Should you have a test to screen for Bowel Cancer?

Making Decisions: Choices for Men Aged 55-64 years
This booklet was developed by members of the Screening and Test Evaluation Program at the University of Sydney Australia. © 2008

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This booklet was illustrated by Fiona Katauskas and designed by Artswift.
This booklet is to help you decide whether to have a bowel cancer screening test to look for blood in your bowel motions, as a possible early sign of bowel cancer. It is called the Faecal Occult Blood Test (FOBT).

The booklet tells you how the screening test may lower your bowel cancer risk and explains some of the advantages and disadvantages of screening. There are 2 booklets, 1 for men and 1 for women.

At the back there is a worksheet to help you to make up your mind.

To make your decision you can either read through the booklet, or take it to your doctor.

Throughout the booklet you will notice a number of words highlighted in yellow (e.g. bowel cancer). Each of these words is explained on page 27-30).
Here are some questions to ask your doctor about the bowel cancer screening test.

Before you start, ask your doctor:

• If she or he has time to discuss your questions
• To explain any words you do not understand

1. Which bowel cancer risk group am I in? (see page 4)

2. If I had screening, what are my chances of dying from bowel cancer in the next 10 years? (see pages 12 – 19)

3. If I do not have screening, what are my chances of dying from bowel cancer in the next 10 years? (see pages 12 – 19)

4. If I want to do the test, how do I do it? (see test kit instructions)

5. What happens if I have an abnormal test result? (see pages 8 – 9)

6. Overall, what are the advantages and disadvantages of bowel cancer screening for me?

Write down any questions you may wish to ask.
What does this booklet include?

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What is cancer screening?

Cancer screening means looking for early signs of cancer or pre-cancer, in people who are well and have no symptoms. If cancer or pre-cancer is found at an early stage it can be treated more easily. There are different types of screening tests to find early signs of different cancers. For example, mammograms to screen for breast cancer, Pap smears to screen for cervical cancer and prostate specific antigen (PSA) to screen for prostate cancer.

This booklet is about screening for bowel cancer with Faecal Occult Blood Testing (FOBT).
What is bowel cancer?

- **Bowel cancer** occurs when a normal cell on the inside wall of the bowel becomes abnormal and grows out of control.
- The cell can grow into a polyp (a small mushroom-shaped lump or growth) which may turn into cancer.
- Most bowel cancers grow in the large bowel (made up of the colon and rectum) - see pictures above.
- It can take a long time before the cancer grows and spreads to other parts of the body. This gives doctors a chance to find bowel cancer and treat it early.
- Sometimes early bowel cancers can cause symptoms, such as bleeding from the rectum and a change in normal bowel motion. Most people with bowel cancer, however, do not have these symptoms.
What increases your risk of getting bowel cancer?

**Your age:** bowel cancer is more common as you get older.

**Your gender:** bowel cancer is a little more common in men.

**Your family history:** bowel cancer is twice as likely to occur in women and men who have at least one family member with bowel cancer. See page 5 to find out your family history group or ask your doctor.

**Note:** Although diet is important for your general health, whether it affects your risk of bowel cancer is unclear.
Is this booklet for you?

This booklet is for people with No Family History or a Weak Family History of bowel cancer.

To find out if this booklet is for you tick [✓] the boxes to the answers below.

If you are unsure, please tick ‘DON’T KNOW’ and ask your doctor.

1. Are you between 55 and 64 years of age?
   - □ YES go to question 2 below
   - □ NO Ask your doctor if you are the right age for bowel cancer screening.

2. Have you ever had bowel cancer?
   - □ NO go to question 3 below
   - □ YES Speak to your doctor about what kind of screening is right for you.

