cancer you may be offered regular scans to check for breast cancer</p>
<p>2. What difference will it make to my chance of developing breast cancer?</p> <p>See pages 9-13 for more information and diagrams to help explain this.</p>	<p>On average, if 1000 women at high risk of developing breast cancer do not take one of these medicines, over 5 years:</p> <ul style="list-style-type: none"> • about 50 women will develop breast cancer • about 950 women will not. <p>Your healthcare professional will explain if your personal risk is more or less than this.</p>	<p>On average, if 1000 women at high risk of developing breast cancer take anastrozole, over 5 years:</p> <ul style="list-style-type: none"> • about 26 women (24 fewer) will develop breast cancer • about 974 women will not. <p>You will continue to benefit for at least 6 years after you stop taking anastrozole. It is expected that the benefits will continue after this, but this has not yet been shown.</p> <p>Anastrozole has not been shown to reduce your risk of dying from breast cancer.</p>	<p>On average, if 1000 women at high risk of developing breast cancer take raloxifene, over 5 years:</p> <ul style="list-style-type: none"> • about 43 women (7 fewer) will develop breast cancer • about 957 women will not. <p>You will continue to benefit for at least 2 years after you stop taking raloxifene. It is expected that the benefits will continue after this, but this has not yet been shown.</p> <p>Raloxifene has not been shown to reduce your risk of dying from breast cancer.</p>	<p>On average, if 1000 women at high risk of developing breast cancer take tamoxifen, over 5 years:</p> <ul style="list-style-type: none"> • about 35 women (15 fewer) will develop breast cancer • about 965 women will not. <p>You will continue to benefit for at least 11 years after you stop taking tamoxifen. It is expected that the benefits will continue after this, but this has not yet been shown.</p> <p>Tamoxifen has not been shown to reduce your risk of dying from breast cancer.</p>

-	No medicine	Anastrozole	Raloxifene	Tamoxifen
<p>3. What difference will it make to my chance of a bone fracture?</p>	<p>Taking no medicine means that your chance of a fracture does not change</p>	<p>Anastrozole may increase your risk of a fracture, but this has not been shown for certain. You may have a DEXA scan to check your bone density before you start taking anastrozole and from time to time while you are taking it.</p>	<p>Raloxifene has been shown to reduce the risk of fractures in the spine, but not other fractures (for example, fractures of the hip or wrist).</p>	<p>Tamoxifen has not been shown to make a difference to your chance of a fracture.</p>
<p>4. What difference will it make to my chance of getting a blood clot such as deep vein thrombosis (DVT) or a blood clot in the lungs (pulmonary embolism)?</p> <p>See pages 14–17 for more information and diagrams to help explain this.</p>	<p>If 1000 women at average risk of getting a blood clot do not take one of these medicines, over 5 years</p> <ul style="list-style-type: none"> • about 10 women will get a blood clot • about 990 will not. <p>Your healthcare professional will explain if your personal risk is more or less than this.</p>	<p>Anastrozole has not been shown to make a difference to your chance of getting a blood clot.</p>	<p>Raloxifene increases your risk of getting a blood clot while you are taking it, but your risk returns to normal after you stop taking it. If 1000 women at average risk of getting a blood clot take raloxifene for 5 years:</p> <ul style="list-style-type: none"> • about 16 women (6 extra) will get a blood clot in that time • about 984 women will not get a blood clot in that time. 	<p>Tamoxifen increases your risk of getting a blood clot while you are taking it, but your risk returns to normal after you stop taking it. If 1000 women at average risk of getting a blood clot take tamoxifen for 5 years:</p> <ul style="list-style-type: none"> • about 20 women (10 extra) will get a blood clot in that time • about 980 women will not get a blood clot in that time.

-	No medicine	Anastrozole	Raloxifene	Tamoxifen
<p>5. What difference will taking it make to my chance of getting endometrial cancer (cancer of the womb)?</p> <p>See pages 14 and 18–19 for more information.</p> <p><i>This does not apply to you if you have had a hysterectomy</i></p>	<p>If 1000 women at average risk of getting endometrial cancer do not take one of these medicines, over 5 years:</p> <ul style="list-style-type: none"> • about 3 women will get endometrial cancer • about 997 will not. <p>Your healthcare professional will explain if your personal risk is more or less than this.</p>	<p>Anastrozole has not been shown to make a difference to your chance of getting endometrial cancer.</p>	<p>Raloxifene has not been shown to make a difference to your chance of getting endometrial cancer.</p>	<p>Tamoxifen increases your risk of getting endometrial cancer while you are taking it, but your risk returns to normal after you stop taking it. If 1000 women at average risk of getting endometrial cancer take tamoxifen for 5 years:</p> <ul style="list-style-type: none"> • About 6 women (3 extra) will get endometrial cancer in that time • About 994 women will not get endometrial cancer in that time.

-	No medicine	Anastrozole	Raloxifene	Tamoxifen
<p>6. What are the other common side effects?</p>	<p>None.</p>	<p>Anastrozole can cause side effects but not every woman gets them. In one large study, the most common side effects seen more often among women taking anastrozole than those taking dummy tablets were:</p> <ul style="list-style-type: none"> • hot flushes • joint aches and stiffness • vaginal dryness. <p>However, some women taking dummy tablets also had these effects. For example, in every 1000 postmenopausal women who took anastrozole about 570 got hot flushes and 430 did not. But in every 1000 similar women who took dummy tablets about 490 got hot flushes and 510 did not.</p> <p>More information on other possible side effects is available in the manufacturer's leaflets, such as this one.</p>	<p>Raloxifene can cause side effects but not every woman gets them. In one large study, the most common side effects seen more often among women taking raloxifene than those taking dummy tablets were:</p> <ul style="list-style-type: none"> • hot flushes • swollen legs and ankles • leg cramps. <p>However, some women taking dummy tablets also had these effects. For example, in every 1000 postmenopausal women who took raloxifene about 80 got hot flushes and 920 did not. But in every 1000 similar women who took dummy tablets about 50 got hot flushes and 950 did not.</p> <p>More information on other possible side effects is available in the manufacturer's leaflets, such as this one.</p>	<p>Tamoxifen can cause side effects but not every woman gets them. In one large study, the most common side effects seen more often among women taking tamoxifen than those taking dummy tablets were:</p> <ul style="list-style-type: none"> • hot flushes • vaginal discharge. <p>However, some women taking dummy tablets also had these effects. For example, in every 1000 postmenopausal women who took tamoxifen about 690 got hot flushes and about 310 did not. But in every 1000 similar women who took dummy tablets about 490 got hot flushes and about 510 did not.</p> <p>More information on other possible side effects is available in the manufacturer's leaflets, such as this one.</p>

