

## Patient decision aid

# Taking tamoxifen to reduce the chance of developing breast cancer

## Decision aid for premenopausal 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 called tamoxifen 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 called tamoxifen 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 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 tamoxifen you will be less likely to develop breast cancer than if you do not take it. However, some women who take tamoxifen will still develop breast cancer.
- Taking tamoxifen 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 it.
- Taking tamoxifen might give you side effects, although not every woman gets these.
- If you start taking tamoxifen 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 5 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	Tamoxifen
<p><b>1. What does this option involve?</b></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><b>2. What difference will it make to my chance of developing breast cancer?</b></p> <p>See pages 6–8 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 to take tamoxifen, over 10 years:</p> <ul style="list-style-type: none"> <li>• about 100 women will develop breast cancer</li> <li>• about 900 women will not.</li> </ul> <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 tamoxifen, over 10 years (the 5 years of taking tamoxifen plus a further 5 years afterwards):</p> <ul style="list-style-type: none"> <li>• about 70 women (30 fewer) will develop breast cancer</li> <li>• about 930 women will not.</li> </ul> <p>You will continue to benefit for at least 11 years after you stop taking it. It is expected that the benefits will continue after this, but this has not yet been shown.</p> <p><b>Tamoxifen has not been shown to reduce your risk of dying from breast cancer.</b></p>
<p><b>3. 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)?</b></p> <p>See pages 9–11 for more information and diagrams to help explain this.</p>	<p>If 1000 women at <b>average</b> risk of getting a blood clot do not take tamoxifen, over 5 years</p> <ul style="list-style-type: none"> <li>• about 10 women will get a blood clot</li> <li>• about 990 will not.</li> </ul> <p>Your healthcare professional will explain if your personal risk is more or less than this.</p>	<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 <b>average</b> risk of getting a blood clot take tamoxifen for 5 years:</p> <ul style="list-style-type: none"> <li>• about 20 women (10 extra) will get a blood clot in that time</li> <li>• about 980 women will not get a blood clot in that time.</li> </ul>
<p><b>4. What are the other common side effects?</b></p>	<p>None.</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</p>

-	No medicine	Tamoxifen
		<p>women taking tamoxifen than those taking dummy tablets were:</p> <ul style="list-style-type: none"> <li>• hot flushes</li> <li>• abnormal vaginal bleeding</li> <li>• vaginal discharge.</li> </ul> <p>However, some women taking dummy tablets also had these effects. For example, in every 1000 premenopausal women who took tamoxifen about 680 got hot flushes (and about 320 did not). But in every 1000 premenopausal women who took dummy tablets about 540 got hot flushes (and about 460 did not).</p> <p>Other side effects have been reported less often. More information is available in the <a href="#">manufacturer's leaflets, such as this one</a>.</p>
<p><b>5. What if I want to try for a baby?</b></p>	<p>Taking no medicine means that there are no extra issues if you want to try for a baby.</p>	<p>You should avoid getting pregnant while taking tamoxifen. Ask your healthcare professional about contraception if this applies to you. You should stop taking tamoxifen at least 2 months before trying for a baby.</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 getting a blood clot					
The possibility of other side effects					
Issues if I want to try for a baby					

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 from taking tamoxifen**

Taking tamoxifen for 5 years reduces your risk of developing breast cancer while you take it. It has also been shown that 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 this, but this has not yet been shown because studies have not been going on for long enough.

