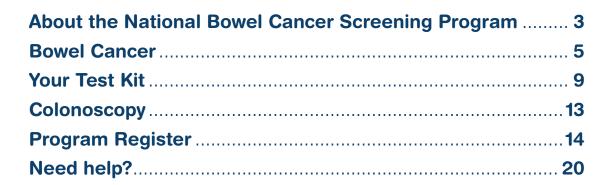


# **Information Booklet**

 Test Kit Helpline: 1800 930 998
 Program Info Line: 1800 118 868

## Contents



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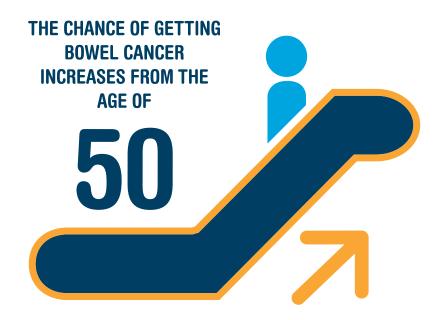
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This information booklet cannot be completely comprehensive and is intended as a guide only. It should not replace individual medical advice and if you have any concerns about your health or further questions you should raise them with your doctor

## About the National Bowel Cancer Screening Program

### Why you should do the test

- Doing this test could save your life
- The test helps to detect bowel cancer early
- Bowel cancer can develop without any symptoms
- The risk of bowel cancer rises sharply from the age of 50
- The good news is that if found early, nine out of 10 bowel cancers can be successfully treated
- Doctors recommend doing an at-home test every two years from the age of 50—74



### Who should do the test?

- ✓ Nearly everyone aged 50-74 years
- $\checkmark$  Both women and men
- ✓ Even healthy people age is the biggest risk factor for bowel cancer
- People who have done it before doctors recommend screening every two years.
- If you have symptoms or a strong family history of bowel cancer (see Bowel Cancer section, page 6) talk to your doctor as soon as possible about the kind of testing you may need.
- You may not need to do the test if you have had a colonoscopy in the last two years or are seeing your doctor about bowel problems.

### What is the test looking for?

- The screening test checks for tiny traces of blood in the bowel motion (poo) of people who do not have symptoms.
- Bowel cancer or polyps (small lumps) can grow on the inside wall of the bowel. Often tiny amounts of blood leak from these growths and can be found in poo before any symptoms are noticed.
- Polyps are not cancers, but may develop into cancers over time. They can be easily removed, reducing the risk of bowel cancer developing.
- If blood is found in your sample this could be due to a number of things other than cancer but you will need to see your doctor to discuss the result. Your doctor may recommend a colonoscopy to find the cause of the bleeding (see Colonoscopy section, page 13).

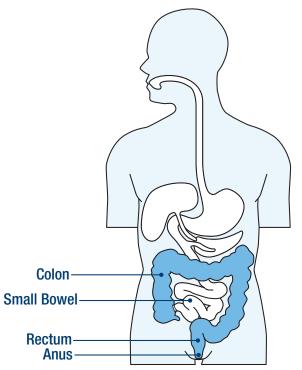


#### What your bowel does

Your bowel is part of your digestive system. This part of your body breaks down food and passes it out of your body in a bowel motion (poo).

#### Your bowel has three parts:

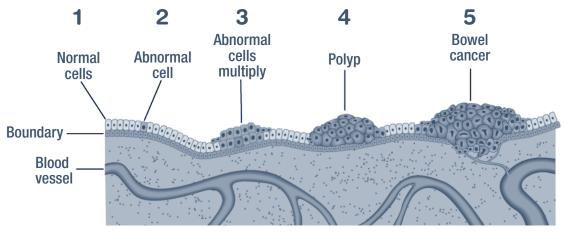
- small bowel which absorbs nutrients from broken-down food
- large bowel (colon) which mainly absorbs water
- rectum which stores poo until it is passed from the body through the bottom (anus).



#### What is bowel cancer?

- Bowel cancer most commonly develops inside the large bowel (colon)
- Most bowel cancers develop from small lumps called polyps in the bowel lining
- Not all polyps turn into cancer
- Removing polyps reduces your risk of bowel cancer.

### The stages of bowel cancer



What are the symptoms of bowel cancer?