How you feel about the options

Issue	How important is this to me?	Very important	Important	Not important	Not at all important
Taking a tablet every day for 5 years					
The difference it makes to my chance of developing breast cancer					
Knowing that it has not been shown to change my chance of dying from breast cancer					
The difference it makes to my chance of a bone fracture					
The difference it makes to my chance of getting endometrial cancer					
The difference it makes to my chance of getting a blood clot					
The possibility of other side effects					

You can use the table to help you make a note about how important the issues are to you.

Other concerns or questions I would like to discuss:

Risk of developing breast cancer – benefits of taking the medicines

Taking any of the medicines for 5 years reduces your risk of developing breast cancer while you take it. It has also been shown that women who take raloxifene continue to benefit for at least 2 years after they stop taking it, women who take anastrozole continue to benefit for at least 6 years after they stop taking it, and women who take tamoxifen continue to benefit for at least 11 years after they stop taking it. It is expected that the benefit from all 3 medicines will continue for longer than this, but this has not yet been shown because studies have not gone on for long enough.

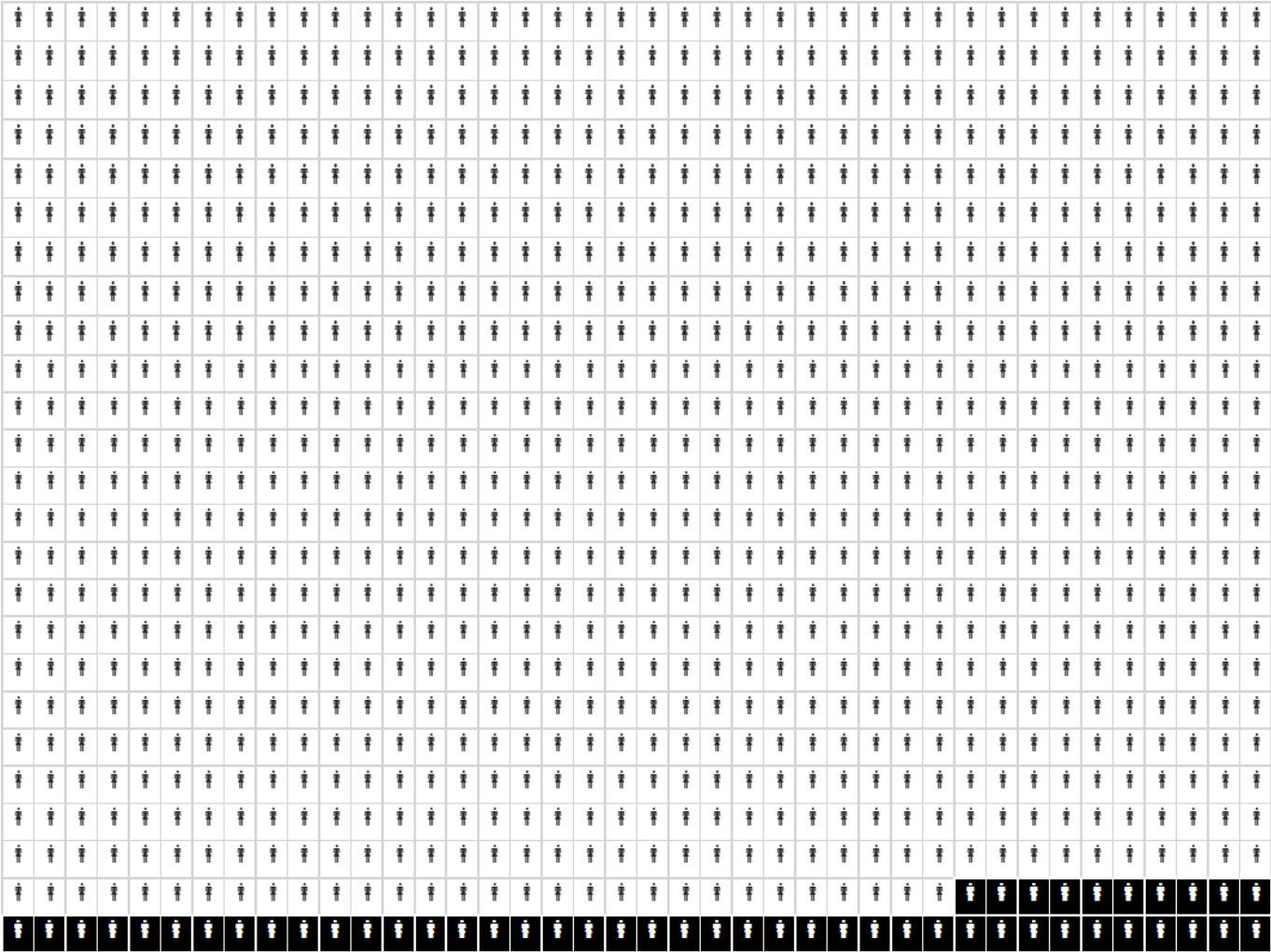
Although some women who take one of the medicines will avoid developing breast cancer because they have taken it, some women who take it would never develop breast cancer anyway. Some women who take one of the medicines still develop breast cancer at some point in their lives. The actual number of women who benefit per 1000 who take one of the medicines depends on the chance of them developing breast cancer anyway (known as their 'baseline risk' of breast cancer), which will be different for different women. In addition, the different medicines each reduce the risk by different amounts.