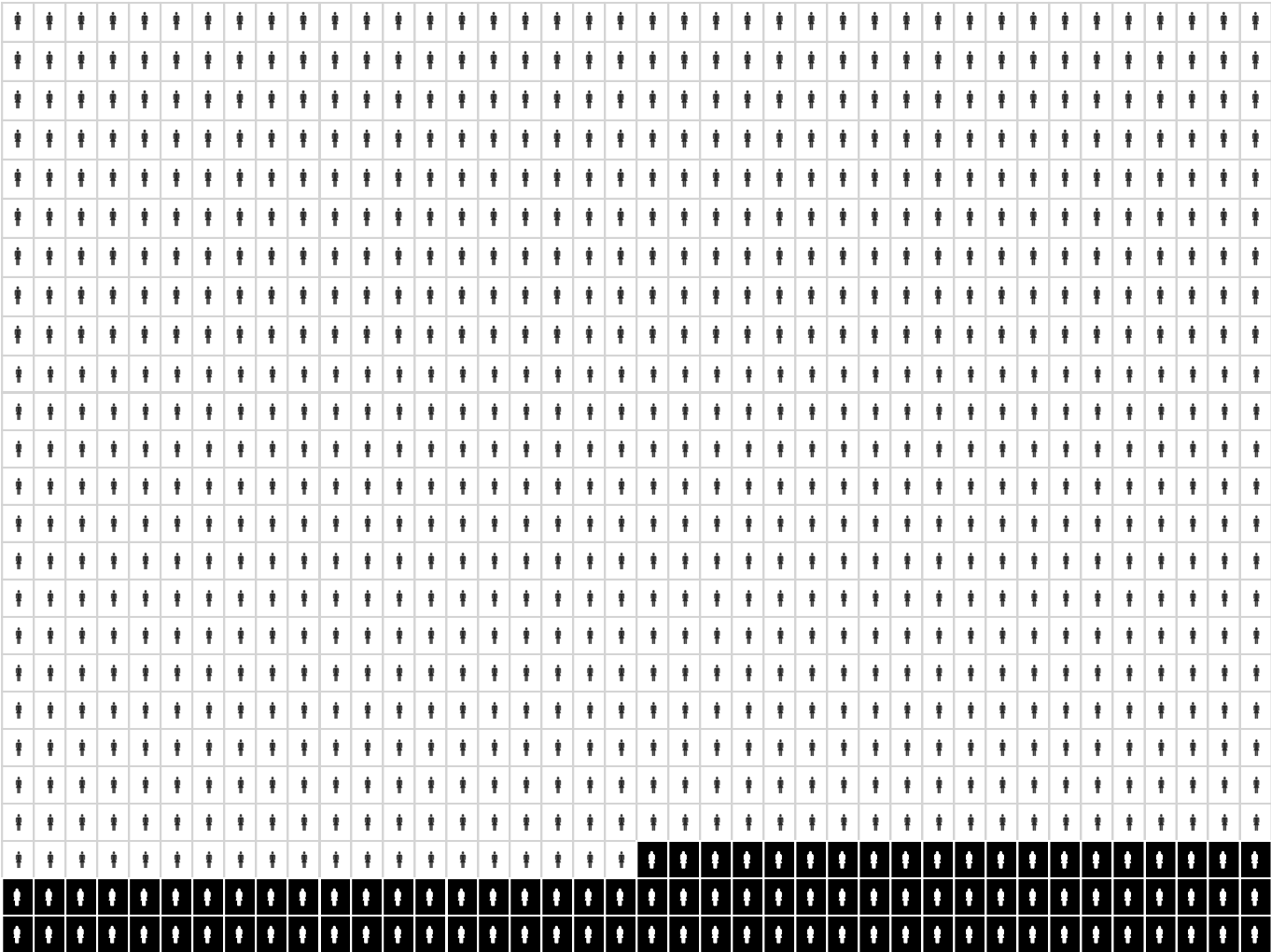
Although some women who take tamoxifen will avoid developing breast cancer because they have taken it, some women who take it would never develop breast cancer anyway. Some women who take tamoxifen still develop breast cancer at some point in their lives. The actual number of women who benefit per 1000 who take tamoxifen 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.

The graphics on the next page show the estimated effects of tamoxifen on women at **10% baseline risk** of developing breast cancer **over 10 years** (100 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 breast cancer 10% over 10 years (100 in 1000)