3. Do you have any of the following bowel symptoms?
   - blood in your faeces
   - a change in normal bowel motions
   - pains in the stomach
   - tiredness (over a long period of time)
   - weight loss
   - □ DON’T KNOW speak to your doctor

   - □ NO go to question 4 on the next page
   - □ YES * These symptoms may be caused by other conditions, and do not mean you have bowel cancer. If you have any of these symptoms, we suggest you see your doctor.
Bowel cancer in your family

4. Has anyone in your family ever had bowel cancer?
   (e.g. a close blood relative – mum, dad, brother, sister or child
   and/or other blood relative - aunt, uncle, grandparent, niece or nephew)

☐ DON'T KNOW speak to your doctor

☐ YES  
   go to question 5 below

☐ NO  
   This means you are in the
   NO FAMILY HISTORY GROUP
   THIS BOOKLET IS FOR YOU
   Go to the shaded box at the bottom of page 6

5. How many of your relatives had bowel cancer?

☐ DON'T KNOW speak to your doctor

☐ 1 ONLY  
   go to question 6 below

☐ MORE THAN 1
   go to question 7 on the
   next page

6. Did any of your close blood relatives (either your mum, dad, brother, sister or child) have bowel cancer before the age of 55?

☐ YES  
   This means you are in the
   STRONG FAMILY HISTORY GROUP
   THIS BOOKLET IS NOT FOR YOU
   Go to the shaded box at the bottom of page 6

☐ NO  
   This means you are in the
   WEAK FAMILY HISTORY GROUP
   THIS BOOKLET IS FOR YOU
   Go to the shaded box at the bottom of page 6

Note: Other relatives such as cousins are not close enough to affect your bowel cancer risk
7. Were any of your relatives on the same side of the family? (e.g. on your mum’s side?)

☐ DON’T KNOW speak to your doctor

☐ NO  go to question 8 below

☐ YES  This means you are in the STRONG FAMILY HISTORY GROUP
       THIS BOOKLET IS NOT FOR YOU

8. Did your relatives have bowel cancer after the age of 55?

☐ YES  This means you are in the WEAK FAMILY HISTORY GROUP
       THIS BOOKLET IS FOR YOU
       Go to shaded box below

☐ NO  This means you are in the STRONG FAMILY HISTORY GROUP
      THIS BOOKLET IS NOT FOR YOU

TICK [✓] Which group you are in:

- No Family History
- Weak Family History
- Strong Family History

Look out for information about your group in GREEN on later pages.

Look out for information about your group in BLUE on later pages.

This booklet is not for you. We suggest you speak to your doctor and raise your concerns. For more information about bowel cancer & cancer screening see page 31.
The Faecal Occult Blood Test (FOBT) is a screening test for bowel cancer. It is a test that looks for blood that you cannot see in your bowel motions. Faecal relates to ‘bowel motions’ and Occult means ‘unseen’ or ‘hidden’.

**Doing the test**

You will need to do the screening test at home not at the doctors. You are provided with a test kit to collect 2 separate samples of faeces (bowel motions) in a tube.

Once you have collected the 2 samples you send them to the laboratory for testing, using the reply-paid envelope provided with the test kit. You will need to fill in and sign the ‘contact details’ form when you send off the test. The test kit instructions give you more information about how to do the test.

**Getting your results**

The laboratory will send you and your doctor (if chosen) a letter with your screening test results within about two weeks of posting your sample. The chart on the next page tells you what your test results mean and what may happen.
What do the test results mean?

Your test result may come back as normal or abnormal.

**Normal Result**
This means no blood was found in your sample. It shows you are unlikely to have bowel cancer.

Think about doing the bowel cancer screening test in 2 years.

**Abnormal Result**
This means some blood was found in your sample. This may mean many things - one may be bowel cancer.

Your doctor may suggest you have a colonoscopy (see the next page)

Results will decide further testing and treatment.
What is a colonoscopy?

If you have an abnormal test result your doctor may suggest that you have a follow-up test called a colonoscopy.

- A colonoscopy involves the doctor putting a long tube inside your bowel to look for pre-cancer and cancer.
- The day before the procedure you will need to take a bowel preparation (often a sweet-flavoured drink). This cleans out your bowel by giving you diarrhoea for a few hours.
- The procedure itself takes about 20-30 minutes as a day-patient in hospital.
- You will be given a drug that will make you feel very sleepy.
- You may feel some discomfort during or after the procedure.
- After the procedure you will have to wait a few hours before you can go home.
- This follow-up procedure will find 95 out of 100 cancers and growths but may miss 5 out of 100.
- Some people have a colonoscopy as a regular screening test every 5 years if they have a strong family history of bowel cancer. If you have further questions about this information please ask your doctor.
- The cost and waiting time for a colonoscopy will vary, depending upon whether you are a public or private patient and the area you live in. We suggest you talk to your doctor and health insurance fund about the possible costs.