The graphics on the next pages show the effects of the medicines on women at **5% baseline risk** of breast cancer **over 5 years** (50 in 1000). Your healthcare professional will explain if you are likely to be at higher or lower baseline risk than this, and what this means about the effects of treatment.

Remember that no-one can say what will happen to any individual woman.

Risk of developing breast cancer 5% over 5 years (50 in 1000)

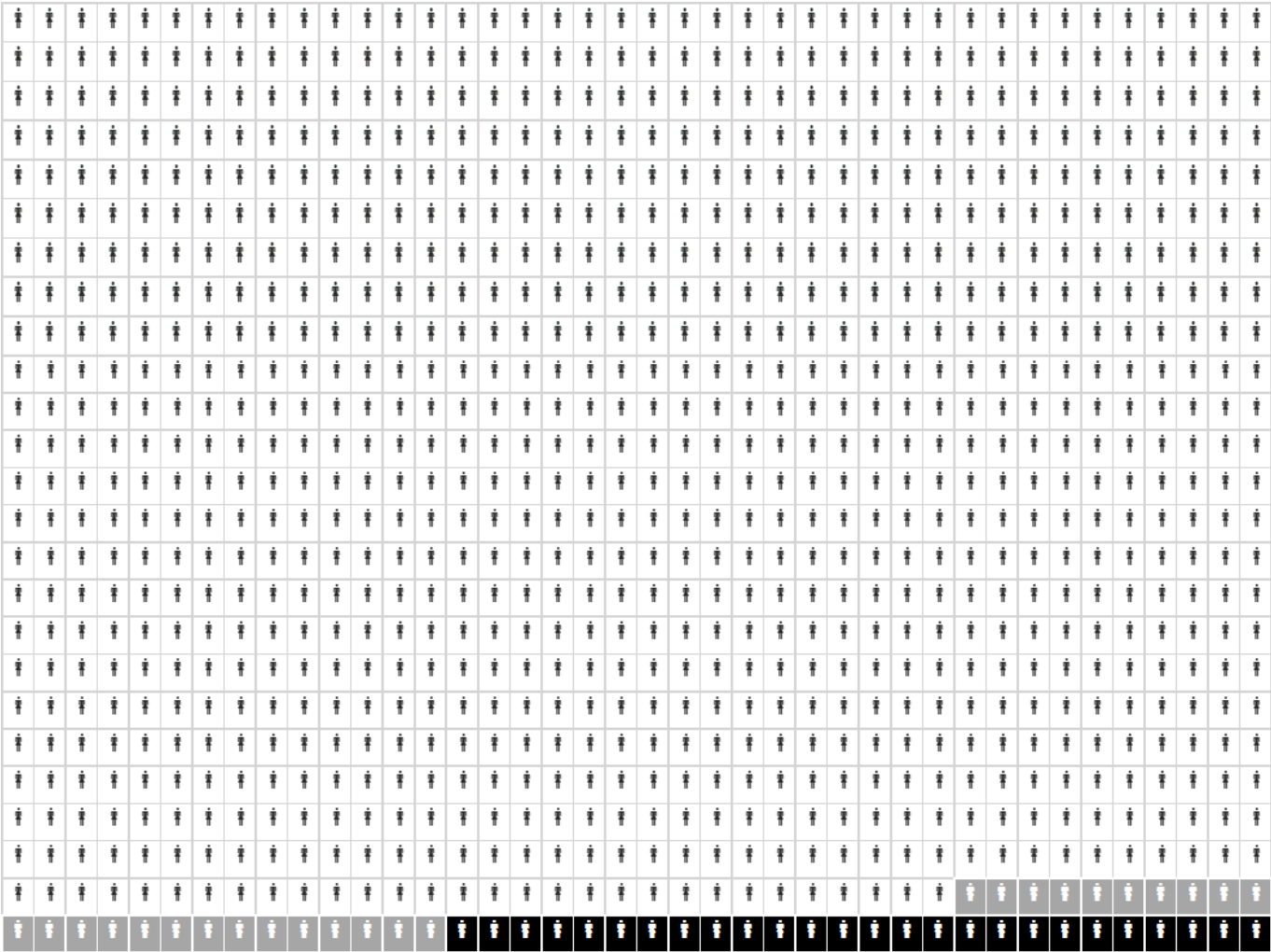
No treatment



If 1000 women at this level of risk take no treatment, over 5 years on average:

- 950 women will not develop breast cancer (the black figures on the white background)
- 50 women will develop breast cancer (the white figures on the black background)

Effect of taking anastrozole daily for 5 years on risk of developing breast cancer over that time