Bowel cancer can develop without any symptoms. This is why it is important to screen every two years. Symptoms can include:

- blood in your urine, poo or in the toilet bowl
- a recent and persistent change in your toilet habit, such as looser poos, severe constipation and/or if you need to poo more often than usual
- unexplained tiredness or weight loss
- stomach pain.

### KNOW THE SYMPTOMS:

- If you notice any of these symptoms, it does not mean that you have bowel cancer, but it is very important that you talk to your doctor.
- Bowel cancer can affect people under 50, so make sure all your family members and friends know these symptoms and talk to their doctor if they are concerned.

Illustrations on page 5 and 6 adapted from original illustrations, courtesy The Cancer Council Victoria.

### You might be at increased risk of bowel cancer if you:

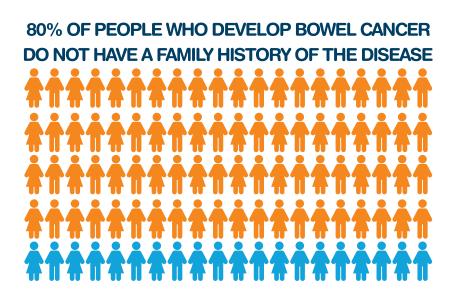
- Are over the age of 50
- Are overweight
- Have a diet high in red meat and processed meats (e.g. bacon, sausages)
- Have a diet low in vegetables, fruit, beans and whole grains (e.g. wholemeal bread, brown rice)
- Smoke
- Drink alcohol
- Have an inflammatory bowel disease (e.g. Crohn's disease or ulcerative colitis)
- Have previously had non-cancerous tumours in the bowel
- Have a strong family history of bowel cancer.

### What is a strong family history of bowel cancer?

A strong family history of bowel cancer is if:

- A close relative (parent, brother, sister or child) developed bowel cancer at a young age (under 55 years); or
- $\Rightarrow$  More than one close relative in your family has had bowel cancer at any age.

If you think you have a strong family history of bowel cancer, talk to your doctor about your risk of getting the disease and what testing is right for you.



### You can lower your risk of bowel cancer

While no cancer is completely preventable, you can lower your risk of bowel cancer by:

- $\checkmark$  eating a healthy diet
  - ⇒ limit red meat (less than 500g per week), avoid processed meat
  - $\Rightarrow$  eat more grains, veg, fruit and beans
  - $\Rightarrow$  avoid high calorie foods and sugary drinks
- $\checkmark$  being physically active for at least 30 minutes every day, and sit less
- $\checkmark$  reducing the amount of alcohol you drink
- $\checkmark$  not smoking
- screening every two years to help detect bowel changes early when they are easier to treat.



BECAUSE IT CAN DETECT BOWEL CANCER BEFORE SYMPTOMS APPEAR





### TIPS TO REMIND YOU TO DO THE TEST KIT

- Put it somewhere you can see it to remind you to do it (e.g. on your vanity or toilet seat).
- Commit yourself to the days you will take your samples (e.g. Monday and Tuesday next week).

### What does the test kit involve?

This free screening test is quick, clean and easy – and you do it at home. You don't have to change your diet or medications. The test involves taking two tiny samples of poo from two separate poos with a collection stick. You then post the samples to the Program lab. The samples are tested for tiny, invisible traces of blood.

### Getting an accurate result - keeping your sample safe

The test is highly accurate for finding blood. However, when there is a delay in testing samples or they are exposed to high temperatures for a long period the blood can break down and be harder to detect. This may result in an inaccurate result.

Taking the samples close together, storing them in the fridge and posting them quickly is important for an accurate result.

### Why do you need to put your samples in the fridge?

The fridge provides the most stable conditions for your sample and with the protective packaging, there is no risk of contamination with other contents of your fridge. Do not put your samples in the freezer.

### Getting your result



Your result will be mailed to you and your doctor (if you have nominated one) a few weeks after you post your samples.

#### **Negative result**

If no blood is found in your samples, your test result will be negative and no further action is needed for now. However, this does not mean that you do not have or can never develop bowel cancer, as some bowel cancers do not bleed or only bleed on and off. Tests like the one used in the Program detect up to 85% of bowel cancers. This is why it is important to screen every two years and talk to your doctor if you develop symptoms after getting a negative result (see the Bowel Cancer section for symptoms on page 6).