There are some rare risks linked to having a colonoscopy:

- 7 in 10,000 may have serious bleeding
- 7 in 10,000 may have bowel damage or tears
- 3 in 10,000 may result in severe stomach pains
- 1 in 10,000 may be linked with death
Here are some points to consider about bowel cancer screening with Faecal Occult Blood Testing.

• Bowel cancer screening may lower your chances of dying from bowel cancer.

• Bowel cancer screening can correctly tell many people that their risk of bowel cancer is low.

• Bowel cancer screening may not lower your chances of getting bowel cancer.

• There is the small chance of getting bowel cancer in between screening tests and some cancers may be missed.

• You may have an abnormal test result and later find out that you do not have cancer. While the doctors find this out, you may worry about whether you have cancer and have follow-up procedures (colonoscopy) that can be uncomfortable.

• There are also some rare risks linked to having the colonoscopy (see page 9).

• Some people find the test a bit unpleasant, but it is simple to do and is designed to be done in the privacy of your home.
How does the bowel cancer screening test help?

On the next few pages there are some diagrams to show how the bowel cancer screening test helps and what happens to men who do the test.

We will compare 1000 men who do not have screening against 1000 men who do, from high quality research findings.

If you have no family history, go to pages 12 to 15.

If you have a weak family history, go to pages 16 to 19.

If you are unsure of your bowel cancer family history group go back to page 4 or ask your doctor.
Of 1000 men your age (55-64) with **NO FAMILY HISTORY** who **DO NOT HAVE SCREENING**, over the next 10 years:

3 may die of bowel cancer without screening over the next 10 years.
Of 1000 men your age (55-64) with NO FAMILY HISTORY who DO HAVE SCRENEING, over the next 10 years:

2 may die of bowel cancer with screening over the next 10 years

In other words, 1 less man dies from bowel cancer with regular screening
The diagram on the next page shows what may happen to 1000 men with **NO FAMILY HISTORY** who have the bowel cancer screening test every 2 years for 10 years.
4 may have bowel cancer found

4 may get bowel cancer between screening tests

11 may have polyps found and taken out (which may have turned into cancer)

187 may have an abnormal test result and after more testing find out that they do not have cancer or polyps.

There are some rare risks linked to having a colonoscopy, see page 9.

2 bowel cancers may be missed by screening.

792 may have a normal test result

Now turn to page 20 →
How does the screening test help men with a weak family history?

Of 1000 men your age (55-64) with a **WEAK FAMILY HISTORY** who **DO NOT HAVE SCREENING**, over the next 10 years:

- 5 may die of bowel cancer without screening over the next 10 years.
Of 1000 men your age (55-64) with **WEAK FAMILY HISTORY** who **DO HAVE SCREENING**, over the next 10 years:

4 may die of bowel cancer with screening over the next 10 years

In other words, **1 less man dies from bowel cancer with regular screening**
The outcomes of bowel cancer screening – weak family history

The diagram on the next page shows what may happen to 1000 men with a weak family history who have the bowel cancer screening test every 2 years for 10 years.
8 may have bowel cancer found

7 may get bowel cancer between screening tests

20 may have polyps found and taken out (which may have turned into cancer)

178 may have an abnormal test result and after more testing find out that they do not have cancer or polyps.

There are some rare risks linked to having a colonoscopy, see page 9.

4 bowel cancers may be missed by screening.

783 may have a normal test result
The Personal Worksheet

This booklet includes a worksheet to help you make up your mind about whether to have the bowel cancer screening test or not.

How to fill in the worksheet
Work through each point by following the instructions on the worksheet. Remember there are NO right or wrong answers. It is your decision.

If you have
NO FAMILY HISTORY
Go to page 21

If you have a
WEAK FAMILY HISTORY
Go to page 23
Your Personal Worksheet
No Family History

Think about how each point makes you feel about bowel cancer screening with FOBT.

