Making Choices
A decision aid for women with breast cancer

Deciding whether to join the SNAC2 trial
(Sentinel Node Biopsy versus Axillary Clearance)
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## Contents

**Introduction**
- How does this booklet help? 4

**Surgery for breast cancer** 5

**Lymph nodes** 6
- How many women will have cancer spread to the lymph nodes? 7
- Surgical removal of the lymph nodes 7
- What are my options in relation to the surgical removal of the lymph nodes in the armpit? 8

**Option 1: Surgical removal of the axillary lymph nodes:**
- Axillary clearance
  - What is axillary clearance (AC)? 9
  - Potential benefits of axillary clearance 9
  - Potential side effects and risks of axillary clearance 10
  - More about lymphoedema 11
  - Summary of the pros and cons of axillary clearance 12

**Option 2: SNAC2 trial:**
- Sentinel node biopsy versus axillary clearance
  - SNAC1 clinical trial: what do we already know about sentinel node biopsy 13
  - SNAC2 clinical trial: what is being investigated? 13
  - Who is participating in the SNAC2 trial? 14
  - What is a clinical trial? 14

- How are sentinel nodes identified? 15
- What happens after sentinel nodes are identified? 16
- Potential benefits of sentinel node biopsy 16
- Potential side effects and risks of sentinel node biopsy 17
- Additional treatment and why it is important 19
- What if I’m allocated to the group that gets axillary clearance surgery? 19
- What else is involved if I join the SNAC2 trial? 20
- Do I have to take part in the SNAC2 trial? 20
- Summary of the pros and cons of the SNAC2 clinical trial 21

**Making a decision that is right for you** 22

**Worksheets**
- Example Worksheets 24
- Your worksheet 26

**Notes** 27

**Further contacts** 28

**References** 29

**Glossary of terms** 30

**Acknowledgements** 32
Introduction

If you are reading this booklet you will have been diagnosed with breast cancer. You will be currently discussing your treatment options with your doctor and making a number of decisions about your treatment and the next steps to take.

Your doctor is the key person to provide you with guidance and recommendations about which options are suitable in your situation. It is likely that you have been advised that the best treatment for you is breast surgery (either breast conserving surgery or mastectomy), followed by the removal of some or all of the lymph nodes under your armpit. For this procedure there are two options available: (1) axillary clearance or (2) joining a clinical trial called SNAC2 (Sentinel Node Biopsy versus Axillary Clearance 2).

In addition to the treatment decisions, there are a number of emotional challenges at this time. Being diagnosed with breast cancer is a shock for most women, particularly if they have few obvious symptoms and are feeling well. Women commonly say that they have feelings of fear, helplessness, anger or anxiety.

One constructive way to cope is to empower yourself with as much information as possible. The more informed you are, the easier it will be to decide what is best for you.

How does this booklet help?

This booklet has been developed to help explain the different ways lymph nodes can be removed during surgery. Specifically it has been designed to help you make an informed decision about whether or not you wish to participate in the SNAC2 clinical trial.

The booklet:

► explains the trial in detail,
► explains the benefits and risks involved in each treatment option available to you,
► offers some advice on how to make an informed decision, and
► provides examples of how other women in similar situations have approached this decision.

Surgery for breast cancer

Breast cancer is a cancer that starts in the cells of the breast. Treatment for breast cancer normally includes surgery with or without additional chemotherapy, hormone therapy and/or radiation. It is important that you talk with your doctor about your options and the likely outcomes of treatment.

Surgery for breast cancer will usually include either:

► a wide local excision, also referred to as breast conserving surgery or a lumpectomy (surgery that removes only the cancer with a small amount of normal tissue around it),

OR

► a mastectomy (surgery that removes the entire breast).

Your medical team will discuss these options with you and provide advice to help you decide which is more suitable to you.

Note: If you would like more information about these procedures, we recommend that you consult the National Breast and Ovarian Cancer Centre website: www.breasthealth.com.au (see the breast health and treatment options sections in particular).
Lymph nodes

The lymph system is made up of tiny vessels that carry fluid from the tissues to lymph nodes and then to the blood stream. The lymph nodes filter the fluid to remove bacteria and other impurities.