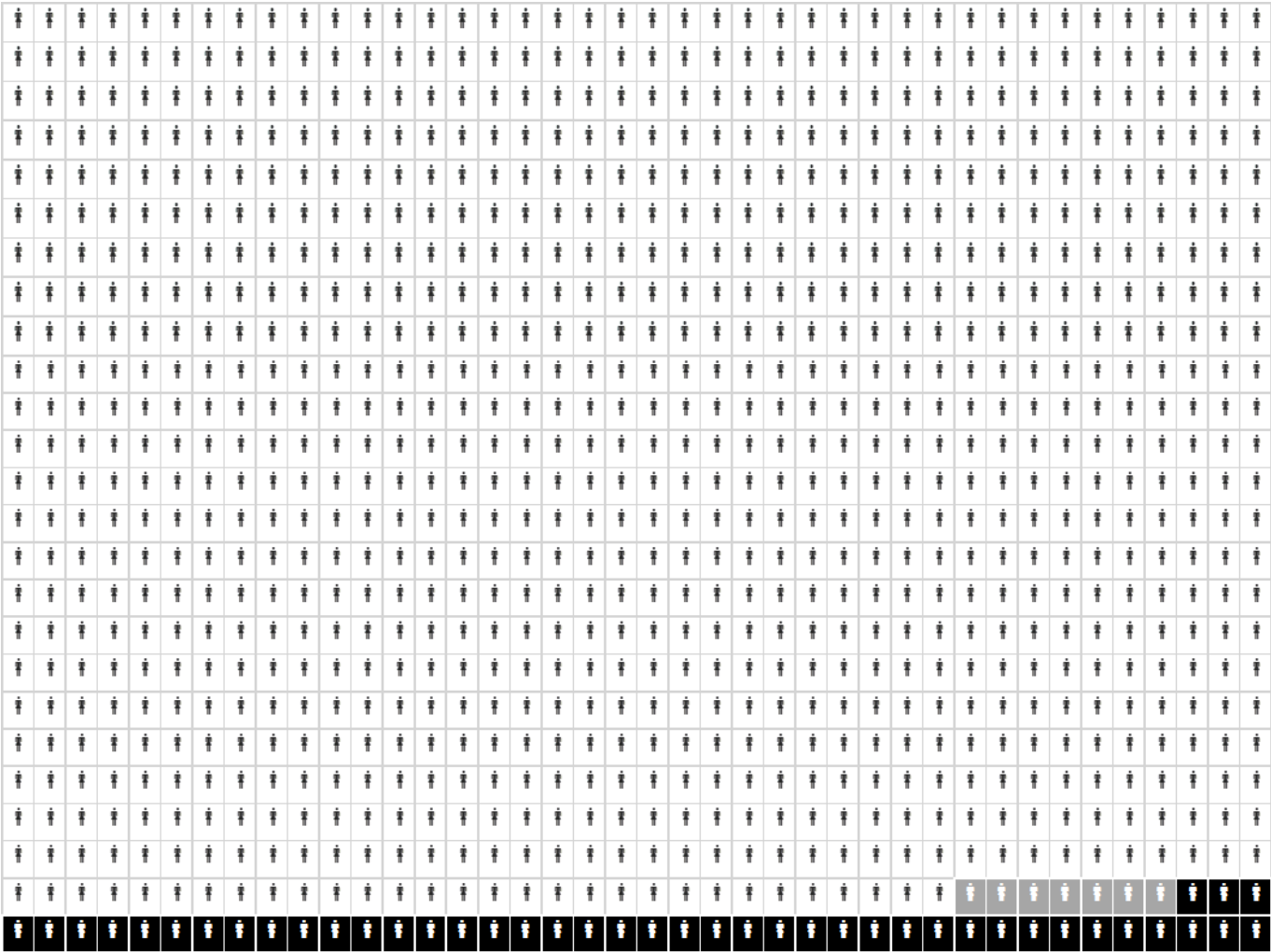


If all 1000 women take anastrozole for 5 years, over that time on average:

- 950 women will not develop breast cancer, but would not have done anyway (the black figures on the white background)
- 24 women will avoid developing breast cancer (the white figures on the grey background)
- 26 women will still develop breast cancer (the white figures on the black background)

Women who take anastrozole continue to benefit for at least 6 years after they stop taking it. It is expected that the benefit will continue for longer than this, but this has not yet been shown because studies have not gone on for long enough.

Effect of taking raloxifene daily for 5 years on risk of developing breast cancer over that time

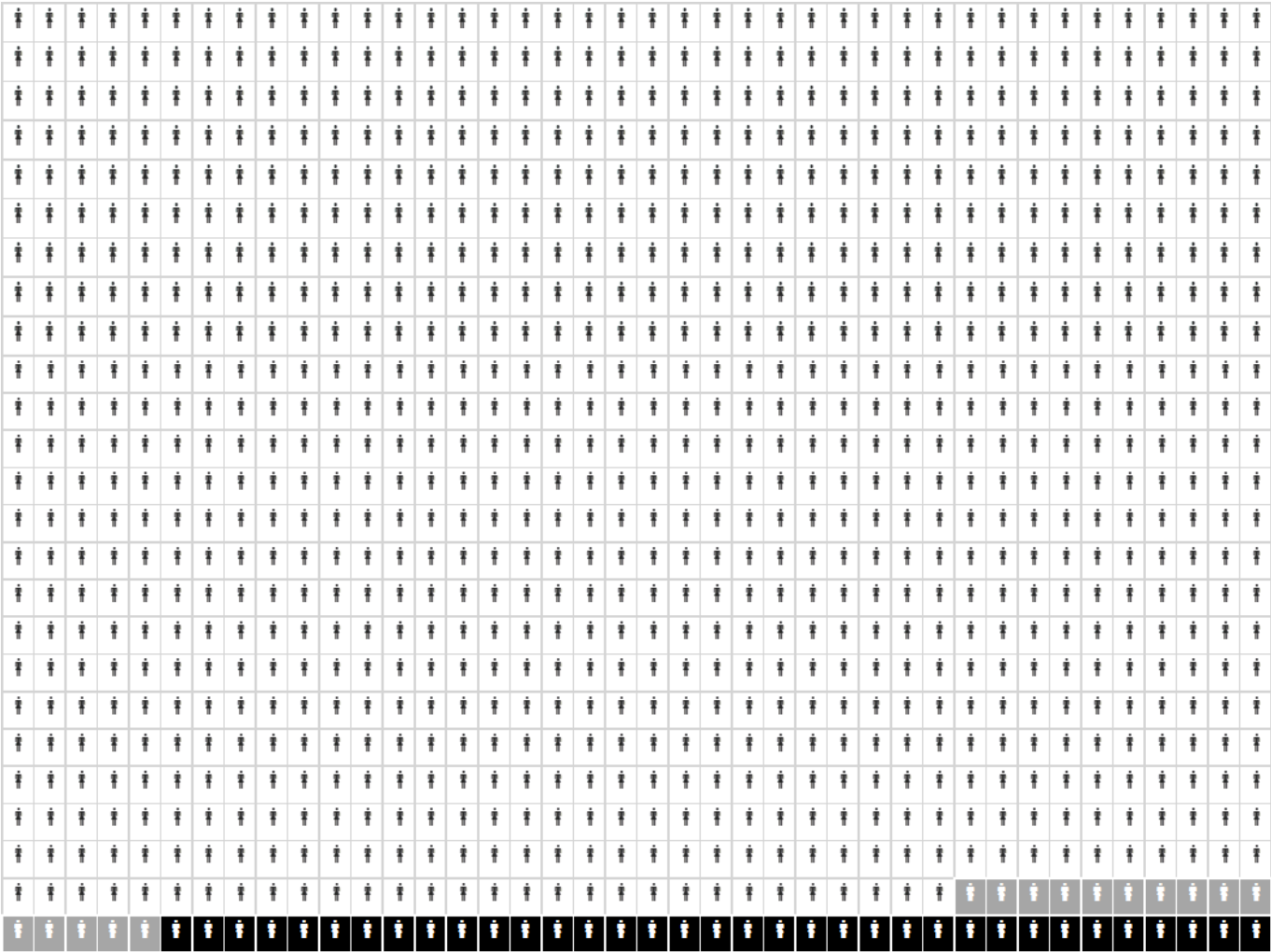


If all 1000 women take raloxifene for 5 years, over that time on average:

- 950 women will not develop breast cancer, but would not have done anyway (the black figures on the white background)
- 7 women will avoid developing breast cancer (the white figures on the grey background)
- 43 women will still develop breast cancer (the white figures on the black background)

Women who take raloxifene continue to benefit for at least 2 years after they stop taking it. It is expected that the benefit will continue for longer than this, but this has not yet been shown because studies have not gone on for long enough.

Effect of taking tamoxifen daily for 5 years on risk of developing breast cancer over that time



If all 1000 women take tamoxifen for 5 years, over that time on average:

- 950 women will not develop breast cancer, but would not have done anyway (the black figures on the white background)
- 15 women will avoid developing breast cancer (the white figures on the grey background)
- 35 women will still develop breast cancer (the white figures on the black background)

Women who take tamoxifen continue to benefit for at least 11 years after they stop taking it. It is expected that the benefit will continue for longer than, but this has not yet been shown because studies have not gone on for long enough.

Side effects from taking a medicine

All medicines can cause side effects, but not everyone gets them. The graphics on the next pages show the effect of

- tamoxifen and raloxifene on your risk of blood clots such as deep vein thrombosis (DVT) or a blood clot in the lungs (pulmonary embolism) while you are taking them. Tamoxifen and raloxifene are not thought to affect your risk after you stop taking them.
- tamoxifen on your risk of getting endometrial cancer (cancer of the womb) while you are taking it. Tamoxifen is not thought to affect your risk after you stop taking it.

Anastrozole has not been shown to make a difference to your chance of getting blood clots.

Anastrozole and raloxifene have not been shown to make a difference to your chance of getting endometrial cancer.

The actual number of women affected per 1000 depends on the chance of the things happening anyway (known as 'baseline risk'), which will be different for different women. The graphics on the next pages show the effects of tamoxifen or raloxifene on women at **average** baseline risk. Your healthcare professional will explain if you are likely to be at higher or lower baseline risk than this, and what this means for your risk with treatment.

Remember that no-one can say what will happen to any individual woman.

Some things make you more likely to get blood clots, including being inactive for long periods – such as after an operation or during a long journey.

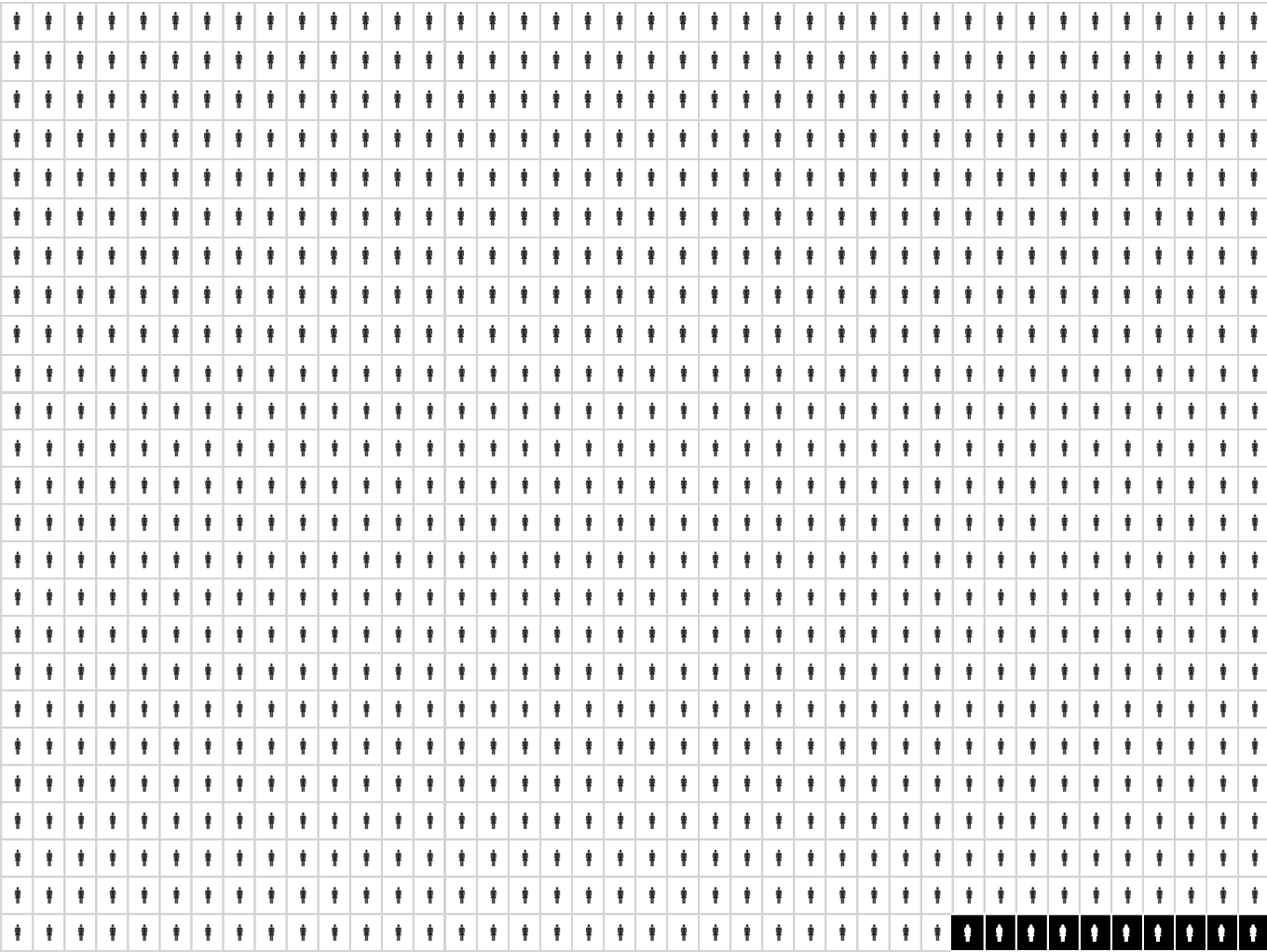
If you need an operation or you will be inactive for a long period should stop taking raloxifene at least 3 days beforehand, and stop taking tamoxifen at least 6 weeks beforehand (if possible).