**Circle the thumbs** to show how each point makes you feel about screening.

_e.g. For screening_

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**Think about your current risk of bowel cancer**

Your risk of dying from bowel cancer over the next 10 years without screening is about 3 in 1000 (see pages 12 – 13). How does this make you feel about screening?

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**Lowering your risk of bowel cancer by screening**

If you have a screening test every 2 years over the next 10 years, you can lower your chances of dying from bowel cancer to about 2 in 1000 (see pages 12 – 13). How does this make you feel about screening?

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Think about the possible screening test outcomes
Bowel cancer screening will tell a large number of people that their risk of bowel cancer is low, but it may not find all cancers and some people will have follow-up procedures (colonoscopy) they do not really need. There are also some rare risks linked to having a colonoscopy (see page 9 and 15). How does this make you feel about screening?

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Doing the bowel cancer test at home
Some people find the test a bit unpleasant but it is simple to do and is designed to be done in the privacy of your own home. How does this make you feel about screening?

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Other things important to you
Write down any other things that are important to your decision.

How does this make you feel about bowel cancer screening?

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Making your decision about the bowel cancer screening test
Thinking about all the points above, how are you feeling about the screening test?

- [ ] Yes, I want to do the test
- [ ] No, I do not want to do the test
- [ ] I am unsure about whether I want to do the test

If you would like more information about what to do next, please go to page 25
Your Personal Worksheet

Weak Family History

Think about how each point makes you feel about bowel cancer screening with FOBT.

**Circle the thumbs** to show how each point makes you feel about screening.

**e.g. For screening**

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**e.g. Against screening**

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**Think about your current risk of bowel cancer**

Your risk of dying from bowel cancer over the next 10 years without screening is about 5 in 1000 (see pages 16 – 17). How does this make you feel about screening?

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**Lowering your risk of bowel cancer by screening**

If you have a screening test every 2 years over the next 10 years, you can lower your chances of dying from bowel cancer to about 4 in 1000 (see pages 16 – 17). How does this make you feel about screening?

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Think about the possible screening test outcomes
Bowel cancer screening will tell a large number of people that their risk of bowel cancer is low, but it may not find all cancers and some people will have follow-up procedures (colonoscopy) they do not really need. There are also some rare risks linked to having a colonoscopy (see page 9 and 19). How does this make you feel about screening?

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Doing the bowel cancer test at home
Some people find the test a bit unpleasant but it is simple to do and is designed to be done in the privacy of your own home. How does this make you feel about screening?

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Other things important to you
Write down any other things that are important to your decision.

How does this make you feel about bowel cancer screening?

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Making your decision about the bowel cancer screening test
Thinking about all the points above, how are you feeling about the screening test?

☐ Yes, I want to do the test
☐ No, I do not want to do the test
☐ I am unsure about whether I want to do the test

If you would like more information about what to do next, please go to the next page
What to do next

Do I have to do the bowel cancer screening test (FOBT)?
No, screening for bowel cancer is your decision.

I am unsure about what to do
If you are unsure about whether to do the screening test, you may wish to read through the booklet again and/or talk with your doctor and raise your concerns.

I would like to do the screening test, how do I do it?
The screening test involves collecting samples from two separate bowel motions. You will need to do the test at home and send off your samples, (using the reply paid envelope provided in the test kit) to a laboratory for testing. There are detailed instructions on how to do the test with the kit. You may also wish to tell your doctor that you plan to do the test.

What if I cannot understand the test kit instructions?
Please call the InSure® bowel cancer screening (FOBT) information line on 1800 556 575 if you are unsure about how to do the test, or also ask your doctor. If you call the information line, please say that you are taking part in the University of Sydney study (reference number: SU208).
What to do next

What if I have lost my test kit?
If you lose or damage your test kit and need another one, please contact the InSure® bowel cancer screening information line on 1800 556 575. Please say that you are taking part in the University of Sydney study (reference number: SU208).

Please note: only one replacement kit will be given per person. If you have reached your limit and would like to do the test, you should speak to your doctor.

When will I get the test results?
The test results will be sent to you and your doctor (if you have chosen one) within about two weeks of posting your sample. The researchers at the University of Sydney will only be informed if you send back your test. They will not see a copy of your actual test result. To find out what the test results mean and what may happen, go to page 8 of this booklet.