The reason that the lymph system and lymph nodes are important is that when breast cancer spreads, it often travels to other parts of the body through the blood and the lymph systems. If cancer cells get into the lymph system, then they may spread to the blood and other parts of the body.

The lymph nodes in the armpit will often be the first place where breast cancer spread is detected. Therefore, knowing whether or not these nodes contain cancer is critical. This will allow your medical team to give good advice about:

1. prognosis (the possible course of a disease and the patient’s chance of recovery or cure)
2. additional treatment (endocrine therapy or chemotherapy).

Below is a picture of lymph nodes with numbers indicating the node levels within the armpit (axilla). The sentinel node/s are the lymph node/s closest to the cancer and are the first node/s that filter fluids draining away from the breast. The sentinel node is usually but not always under the armpit.

How many women will have cancer spread to the lymph nodes?

The diagram to the right has 100 dots that represent 100 women.

The first 30 dots are shaded in orange to indicate that of these 100 women, 30 will have cancer that has spread to the lymph nodes.

The next 30 dots shaded in gold indicate that an additional 30 women may have cancer that has spread to the lymph nodes. This figure is uncertain as the exact number depends on various features of the woman’s cancer.

The final 40 unshaded dots represent the 40 women who will not have cancer in their lymph nodes. In other words, you have a 30-60% chance of having cancer spread to the lymph nodes.

Surgical removal of lymph nodes

Your surgeon will remove and examine some or most of the lymph nodes under your armpit to:

► determine whether or not they contain any cancer cells,
► remove these cancer cells (as an effective means to prevent local recurrence),
► give advice about prognosis and treatment.

Your doctor will use one of the following two techniques to remove the lymph nodes:

1. axillary clearance, or
2. sentinel node biopsy (performed as part of the SNAC2 trial).

These will be discussed in more detail over the following pages.
What are my options in relation to the surgical removal of the lymph nodes in the armpit?

There are two options for the surgical removal of the lymph nodes in the armpit (axilla).

**Option 1: Axillary Clearance**

**What is axillary clearance (AC)?**

In standard treatment, the surgical team will perform an axillary clearance to remove and examine the lymph nodes in the armpit (axilla). Usually with axillary clearance the Level 1 and 2 (and sometimes Level 3) nodes are removed (see page 6 for a diagram of lymph nodes). A pathologist will then examine the nodes in detail to determine if cancer cells are present within these lymph nodes.

**Potential benefits of axillary clearance**

- **All the surgery is done in a single operation**
  The breast and lymph node surgery is all completed at the same time and you will only require one operation and anaesthetic.

- **Low risk of leaving behind lymph nodes containing cancer**
  With axillary clearance most of the nodes are removed. As a consequence, the risk of leaving behind lymph nodes containing cancer is very low, about 1 or 2 in 100 women.

- **Low risk of the cancer coming back in the armpit**
  Axillary clearance is very effective in detecting and preventing the return of cancer in the armpit. Only about 1 woman in 100 will have their cancer return in the armpit.

- **Currently the standard treatment**
  Axillary clearance is the standard treatment and its risks and safety record are very well known.

*Please note that some centres may offer sentinel node biopsy outside of a trial.*
Potential side effects and risks of axillary clearance

Risks associated with axillary clearance include:

➤ Seroma formation
Serous fluid is the pale yellow fluid that is produced by lymph vessels and by the tissues that lie beneath the skin. You will have seen serous fluid if you’ve ever had a blister on your hand or foot - the fluid that comes out when you puncture a blister is serous fluid. After surgery, the serous fluid can gather in the armpit forming a swelling called a seroma.

About 30-40 out of 100 patients who have axillary clearance develop a seroma. The doctor may use a syringe/needle to drain the seroma and this may be done more than once. This can be uncomfortable and uncommonly can lead to local infection but is normally only a problem for a short time after the surgery.

➤ Haematoma
A haematoma is where the blood collects in the tissues surrounding the operative wound and causes swelling, discomfort and hardness. This can occur in around 5 out of 100 patients who have axillary clearance. Over several weeks your body will reabsorb the blood, although if the haematoma causes you a lot of discomfort your surgeon may decide to drain the fluid using a syringe and needle (or uncommonly you may need to return to theatre to remove the clot and stop any ongoing bleeding).