#### Positive result



If blood is found in your samples, your test result will be positive and you will need to discuss the result with your doctor. A positive result may be due to conditions other than cancer (such as polyps, haemorrhoids or inflammation of the bowel), but it is important to investigate. Your doctor may recommend a further test to find the cause of the bleeding, usually a colonoscopy.

### What is the test provided by the Program?

The test is an immunochemical faecal occult blood test (iFOBT).



### Don't need the test now or don't want to be a part of the Program?

Participating in the Program is your choice.

You can delay your test (suspend) or choose to be removed from the Program (opt off). Call the Program Info Line on **1800 118 868** or complete the form at the back of this booklet (page 17).

- If you *suspend* from the Program, you can choose a date you wish to re-join. You can suspend your participation for up to one year.
- If you choose to *opt off* the Program, you will receive no further free test kits or correspondence from the Program. No further clinical information relating to bowel screening will be stored on your record on the Program Register.

You can re-join the Program at any time.

For information on how your personal information will be managed please see the Program Register section on page 14 or visit www.cancerscreening.gov.au/nbcsp-privacy.

### What should you do with your test kit if you don't want to take part?

Put your unwanted test kit in your rubbish bin. Do not return your unused kit or give it to another person.

### What if you know someone who wants a kit?

If you know someone aged 50–74 who wants to do a test, they can call the Program Info Line on **1800 118 868** or visit www.cancerscreening.gov.au/bowel for more information.

# Colonoscopy



If your test results come back positive for blood in your bowel motion, your doctor may refer you for a colonoscopy.

### What is a colonoscopy?

A colonoscopy is a procedure to look inside your bowel while you are under sedation (asleep). The doctor inserts a narrow flexible tube with a tiny camera attached into the rectum to look for polyps or cancerous growths. As with all medical procedures, there are risks as well as benefits. However, the benefits of finding cancer early far outweigh the potential risks of a colonoscopy. It is important that you discuss the risks and benefits with your doctor before having a colonoscopy.

### Will you have to pay for a colonoscopy?

There is no cost for a colonoscopy as a public patient. You may have to pay a fee if you have your colonoscopy as a private patient. You should talk to your doctor about any financial costs before the colonoscopy.

### What happens if something is found during the colonoscopy?

If polyps or other growths are found, the doctor will usually remove them immediately and send them to a lab to be tested for cancer.

You may need surgery if a bowel cancer is found. If it is found at an early stage, the chance of a full recovery is high and most people will be able to return to their normal lifestyle. Most cancers found through the Program are at an early stage.

### What if the colonoscopy doesn't show anything?

If no polyps or cancerous growths are found, the Program will send you another test when you are next eligible. In the meantime, if you develop any symptoms (see the Bowel Cancer section on page 6), you should see your doctor.

# **Program Register**



### What information is kept by the Program Register?

The Program Register holds personal information such as:

- your Medicare number
- your contact details
- results of your Program screening test
- the name of your nominated doctor
- results of further tests (e.g. a colonoscopy) you may have after your Program screening test.

### What will this information be used for?

This information will be used to:

- remind you to do your test kit
- assist you to receive follow up and access to health services
- invite you to do another test kit in the future
- contact medical service providers to request your test results
- monitor and evaluate the Program and its impact on bowel cancer in Australia.

### Who will my information be provided to?

Personal information kept on the Register may be provided to health and other professionals who provide services under the Program, such as:

- your nominated doctor
- medical specialists
- the pathology laboratory responsible for testing your samples
- employees and contracted service providers of state and territory health
   departments
- the Australian Government Department of Health
- the Australian Institute of Health and Welfare
- authorised third party service providers
- any authorised third party you nominate.

## **Privacy**

Your personal information and test results kept on the Program Register are protected by the *Privacy Act 1988* and will be handled in accordance with the Australian Privacy Principles set out within that Act.

Further information is available on the Program website: www.cancerscreening.gov.au/nbcsp-privacy



# OF BOWEL CANCERS CAN BE SUCCESSFULLY TREATED IF DETECTED EARLY

For information in your language go to www.cancerscreening.gov.au/translations or call the Translating and Interpreting Service on 13 14 50.