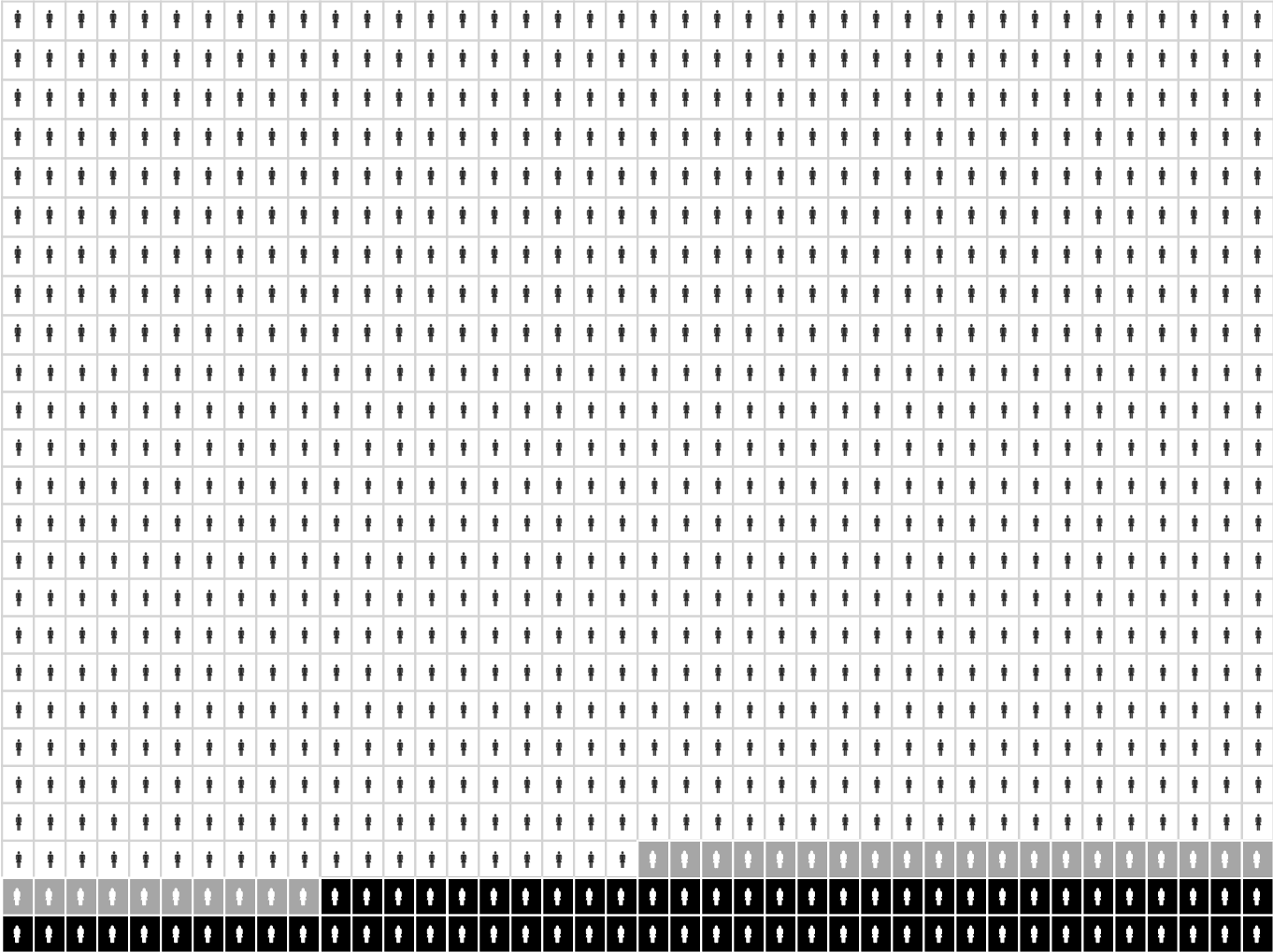
## No treatment



If 1000 women at this level of risk take no treatment, over **10** years on average:

- 900 women will not develop breast cancer (the black figures on the white background)
- 100 women will develop breast cancer (the white figures on the black background)

**Effect of taking tamoxifen daily for 5 years on risk of developing breast cancer over 10 years**



If all 1000 women take tamoxifen for 5 years, **over 10 years** on average:

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

The graphic shows the benefits over the 5 years of taking tamoxifen plus a further 5 years afterwards. 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 this, but this has not yet been shown because studies have not been going on for long enough.



## **Risk of blood clots while taking tamoxifen**

Tamoxifen increases your risk of certain side effects. The graphics on the next pages show the effect of tamoxifen on your risk of blood clots, such as deep vein thrombosis (DVT) or a blood clot in the lungs (pulmonary embolism). Tamoxifen increases your risk of having a blood clot while you are taking it, but after you stop taking it your risk would be the same as similar women who have not taken tamoxifen.