➤ Wound infection
Postoperative wound infection of the axillary wound can occur in about 14 out of 100 patients. It can be managed using oral antibiotics, together with drainage of any infected seroma fluid.

➤ Risk of arm problems and lymphoedema
Axillary clearance can result in arm problems for some women, including altered sensation (numbness and/or uncomfortable sensation or even pain), less commonly some reduction in range of shoulder movement, and rarely some loss of function. These arm problems may be uncomfortable and can sometimes lead to difficulties in performing daily activities, such as carrying shopping, cooking, cleaning etc.

However, they are not normally severe enough to affect a woman’s quality of life after 12 months. The number of women reporting arm problems varies a lot between different studies but most women will improve by 6-12 months.

To manage arm problems such as loss of movement, you may require a referral to other professionals such as a physiotherapist, specialised nursing staff or an occupational therapist.

Lymphoedema is a particular arm problem that can result from lymph surgery. It is a swelling of a part of the body (in this case the arm) that occurs because of a build-up of lymph fluid in the body’s tissues. Lymphoedema can be mild, moderate or severe. With axillary clearance, it is estimated that around 7 out of 100 women will develop some degree of lymphoedema within the first 12 months post-surgery, and this rate increases with time. Overall, the risk of lymphoedema after axillary clearance is somewhere between 5-30% (or affecting 5-30 out of 100 women). See the box below for more information.

More about lymphoedema

Surgery to the lymph nodes can stop the lymph fluid from flowing through some of the arm channels (lymphatics) and can cause fluid to build up in the arm or breast, leading to lymphoedema.

Lymphoedema usually develops gradually and it is likely to develop months or even years after treatment for breast cancer. Symptoms can include tension, swelling, tightness, fullness, heaviness, aches and pain in the arm. Women with lymphoedema are also at an increased risk of infection.

As a result of the physical symptoms, lymphoedema may affect a woman’s lifestyle and work. It is not uncommon to feel upset or embarrassed by the condition when first diagnosed but these emotions often lessen with time as the condition is managed.

While lymphoedema cannot be cured, the swelling can be controlled and managed with appropriate care from a physiotherapist, trained nurse or occupational therapist. Treatment may combine a number of therapies including:

➤ Manual Lymphatic Drainage (a massage technique which encourages lymph drainage),
➤ wearing a compression sleeve or sometimes using compression bandaging (which limits the swelling),
➤ rehabilitation exercises, and
➤ elevation of the limb.
Option 2: Sentinel Node Biopsy versus Axillary Clearance on the SNAC2 trial

As axillary clearance has a number of disadvantages and side effects, surgeons are trying to find better ways to check if the cancer has spread to the lymph nodes. This has led to a new surgical technique called sentinel node biopsy (SNB). This technique is now available through a clinical trial called Sentinel Node Biopsy versus Axillary Clearance in Operable Breast Cancer-2 (SNAC2) which will test whether this is better or not than axillary clearance.

SNAC2 is a research study specifically available to women with a diagnosis of early breast cancer:
- over 2-3cm in size and/or
- with more than one cancer identified in the breast (multifocal cancer).

In SNAC2, women will be randomised to receive either:
- sentinel node biopsy (SNB) followed immediately by an axillary clearance (AC),
- sentinel node biopsy (SNB) only to be followed by axillary clearance if cancer is found in the sentinel node/s.

SNAC1 clinical trial: what do we already know about sentinel node biopsy?

The two surgical techniques (axillary clearance versus sentinel node biopsy) were compared in an earlier trial, called Sentinel Node Biopsy versus Axillary Clearance in Operable Breast Cancer trial-1 (SNAC1). This trial involved 1,088 women with smaller breast cancers (less than 2-3cm). In SNAC1, sentinel node biopsy was found to result in fewer side effects than axillary clearance. As a result, sentinel node biopsy has now become the standard treatment for women with cancers of less than 2-3cm.

SNAC2 clinical trial: what is being investigated?

SNAC2 extends the work which begun with SNAC1. SNAC2 is asking the question, 'Does sentinel node based management work only for small breast cancers (less than 2-3cms) or is it appropriate for women with larger breast cancers or with more than one cancer in their breast?' If it is found to be appropriate, then sentinel node biopsy will become standard treatment for these types of tumours too.
Who is participating in the SNAC2 trial?