#### ARABIC

للمعلومات باللغة العربية تفضل بزيارة الموقع الإلكتروني www.cancerscreening.gov.au/translations أو اتصل بخدمة الترجمة الخطية والشفهية على الرقم 10 18 13.

#### ASSYRIAN

شڼ ښمډکىمې، حکيتې نهمۇدې، مَسمىمې كېمۇنې www.cancerscreening.gov.au/translations ج ھەنى شڼ يىكىنىم دېدېچمې مدېنېسې (Translating and Interpreting Service) خك چىچەنى 13 14 13.

#### CHINESE SIMPLIFIED

关于这个计划的中文资料请见: www.cancerscreening.gov.au/translations您也可以致电翻译 口译服务处,号码是13 14 50。

#### CHINESE TRADITIONAL

關於這個計劃的中文資料請見: www.cancerscreening.gov.au/translations 您也可以致電翻譯 口譯服務處,號碼是13 14 50。

#### CROATIAN

Za informacije o programu na hrvatskom jeziku idite na www.cancerscreening.gov.au/translations, ili nazovite Službu prevoditelja i tumača na 13 14 50.

#### GREEK

Για πληροφορίες στα ελληνικά επισκεφθείτε το www.cancerscreening.gov.au/translations ή καλέστε την Υπηρεσία Μεταφραστών και Διερμηνέων στο 13 14 50.

#### HAZARAGI

بلده مالومات ده زیبون هز ارگی، ده ویبسایت زیر مراجعه کنین www.cancerscreening.gov.au/translations و یا که ده شماره 13 14 13 با خدمات ترجمانی تماس بیگرین.

#### HINDI

हिन्दी में सूचना के लिए www.cancerscreening.gov.au/translations देखें या अनुवाद एवं दुभाषिया सेवा (Translating and Interpreting Service) को 13 14 50 पर फोन करें।

#### ITALIAN

Per informazioni in italiano visitate www.cancerscreening.gov.au/translations o chiamate il Servizio traduzioni e interpretariato al numero 13 14 50.

#### KHMER

សម្រាប់ព័ត៌មានបន្ថែមទៀតជាកាសាខ្មែរ សូមមើលគេហទំព័រ www.cancerscreening.gov.au/translations ឬទូរស័ព្ទទៅសេវាបកប្រៃ សរសេរ និងនិយាយ តាមលេខ 13 14 50។

#### KOREAN

한국어로 된 정보를 원하시면

www.cancerscreening.gov.au/translations 를 방문하시거나 통번역 서비스13 14 50로 연락하시기 바랍니다.

#### MACEDONIAN

За информации на македонски јазик одете на www.cancerscreening.gov.au/translations или јавете се на Службата за писмено и усмено преведување на 13 14 50.

#### NEPALESE

त्रको माथिल्लो भागमा उल्लेख गरिए बमोजिम नेपालिमा जानकारीको लागि www.cancerscreening.gov.au/translations मा जानुहोला अथवा ट्रान्सलेटिङ्ग एण्ड ईन्टरपेटिंङ्ग सर्भिस को १३१४५० मा सम्पर्क गर्नुहोला।

#### PERSIAN

بر ای کسب اطلاعات به فار سی، به آدر س www.cancerscreening.gov.au/translations مر اجعه کنید یا با خدمات تر جمه کنبی و شفاهی به شماره 13 14 13 تماس بگیرید.

#### POLISH

Informację o programie w języku polskim znaleźć można na stronie www.cancerscreening.gov.au/translations, lub dzwoniąc do Telefonicznej Służby Tłumaczy pod numer 13 14 50.

#### PORTUGUESE

Para informações em português acesse www.cancerscreening.gov.au/translations ou ligue para o Serviço de Tradutores e Intérpretes discando 13 14 50.