If I want to screening test in the future, what do I do?
If you decide to do the test you will be offered the option of receiving a test kit (from Insure®) in the future.

If you decide not to do the test, but would like to do it in the future, you can either speak to your doctor or buy a test kit from your local pharmacy. Please remember that the screening test is recommended every two years. We suggest you speak to your doctor before you do the test.

If you would like more information about bowel cancer and bowel cancer screening, please go to page 31.

Before you make your final decision, you may wish to talk to your doctor.
Here is a list of medical terms and what they mean:

**Abnormal** Not normal.

**Anus** The opening through which faeces pass out of the body. See faeces.

**Bowel** The bowel is part of the digestive system. It is made up of three parts - the small bowel, the large bowel and the rectum. It gets rid of any waste material known as bowel motions or faeces from the body. See bowel motions. See colon. See digestive system. See faeces. See growth. See large bowel. See large intestine. See rectum. See small bowel.

**Bowel cancer** Bowel cancer is a cancerous growth that starts on the inside wall of the bowel. It can grow there for a long time before spreading to other parts of the body. Bowel cancer can grow in any part of the bowel, but it is more common in the large bowel than in the small bowel. It is also known as colorectal cancer, or cancer of the colon. See bowel. See cancerous. See colon. See colorectal cancer. See large bowel. See small bowel.

**Bowel motions** Relates to the body getting rid of waste material or faeces from the body. See faeces.

**Cancer screening** Tests you have when you are well or healthy to look for cancer early. Cancer screening is not for people who have symptoms. See symptoms.

**Cancer, Cancerous** Abnormal cells that grow and take over healthy cells. See cell.

**Cell** A very small unit of living matter.

**Check-up** A visit to a doctor when a person is not sick.

**Close blood relative** This includes the following family members - mum, dad, sisters, brothers, children.

**Colon** Part of the large intestine above the rectum. It is also called the bowel. See bowel. See large intestine. See rectum.

**Colorectal cancer** Cancer of the bowel. Also called bowel cancer. See bowel cancer. See cancer. See colon. See large bowel. See rectum.
Colonoscopy  A follow-up test to look for cancers and growths. The test involves putting a long tube inside the bowel. The doctor may suggest a colonoscopy following an abnormal test result. Some people will also have a colonoscopy as part of regular screening every 5 years. See bowel. See cancer. See faecal occult blood test. See follow-up.

Diarrrhoea  Diarrhoea is the passing of increased (occurring more than 3 times per day, for a few days) amounts of loose, watery faeces out of the anus. See anus. See faeces.

Digestive system  The digestive system changes all the food we eat and turns it into energy. It gets rid of any waste material known as bowel motions or faeces from the body. See bowel motions. See faeces.

Disease  Sickness or illness.

Detect, detection  To find out early or soon. It relates to tests that find cancer at a time when it may be easily treated. See cancer. See treat.

Faecal, Faeces  Relates to waste material called bowel motions. See bowel motions.

Faecal Occult Blood Test (FOBT)  A screening test for bowel cancer. It is a test that looks for blood (that you cannot see) in your bowel motions. See abnormal. See bowel cancer. See bowel motion. See faeces. See occult. See screening test.

Family history (medical)  Information about all the health problems in a person’s family including parents, brothers, sisters, children, grandparents and other family members.

Follow-up  To watch closely. For example, the doctor may suggest carrying out a further test if a person has an abnormal test result. See abnormal.

Gene, Genetic  Genes are passed on from parents to their children. Genes carry information about a person’s characteristics, such as eye colour and hair colour. Genes can also make people more likely to get a disease. See cells. See disease.

Gene defect  A change in a gene so that it does not work in the normal way.
**Genetic risk**  The likelihood that a person has a gene defect so that it does not work in a normal way - that makes them have a high chance of getting a disease, such as cancer. See cancer. See disease. See gene. See gene defect.

**Growth(s)**  An abnormal group of cells that may turn into cancer. Also known as a polyp. See abnormal. See cells. See polyp.