The SNAC2 trial is being carried out in hospitals around Australia, New Zealand and some parts of Asia. It is coordinated by the Royal Australasian College of Surgeons and the NHMRC Clinical Trials Centre. Approximately 1,000 women will take part in this study. The surgeons involved in this study are highly experienced with both surgical techniques: axillary clearance and sentinel node biopsy.

What is a clinical trial?

Clinical trials are a vital part of research into new and more effective medical techniques. Surgical procedures used today (i.e. current standard treatment procedures) have been tested in clinical trials in the past. For some people, however, clinical trials raise the fears of ‘experimentation’ and ‘being a guinea pig’. Understanding more about clinical trials may reduce these concerns.

Strict controls govern how clinical trials are conducted. An ethics committee must approve each clinical trial. This committee makes sure that the rights of the study participants are protected. New surgical techniques are only assessed in clinical trials after extensive testing by experienced surgeons. As a result, much is already known about the benefits and risks of the techniques offered. Sometimes the technique is not “new”; it is simply being used with different patients. For example, with sentinel node biopsy, this technique has been shown (in earlier clinical trials) to be effective in women with smaller breast cancers (2-3cm or less).

What is a randomised trial?

In a randomised clinical trial, the treatment each participant receives (either standard or new) is determined “by chance” (using a computer). Randomisation makes sure that the study groups are as similar as possible. This gives a more reliable picture of the effects of the techniques. The researchers will be able to compare the effectiveness of the techniques and find out which technique is better.

When you are part of a randomised clinical trial, you are not disadvantaged, because you will either receive the current best treatment or the new procedure, which is believed to be at least as good as or better than the standard treatment, or with less side effects.

What is a sentinel node biopsy (SNB)?

At present, the standard way to remove lymph nodes for women with breast cancer that is larger than 3 cm or with multiple (multifocal) cancers, is an axillary clearance (AC). A newer surgical diagnostic technique is a sentinel node biopsy, in which a small number of lymph nodes (most likely to contain cancer cells) are removed via biopsy. Sentinel node biopsy is sometimes referred to as SNB or SNBM.

During the sentinel node biopsy, the surgeon performs a smaller operation to identify and remove the sentinel node/s, which are the first node/s that filter fluids draining away from the breast (sentinel node biopsy). If these node/s are negative (i.e. without cancer cells) then it is likely that the other nodes have not been affected and the woman will not need further lymph nodes removed. This means that axillary clearance may be avoided for many women and by minimising the amount of surgery to the armpit, the risk of side effects is also minimised.

Sentinel node biopsy is currently the recommended standard treatment for women with breast tumours of less than 2-3cm.

How are sentinel nodes identified?

Most women taking part in the SNAC2 trial will have a scan to help find the sentinel node/s. This is called a lymphoscintigram and is done in the Nuclear Medicine Department a day or a few hours before the operation. Once a woman is asleep on the operating table, a small amount of blue dye is injected near the cancer. Using a combination of seeing blue colour in lymph channels and node/s, and a probe that can detect radioactivity, sentinel node/s can almost always be found.

The blue dye and the radioactive fluid are both safe although the injection is usually uncomfortable and can be sometimes painful. Allergic reactions such as redness or itching occur occasionally, and uncommonly severe allergic reactions may occur. The amount of radiation involved in this procedure is minimal, much less than a standard x-ray and about one-fiftieth of the dose used for a bone scan. More than 95% of the radiation is gone by the end of the operation. Sometimes people wake with blue tinged skin or have blue urine but this only lasts for a short time.

Note: Sometimes sentinel node/s are not found (this occurs in less than 1 in 20 operations). If this happens then a standard axillary clearance is recommended.
What happens after the nodes are identified?

Often there is only one sentinel node identified but there may be a few (rarely more than four). In some centres, the sentinel node(s) may be partially examined while a woman is still under anaesthetic for her mastectomy or lumpectomy. If cancer is identified in the sentinel node(s) then axillary clearance can be performed under the same anaesthetic.

For all women, in the days after the operation the pathologist examines the sentinel node(s) in greater detail, and if no cancer cells are found, no further surgery is required. If cancer cells are found in the sentinel node(s), then an axillary clearance is recommended. The reason for this is that there may be cancer cells in the remaining lymph nodes, although in some cases there are none. We expect that 30-60% of women having sentinel node biopsy (SNB) in the SNAC2 trial will need an axillary clearance. That is, between 30 and 60 women in every 100 women in SNAC2 who initially have a sentinel node biopsy will need to have an axillary clearance, possibly as a second operation.