#### PUNJABI

ਪੰਜਾਬੀ ਵਿੱਚ ਜਾਣਕਾਰੀ ਵਾਸਤੇ www.cancerscreening.gov.au/ translations ਉੱਤੇ ਜਾਓ ਜਾਂ ਅਨੁਵਾਦ ਤੇ ਦੁਭਾਸ਼ੀਆ ਸੇਵਾ (Translating and Interpreting Service) ਨੂੰ 13 14 50 ਤੇ ਫੋਨ ਕਰੋ।

#### RUSSIAN

За информацией на русском языке перейдите на сайт: www.cancerscreening.gov.au/translations или позвоните в Службу письменного и устного перевода TIS по тел. 13 14 50.

#### SERBIAN

За информације на српском, погледајте www.cancerscreening.gov.au/translations или назовите Службу преводилаца и тумача на 13 14 50.

#### SPANISH

Para obtener información en español, visite www.cancerscreening.gov.au/translations, o llame al Servicio de Traducción e Interpretación, en el 13 14 50.

#### TURKISH

Türkçe bilgi için www.cancerscreening.gov.au/translations adresini ziyaret edebilir veya 13 14 50'den Yazılı ve Sözlü Çeviri Servisi'ni arayabilirsiniz.

#### VIETNAMESE

Muốn biết thông tin tiếng Việt, truy cập www.cancerscreening.gov.au/translations, hoặc gọi cho Dịch vụ Thông Phiên dịch (TIS) qua số 13 14 50.

# Opt off form

This form is to be used if you do not wish to participate in the program.

ID number (you will find this on the top of your invitation letter)					
Family Name	Date of Birth / /				
Given Name(s)	Female Male				
Please provide your reason for opting off the program:         having regular colonoscopies         having regular FOBT screening         medical advice not to participate         I understand by choosing to opt off:         I will not receive any reminder letters and will not be invited to screen in the future, unless I notify the program that I want to be involved.					
<ul> <li>If I have opted off the program but then decide to participate by doing the program FOBT, I will be considered a participant in the program. This means my test results will be recorded on the Program Register and reminder letters will be sent to me if necessary.</li> </ul>					
Signed	Dated / /				
Please Note: This form must be signed by the person invited to participate in the program or a third party authorised to act on their behalf. If signing on behalf of the invitee please provide your name and contact information:					
Authorised third party name					
Authorised third party contact numbers:					
Work: ( ) Home: ( )	(Mobile)				
remove it from the booklet and send it to the Program Register at the following address	NBCSP Register Reply Paid 83245 Canberra BC ACT 2610				

# **Suspend form**

This form is to be used if you wish to suspend your participation in the program for a period of time.

ID number	(you will find thi	s on the top of yo	ur invitation lett	er)	
Family Name			Date of B		
Given Name(s)			Female Male		
seeking doctor's advice       illness         recent bowel cancer       travelling         screening       other         recent colonoscopy       other					
I wish to suspend my participation until (tick one of the following):         / /       (Please enter the date you wish to recommence in the program. This cannot be greater than one year from the date you were invited to participate)         I am next eligible to participate in the program					
Signed			Dated	/ /	
Please Note: This form must be signed by the person invited to participate in the program or a third party authorised to act on their behalf. If signing on behalf of the invitee please provide your name and contact information:					
Authorised third	party name				
Authorised third party contact numbers:					
Work: ( )	Hon	ne: ( )	(Mobi	le)	
Once you have completed this form, please remove it from the booklet and send it to the Program Register at the following address (no postage stamp required): NBCSP Register Reply Paid 83245 Canberra BC ACT 2610					

## **Need help?**

If you need more information the organisations below will be able to help you.

If you want to	Organisation	Contact Info
• Find out more about the Program	National Bowel Cancer Screening Program Information Line	1800 118 868 www.cancerscreening.gov.au/bowel
<ul> <li>Ask questions about how to do the test kit</li> </ul>		1800 930 998
	Test Kit Helpline	or watch a quick video at <u>www.cancerscreening.gov.au/bowel</u>
Access interpreter services	Translating and Interpreting	13 14 50
	Service	www.tisnational.gov.au
Access translated materials and letters	National Bowel Cancer Screening Program	www.cancerscreening.gov.au/translations
Access services to help with a hearing impairment	Teletypewriter (TTY) service	1800 810 586
Talk to trained staff about cancer	Concer Coursil	13 11 20
Find out what local cancer services are available	Cancer Council	www.cancer.org.au

All information in this publication is correct as at November 2017