**High quality research**  A piece of research or a study that is well designed and carried out.

**Interval cancer**  Cancer that can grow fast between two screening tests. See cancer. See screening test.

**Laboratory**  A building designed for scientific research or testing.

**Large intestine**  A tube-like part of the body in which food waste travels to the rectum. See rectum.

**Large bowel**  The large bowel is made up of the colon and rectum. When people talk about bowel cancer, they often mean cancer of the large bowel and not the small bowel. See cancer. See colon. See large bowel. See rectum. See small bowel.

**Multiple bowel cancers**  Many/lots of polyps or growths in the bowel. See growth. See polyp.

**No Family History (of Bowel Cancer)**  This means that a person has never had bowel cancer and no one in their family has had bowel cancer.

**Occult**  Means unseen or hidden. Relates to the Faecal Occult Blood Test - a screening test that looks for blood in your bowel motion that cannot be seen. See bowel cancer. See bowel motion. See Faecal Occult Blood Test.

**Other blood relative**  This includes the following family members - aunts, uncles, nieces, nephews, grandparents and grandchildren.

**Outcome(s)**  Results, what may happen.

**Polyp**  A mushroom-shaped lump or growth on the inside wall of the bowel. Most bowel cancers slowly grow from polyps. See bowel. See bowel cancer. See growth.
Pre-cancer Changes in cells that do not mean cancer but may become cancer, if not treated early. See cancer. See cells. See growths. See polyps. See treat.

Rectum The back passage which joins the opening of the bowel to the outside, the anus. The waste material is stored in the rectum, or back passage, until it is ready to be passed out of the body as a bowel motion. See anus. See bowel. See bowel motion.

Reproductive system Reproduction relates to reproducing - having a baby. The male and female reproductive systems work together to make a baby.

Screening test A test you have when you are healthy or well to find disease early. See disease.

Sedative A drug to make you feel sleepy or drowsy.

Small bowel The longest part of the bowel. Cancer of the small bowel is not as common as cancer of the large bowel. See cancer. See large bowel.

Strong Family History (of Bowel Cancer) This means that a person has had 1 close relative (e.g. mum, dad, brother, sister or child) with bowel cancer before the age of 55 OR 2 relatives on the same side of the family (e.g. all on mum’s side).

Symptoms Feelings or changes in the body that may be a sign of illness or disease e.g. pain, unusual bleeding, weight loss.

Treatment, treat To give medical help to a patient to make them better.

Weak Family History (of Bowel Cancer) This means that a person has 1 close relative (e.g. mum, dad, brother, sister or child) with bowel cancer over the age of 55 OR 1 relative on each side of the family (e.g. 1 on mum’s side and 1 on dad’s side) over the age of 55 OR 1 relative (e.g. aunt, uncle, grandparent, nephew or niece) who had bowel cancer before or after the age of 55.

If you are not sure what the medical words mean, please ask your doctor.
If you have further questions, or would like more information about screening for bowel cancer you can go to the following sources:

**Insure® Bowel Cancer Screening Service**
Information LIne 1800 556 575
(For information about how to do Faecal Occult Blood Test

**Cancer Council of Australia**
Cancer Council of Australia Helpline 13 11 20

**Talk to your doctor**

A **STRONG FAMILY HISTORY** of bowel cancer means that a person has had:

- One close relative (parent, brother, sister or child) with bowel cancer before the age of 55, **OR**
- More than one relative on the same side of the family with bowel cancer (e.g. all on mum’s side).

If you think you have a strong family history of bowel cancer we suggest you talk to your doctor about the screening options which are best for you.

You can also get more information from:

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

If you would like to read some of the original research, go to your favourite search engine (eg www.google.com.au) and type in ‘PubMed’. This will take you to the US National Library of Medicine, which hosts a free version of the medical database ‘Medline’. Type in the surname of the first author (e.g. Kronberg) AND a keyword (s) (e.g. faecal occult blood test), from the title and you should be able to find the article of interest. (NB: Not all journal articles are available in their complete form free of charge).


Cancer & Population Statistics

- Australian Institute of Health & Welfare [www.aihw.gov.au]
- The Cancer Council of Australia [www.cancer.org.au]