Potential benefits of sentinel node biopsy

Benefits of sentinel node biopsy include:

- **Axillary clearance is avoided in about 40-70% of women (40-70 out of 100)**
  For 40-70% of women, cancer will not have spread to the lymph nodes and axillary clearance can be avoided.

- **The sentinel nodes can be investigated in more detail**
  Sentinel node biopsy allows a close investigation of the sentinel node(s), which helps doctors to assess whether or not cancer has spread to the remaining armpit lymph nodes. This will then give the medical team better information about your prognosis and treatment options.

- **A smaller operation with a lower risk of side effects**
  By removing only those nodes most likely to show the spread of cancer, sentinel node biopsy can potentially help to avoid or reduce the likelihood of the complications and side effects commonly associated with axillary clearance. The operation, hospital stay and recovery time are shorter for women having sentinel node biopsy compared to those having axillary clearance.

Potential side effects and potential risks of sentinel node biopsy

Sentinel node biopsy is a smaller operation than axillary clearance, and is associated with fewer risks of side effects. (For more information about the side effects of axillary clearance see page 10).

Potential side effects and risks of sentinel node biopsy include:

- **Seroma formation**
  About 11 out of 100 women who have sentinel node biopsy develop a seroma (versus 34 out of 100 after axillary clearance).

- **Haematoma**
  A haematoma occurs in around 6 out of 100 women who have sentinel node biopsy (this rate is similar to axillary clearance).

- **Wound infections**
  Post-operative wound infection is uncommon in sentinel node biopsy, occurring in 8 out of 100 women (versus 14 out of 100 after axillary clearance).

- **Arm problems and lymphoedema**
  Sentinel node biopsy can result in arm problems including reduced shoulder mobility, pain in the armpit, numbness and loss of function, however this occurs in a much smaller number of women than after axillary clearance.

Lymphoedema can still occur with sentinel node biopsy alone and be mild, moderate or severe. With sentinel node biopsy, about 3 out of 100 women will develop lymphoedema within the first 12 months post-surgery (versus 7 out of 100 after axillary clearance). This figure includes both those women who have sentinel node biopsy alone and those that require additional axillary clearance surgery after the biopsy due to cancer identified in the lymph nodes. The number of women with lymphoedema is likely to increase as lymphoedema develops gradually months or years after the treatment, particularly for those having axillary clearance.
Possible need for a second operation if cancer is found in the sentinel node/s

For 30-60% of women (30-60 out of 100), sentinel node/s are likely to be found to be positive during or after the initial operation. For these women, a second operation in the form of an axillary clearance will be required. At the centres where sentinel nodes are pathologically reviewed during the first operation, the likelihood of a second operation for axillary clearance reduces to between 10-20% of women (10-20 out of 100).

There is a risk that undetected cancer cells may be left behind in the remaining lymph nodes in the armpit (axilla)

The risk of this happening will depend on two factors:
1. the size and some other pathological features of the cancer; and
2. the skill of the team in identifying sentinel nodes. In the SNAC2 trial the surgeons meet a very high level of expertise in performing sentinel node biopsy assessments.

For women eligible for the SNAC2 trial, about 2 - 7 out of 100 may have undetected cancer cells remaining in the other lymph nodes in the armpit after sentinel node biopsy.

It is not known what effects leaving small amounts of cancer cells in the lymph nodes can have. It is possible that leaving cancer cells in the body could mean that it spreads to other parts of the body and this results in an increased risk of cancer recurrence. The SNAC2 trial is being carried out to determine if this is the case. Preliminary evidence suggests that the risk of cancer cells being left in the armpit and leading to local recurrence of cancer is much less than the risk that cells being left suggests. This is likely because most women have additional therapy (chemotherapy or endocrine therapy or radiotherapy) that may prevent these cells causing further trouble.

Additional treatment and why it is important

As part of your management plan, your medical team will discuss with you the need for additional treatment. This will normally happen following surgery, depending on what is found. Most women in the SNAC2 trial will need additional drug treatment; either chemotherapy or hormonal therapy or both. If the affected nodes are in the lower armpit, these may be treated by radiotherapy.