The actual number of women affected per 1000 who take tamoxifen depends on the chance of them having a blood clot anyway (known as their 'baseline risk' of blood clots), which will be different for different women. The graphics on the next pages show the effects of tamoxifen on women at **average** baseline risk of blood clots. 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**

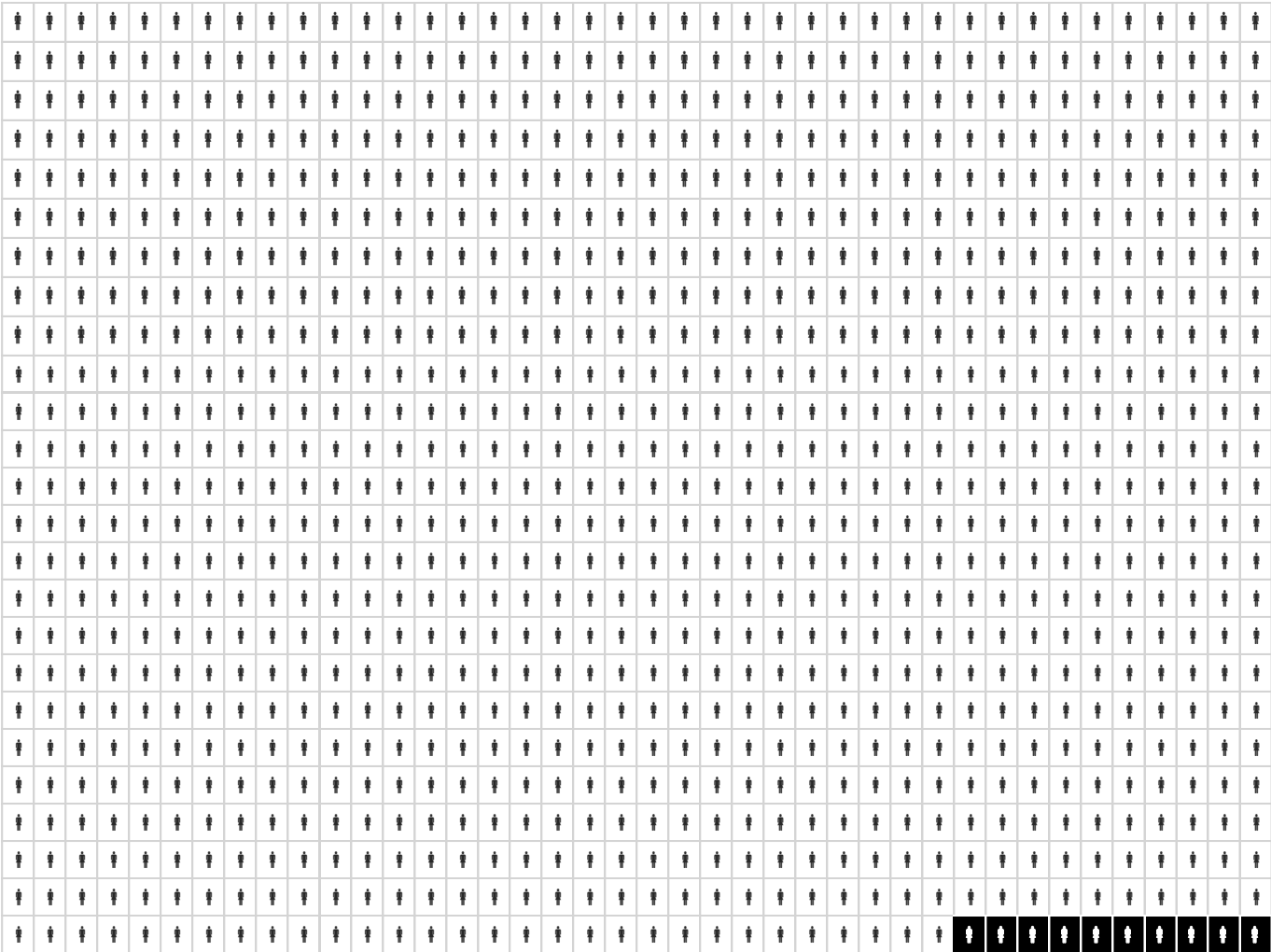
Some things make you more likely to get blood clots, including being inactive for long periods – such as after an operation or during a long journey.