Your healthcare professional will be able to advise you.

More information about blood clots is available on [the NHS website](#).

Risk of blood clots

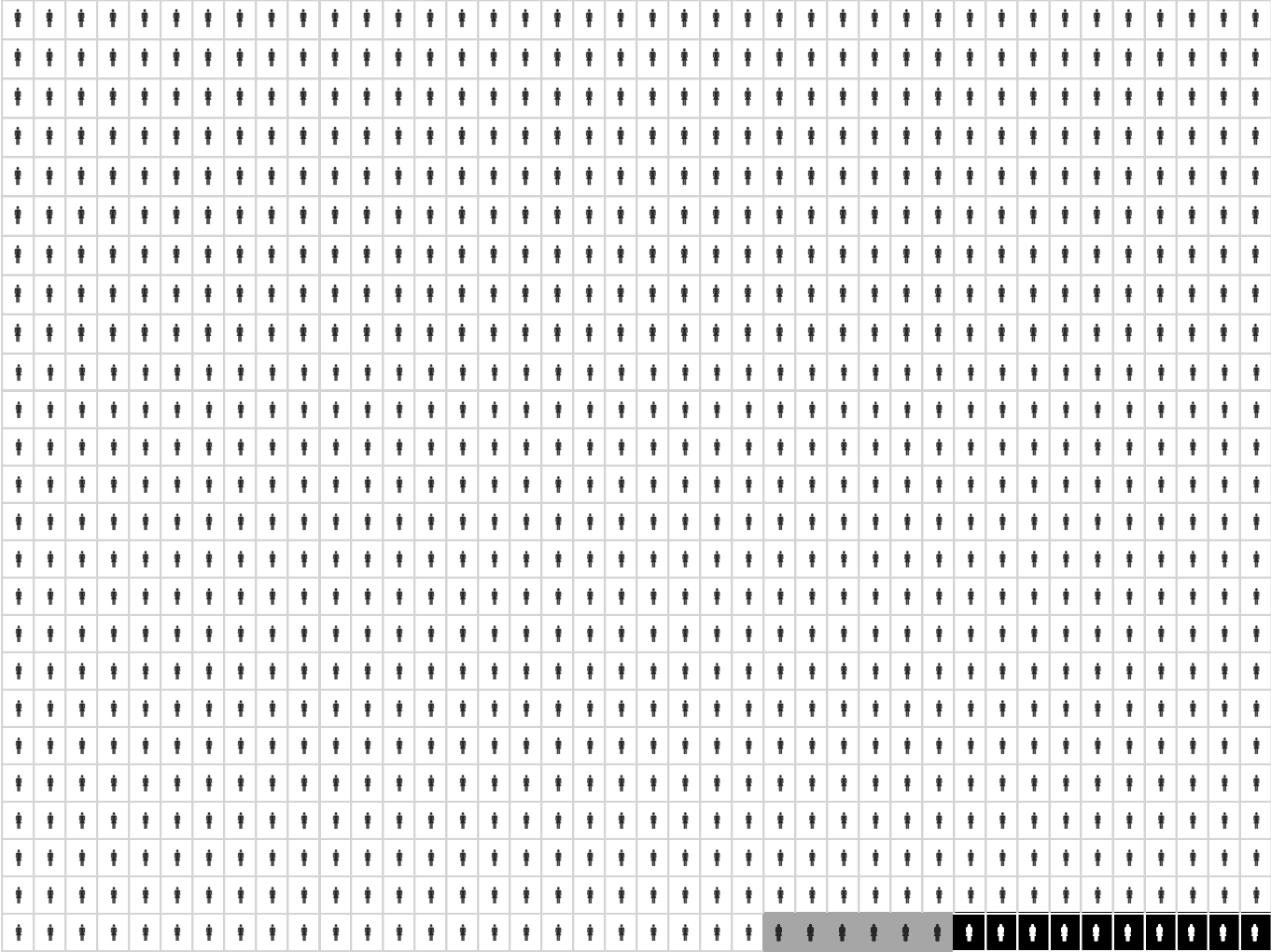
No treatment



If 1000 women at this level of risk take no treatment, over **5 years** on average:

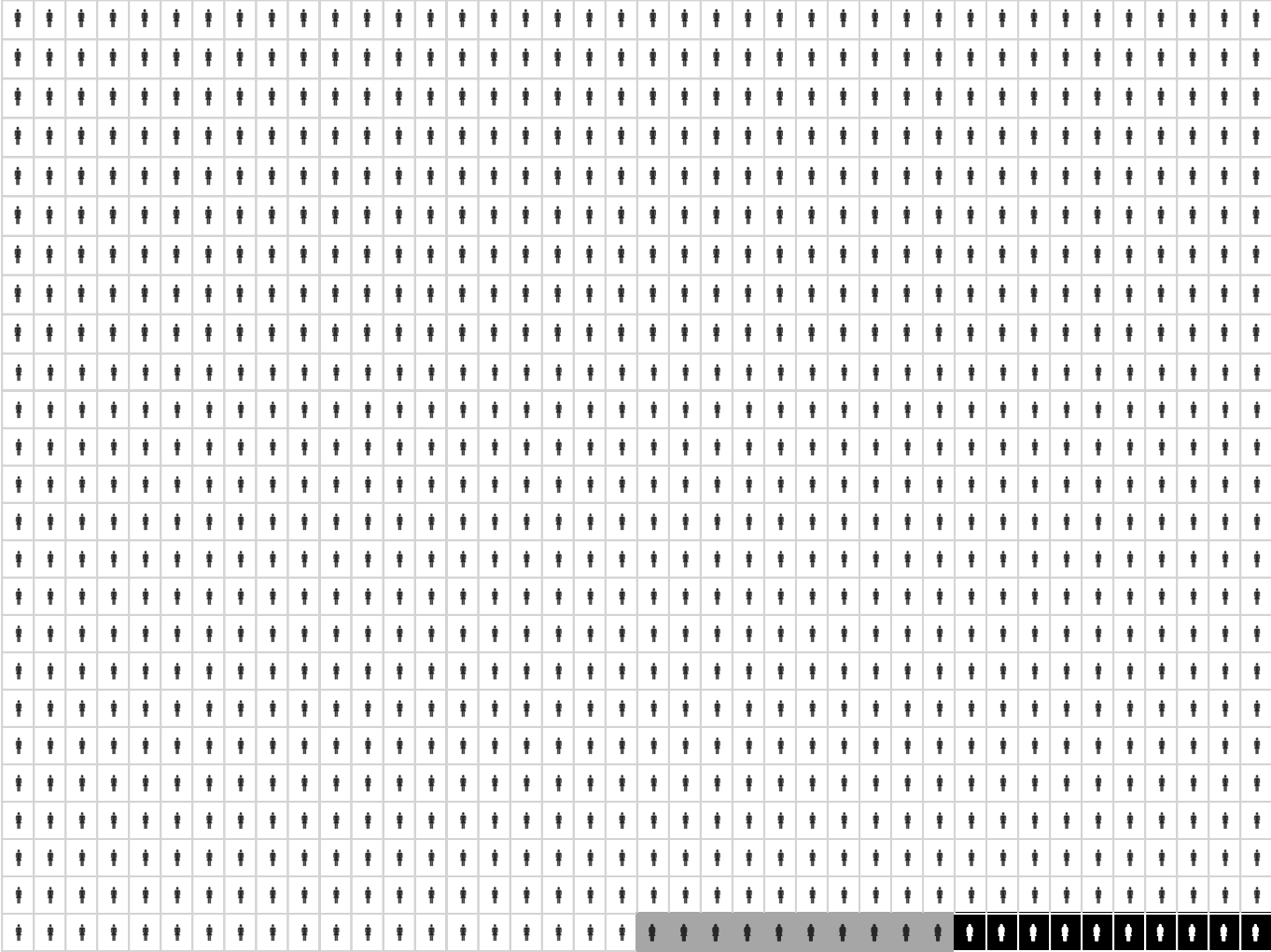
- 990 women will not get blood clots (the black figures on the white background)
- 10 women will get blood clots (the white figures on the black background)

Effect of taking raloxifene daily for 5 years on risk of blood clots while taking it



- If all 1000 women take raloxifene for 5 years, **over that time** on average:
- 984 women will not get blood clots (the black figures on the white background)
 - 10 women will get blood clots but would have done anyway (the white figures on the black background)
 - 6 extra women will get blood clots (the black figures on the grey background)

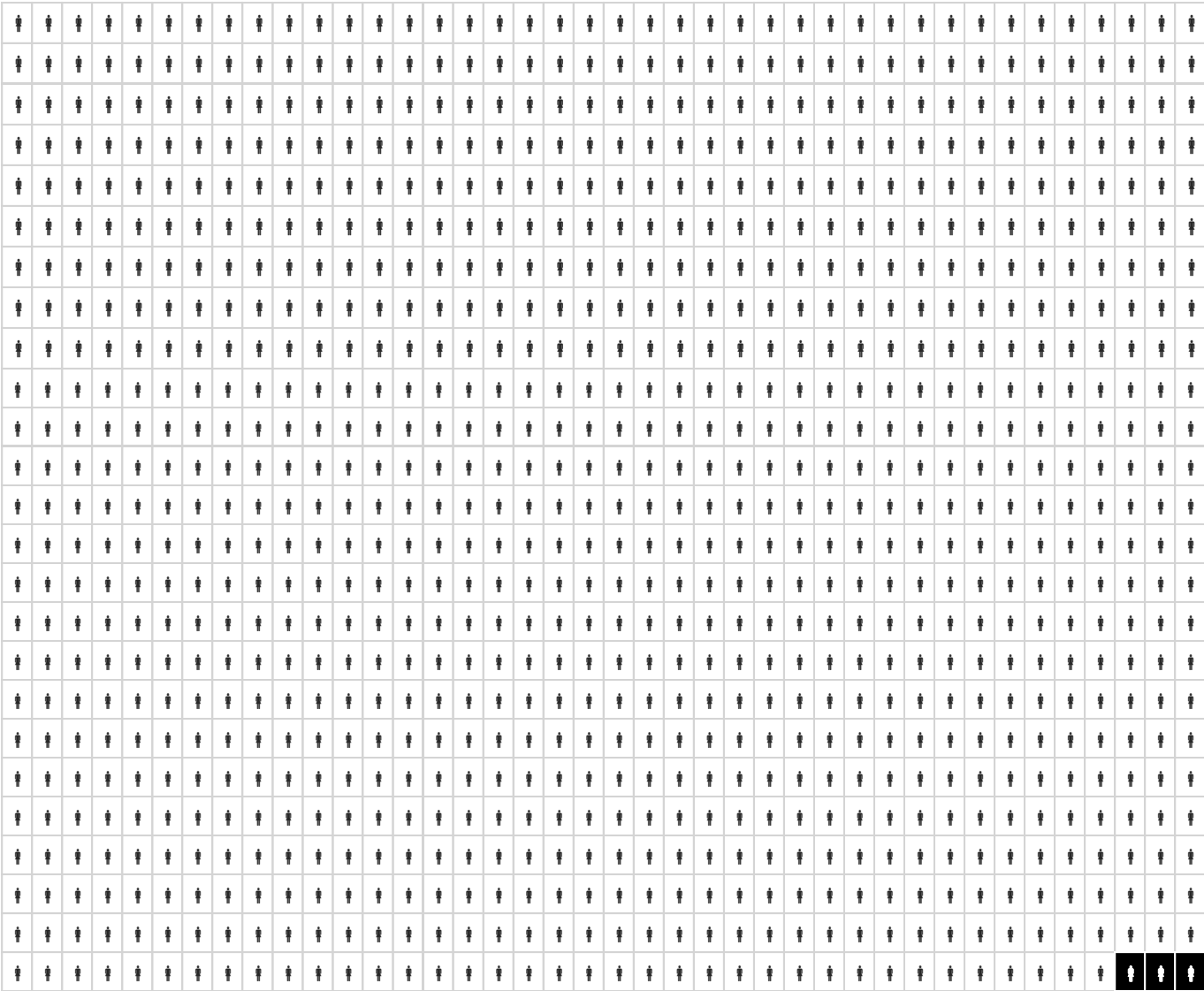
Effect of taking tamoxifen daily for 5 years on risk of blood clots while taking it