These treatments provide an important “mopping up” function for any remaining cancer cells left in the breast and lymph system but are not perfect.

I will be injected with blue dye and the radioactive fluid

To identify the sentinel nodes, you will have a lymphoscintigram through the Nuclear Medicine Department. Once you are asleep in the theatre, you will also have a small amount of blue dye injected near the tumour. In some women, these procedures may cause some reactions such as allergies and pain. For more information see page 15.

What will happen if I’m allocated to the group that has axillary clearance surgery on the SNAC2 trial?

If you are allocated to the standard arm (immediate axillary clearance), you will have the same initial steps:
1. the sentinel nodes will be identified with a scan and blue dye, and
2. the sentinel node/s will be removed first.

This is for research purposes so that your medical team can check the status of the sentinel node/s and determine whether or not an axillary clearance would have been required anyway.

Following the removal of your sentinel nodes, a standard axillary clearance is done in the same operation. (See page 8 for a flowchart of the process.)
What else is involved if I join the SNAC2 trial?

If you join the SNAC2 trial, your wellbeing will be closely monitored and all information regarding your condition will be carefully and confidentially recorded. You will have access to a support team (including your study doctor) who can provide information on a regular basis during the study.

You will be receiving the same level of screening and clinical examinations as you would as part of your standard follow-up routine following surgery. During the first year of the trial you will be asked to come into the clinic (at 6 and 12 months) for a breast examination and to check your general health. After the first year of the study, your study coordinator will arrange your annual follow-up visits. Screening mammograms and clinical examinations will be done at least once a year.

All patients on the SNAC2 trial will need to have additional procedures: scan, dye and initial sentinel node removal regardless of which group (sentinel node or axillary clearance) they are allocated to.

Summary table of assessments & follow-up schedules whilst on SNAC2 (these are the same as for women receiving standard care)

<table>
<thead>
<tr>
<th></th>
<th>Prior to study entry</th>
<th>0-1 year</th>
<th>2-10+ years</th>
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<td>At study entry</td>
<td>Every 6 months</td>
<td>Every year</td>
</tr>
<tr>
<td>Mammogram</td>
<td>Less than 3 months prior to study entry</td>
<td>At 1 year</td>
<td>Every year</td>
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<tr>
<td>Clinical examination</td>
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<td>Every 6 months</td>
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</tr>
<tr>
<td>Forms</td>
<td>Written consent provided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Prior to deciding whether or not to participate in the study, it is recommended that you thoroughly read through the patient information form and this booklet and discuss any concerns with your medical team. If you agree to participate in the study, you will be asked to sign a consent form.

Do I have to take part in the SNAC2 trial?

Participation in this trial is entirely voluntary – you do not have to take part, and if you do take part, you can withdraw at any time. Whatever your decision, it will not affect your treatment or your relationship with your doctor or other medical staff.

Summary of the pros and cons of the SNAC2 clinical trial

What are some “PROS” of the “clinical trial” option?

▸ You will receive a sentinel node biopsy by an experienced surgeon and your sentinel node/s will be investigated in more detail than is possible with axillary clearance.

▸ If you are allocated to the “sentinel node biopsy” arm, there is between 40-70% (40-70 out of 100) chance of avoiding axillary clearance. Sentinel node biopsy is a smaller operation than axillary clearance, with a lower risk of side effects, particularly lymphoedema (see pages 10-11).

▸ You will receive extra support and care from the research team.

▸ The information obtained from your case will be combined with that from other trial participants and will help to guide the use of sentinel node biopsy for women diagnosed with breast cancer in the future.

What are some “CONS” of the “clinical trial” option?

▸ You will not get to decide which treatment (axillary clearance or sentinel node biopsy) you will have.

▸ You may receive a treatment (sentinel node biopsy) that is still being investigated and that may result in a slightly higher risk of cancer cells remaining in the lymph nodes and of recurrence of cancer in the armpit.

▸ If you are allocated to the “sentinel node biopsy” arm, and the sentinel node/s are found to be positive after the first operation, you may require a second operation.