If you need an operation or you will be inactive for a long period you should stop taking tamoxifen at least 6 weeks beforehand (when 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

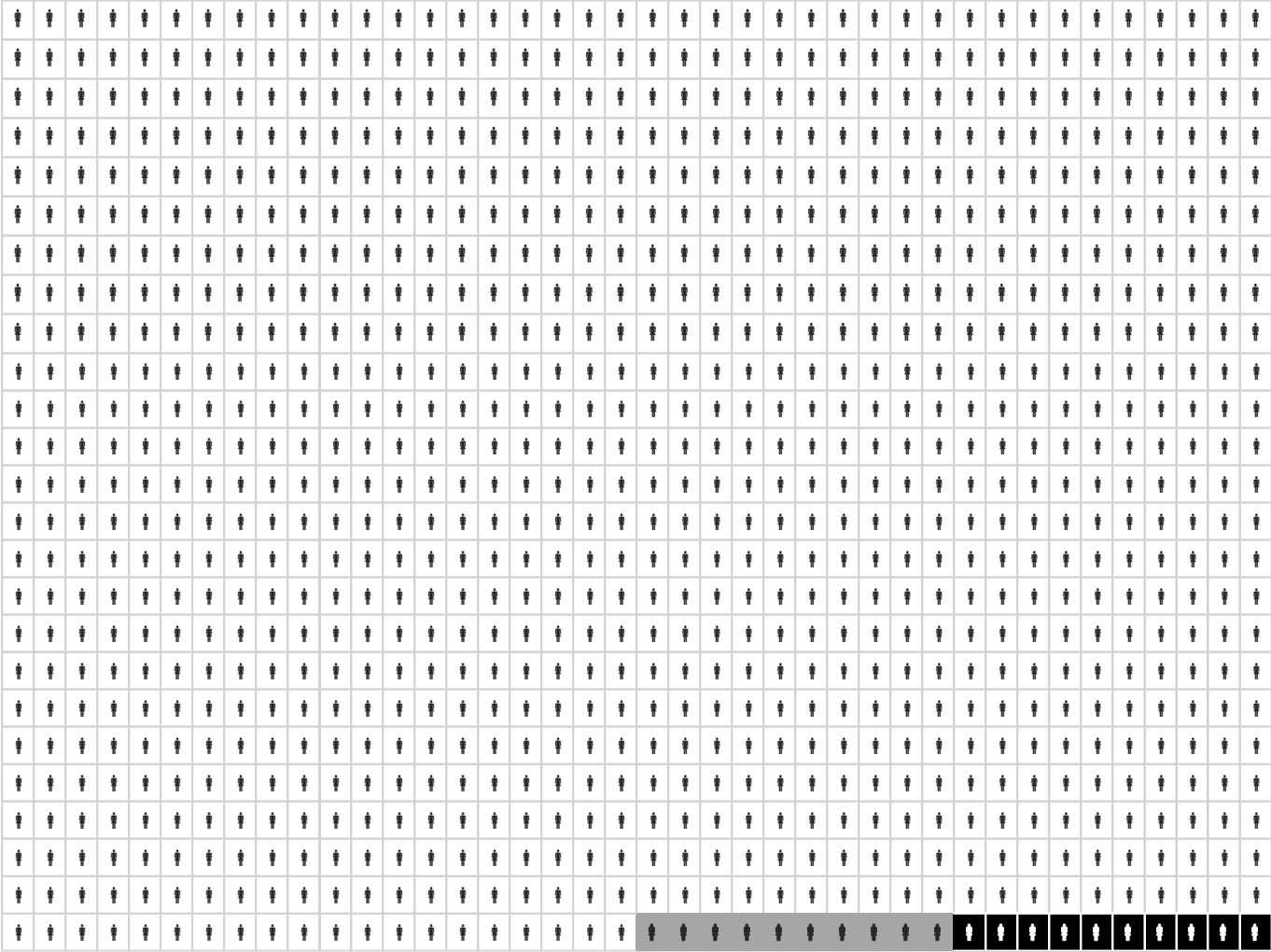
## No treatment



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 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)