- If all 1000 women take tamoxifen for 5 years, **over that time** on average:
- 980 women will not get blood clots (the black figures on the white background)
 - 10 women will get blood clots but would have done anyway (the white figures on the black background)
 - 10 extra women will get blood clots (the black figures on the grey background)

Risk of endometrial cancer

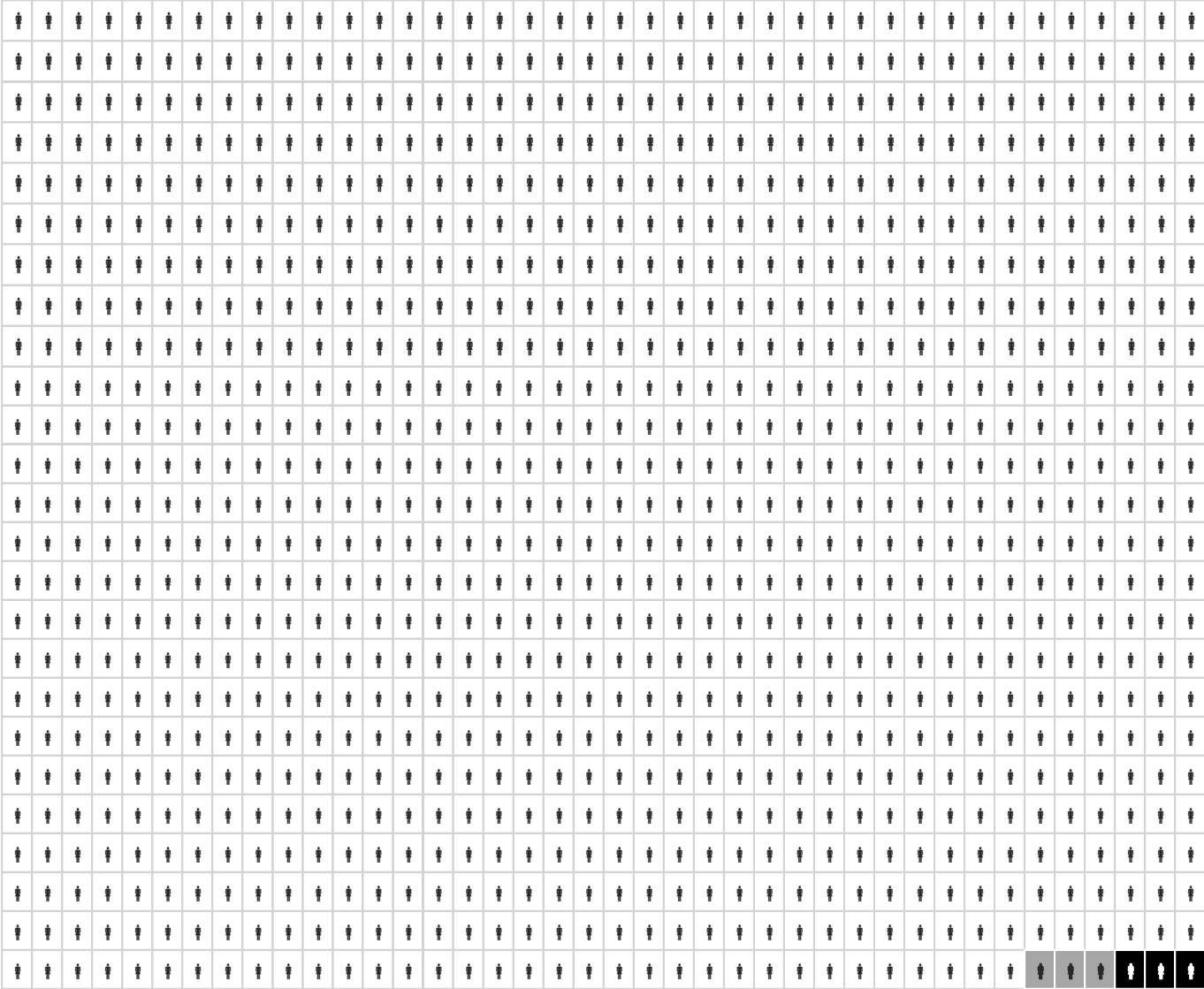
No treatment



If 1000 women at this level of risk take no treatment, over **5 years** on average:

- 997 women will not get endometrial cancer (the black figures on the white background)
- 3 women will get endometrial cancer (the white figures on the black background)

Effect of taking tamoxifen daily for 5 years on risk of endometrial cancer while taking it



If all 1000 women take tamoxifen for 5 years, **over that time** on average:

- 994 women will not get endometrial cancer (the black figures on the white background)
- 3 women will get endometrial cancer, but would have done anyway (the white figures on the black background)
- 3 extra women will get endometrial cancer (the black figures on the grey background)