▸ You will need additional scans and blue dye injection even if you are allocated to the “axillary clearance” arm.
Making a decision that is right for you

The previous pages have outlined the main options available to you. Not everyone will feel the same about what to do next. Some women may be willing to put up with the side effects of axillary clearance in exchange for the peace of mind that they are minimising their risk of recurrence. Others may want to reduce their chances of having side effects and they would rather be part of a trial that will find out whether women can safely have a sentinel node biopsy which minimises the side effects of surgery.

The following steps may help you to decide which option best suits you:

1. Decide on the level of involvement that you want from your doctor in the decision-making process and tell them your preferences as appropriate,
2. Understand your current options and the benefits, side effects and risks of each option,
3. Review the pros and cons of each option,
4. Assess the importance to you of the pros and cons of each option,
5. Get more information and clarify any uncertain areas,
6. Work out which option you are leaning towards.

Whether or not you choose standard treatment or take part in the clinical trial, your care will not be compromised.

Worksheets

On the next two pages there are examples of how some women viewed the pros and cons of the options available. This is followed by your own worksheet where we invite you to list the pros and cons of the statements related to each option and rate how important these are to you.

There are no right or wrong answers. Your personal values and preferences should guide you when rating the importance of the pros and cons of each option.

Each statement has three options beneath it describing a level of concern/benefit that you may have about the issue raised by the statement. By circling the one of the options you can indicate (and see at a glance) how important each issue is to you:

- Circling “Not important” indicates that the issue is not a concern or issue for you.
- Circling “Somewhat important” indicates that the issue is somewhat of a concern or issue for you.
- Circling “Very important” indicates that the issue is a very important concern or issue for you.

For example: One of the cons of the clinical trial option is that women will need to have additional scans and a blue dye injection. If a woman feels that she will be able to handle these (i.e. this issue is not a concern for her), she circles “not important” under this statement.

At the bottom of the worksheet you can indicate (by circling one of the 1-5 diamonds) which way you are leaning in your decision.

Where am I leaning? Participating in the trial

By circling the 3rd diamond, this woman is indicating she is still unsure about her participation in the trial.
Example Worksheet

Elizabeth’s thoughts: “Will the SNAC2 trial suit me?”

Note: SNB = sentinel node biopsy and AC = axillary clearance

PROS of the trial

- I want to maximise my chances of receiving a SNB, so that I don’t have nodes removed unnecessarily.
- I may receive SNB, which may result in a slightly higher risk that cancer will return in the armpit.
- My sentinel nodes will receive closer examination.

CONS of the trial

- Not participating in the trial
  - Not Important
  - Somewhat Important
  - Very Important
- Participating in the trial
  - Not Important
  - Somewhat Important
  - Very Important

Any further questions? What do I need to do to get onto the trial?

Where is Elizabeth leaning?

- Participating in the trial: ★★★★
- Not participating in the trial: ★★★★

Elizabeth is leaning towards participating in the SNAC2 trial.

Example Worksheet (cont.)

Jenny’s thoughts: “Will the SNAC2 trial suit me?”

Note: SNB = sentinel node biopsy and AC = axillary clearance

PROS of the trial

- I want to maximise my chances of receiving a SNB, so that I don’t have nodes removed unnecessarily.
- I may receive SNB, which may result in a slightly higher risk that cancer will return in the armpit.
- My sentinel nodes will receive closer examination.

CONS of the trial

- Not participating in the trial
  - Not Important
  - Somewhat Important
  - Very Important
- Participating in the trial
  - Not Important
  - Somewhat Important
  - Very Important

Any further questions? When can I book in for the AC operation?

Where is Jenny leaning?

- Participating in the trial: ★★★★★
- Not participating in the trial: ★★★★★

Jenny is leaning towards not participating in the SNAC2 trial.
Your Worksheet

“Will the SNAC2 trial suit me?”

Note: SNB = sentinel node biopsy and AC = axillary clearance

**Pros of the trial**

I want to maximise my chances of receiving a SNB, so that I don’t have nodes removed unnecessarily.

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If I have SNB and don’t need an AC then I’ll have less risk of side effects and perhaps a better recovery.

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My sentinel nodes will receive closer examination.

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**Cons of the trial**

I may receive SNB, which may result in a slightly higher risk that cancer will return in the armpit.

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If I have SNB and positive nodes are found, I’ll need another operation.

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I will need additional scans and a blue dye injection.

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**Any further questions?**

Where am I leaning?  Participating in the trial

Not participating in the trial

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Notes:
Further contacts

Many women seek information on the internet about breast cancer treatments, research, clinical trials and support services. However not all information reported on the internet is accurate or reliable.

Listed below are a number of websites and contacts for cancer organisations. As the information can only be general and not specific to your situation, it is important to discuss any questions you have with your treating doctor.

**Australia**

**Aussie Breast Cancer Forum**
www.bcaus.org.au

**Breast Cancer Network Australia**
Information service
Free “My Journey Kit”
www.bcna.org.au
1800 500 258 (freecall)
1300 78 55 62

**Cancer Council of Australia**
Cancer Council Helpline
www.cancer.org.au
13 11 20

**Kim Walters Choices Program**
Information service
1800 227 271 or (07) 3232 7064

**National Breast and Ovarian Cancer Centre, Australia**
www.nbcc.org.au

**YWCA Encore Program**
www.ywcaencore.org.au
1800 305 150

**New Zealand**

**Breast Cancer Network New Zealand**
Email contact
brencanz@xtra.co.nz

**Cancer Society of New Zealand**
Cancer Information Helpline
www.cancernz.org.nz
0800 226 237

**New Zealand Breast Cancer Foundation**
Information service
www.nzbcf.org.nz/home
0800 902 732 or 0-9-523 4397

**USA**

**Breastcancer.org**
www.breastcancer.org

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**References**

If you are interested in these papers, please ask a member of your medical team and they will help you obtain them.


Glossary of Terms

**Axilla:** The armpit.

**Axillary Clearance (AC):** A surgery to remove most of the lymph nodes in the lower and upper parts of the armpit to determine if cancer has spread.

**Biopsy:** The removal and examination of a sample of tissue from a living body for diagnostic purposes.

**Cancer:** A group of diseases in which malignant cells grow out of control and may spread to other parts of the body.

**Clinical Trial:** A scientific study of the effectiveness and safety of a drug or treatment option involving consenting human participants.

**Diagnosis:** Process of identifying a disease from symptoms and tests.

**Grade:** A system used by doctors to classify cancer cells in terms of how they look under a microscope and how quickly the cancer is likely to grow and spread.

**Lymph:** An almost colourless fluid that travels through vessels called lymphatics, carrying cells that help fight infection and disease. The lymphatics drain to lymph nodes.

**Lymph Nodes:** Small bean-shaped parts of the lymphatic system that filter bacteria and foreign particles from lymph fluid.

**Lymphoedema:** A condition that occurs when lymph nodes have been removed or damaged and lymphatic fluid collects in those tissues, causing swelling (oedema).

**Lymphoscintigram:** A technique that is used to identify the sentinel lymph node.

**Mammogram:** An x-ray of the breast used to detect and diagnose breast disease.

**Mastectomy:** A surgical procedure in which most or all of the breast tissue is removed in order to remove breast cancer.

**Multifocal Cancer:** Breast cancer in which there is more than one cancer or lump in the same breast.

**Pathologist:** A doctor who identifies diseases by studying cells and tissue under a microscope.

**Prognosis:** The possible course of a disease and the patient’s chance of recovery / cure.

**Risk:** The likelihood of an outcome.

**Sentinel nodes:** The lymph node/s closest to the cancer. These are the first node/s that filter fluids draining away from the breast.

**Sentinel node biopsy (SNB):** A surgical diagnostic technique in which a small number of lymph nodes (which are most likely to contain cancer cells) are removed via biopsy.

**Sentinel node based management (SNBM):** A surgical diagnostic technique in which a sentinel node biopsy is performed and the sentinel node is checked for cancer cells. If the sentinel nodes contain cancer, an axillary clearance is performed. If the sentinel node/s are clear, further axillary surgery is not required.

**Wide open excision:** A surgical removal of the cancer as well as a small amount of normal tissue surrounding it (also called lumpectomy).
Acknowledgements

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Graphic design was undertaken by Ben Carew who can be contacted on +61 2 8307 3800

Note: It is against the law to photocopy or otherwise reproduce this booklet without the publisher’s written permission. Authorisation may be sought by contacting Dr Ilona Juraskova at the below address:

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