

## NSW Bowel Cancer Care Follow-up Survey

This is the follow-up questionnaire to the **NSW Bowel Cancer Care Survey** you completed 6 months ago. This questionnaire asks about your follow-up care and arrangements, and gives you an opportunity to share your bowel cancer experience to help improve future care for patients with bowel cancer.

**Any questions or concerns?** Please call us on 1800 210 841 or email: [connect@sswahs.nsw.gov.au](mailto:connect@sswahs.nsw.gov.au)

Thank you for your ongoing participation in this study.

**1. What is today's date?**

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### Your Health and Recovery

**2. In general, would you say your health is:**

- Excellent
- Very good
- Good
- Fair
- Poor

**3. At any time since you were diagnosed with cancer, did a doctor or other health professional tell you that your cancer had come back (that is, you had a recurrence)?**

- Not sure
- No
- Yes **Where is it located?**
  - Bowel
  - Lungs
  - Liver
  - Other (please specify): \_\_\_\_\_

Sometimes, a patient will be given a **written follow-up plan** that outlines the follow-up arrangements and tests that are planned for the future.

**4. Have you been given a written follow-up plan?**

- Yes
- No
- Not sure
- I have been told that I will receive a written follow-up plan after I complete my treatment

## Your Follow-up Care

**5. Since completing treatment for your bowel cancer, have you seen any of the following health professionals for routine follow-up?**

*Please tick all that apply*

- GP
- Surgeon
- Gastroenterologist
- Medical oncologist
- Radiation oncologist
- Other specialist (*please specify*): \_\_\_\_\_

**6. Have you had any of the below tests since completing your treatment?**

*Please tick all that apply*

- Barium Enema
- Colonoscopy
- Sigmoidoscopy
- CT scan of abdomen
- CT scan of chest
- Chest X-Ray
- Faecal Occult Blood Test (FOBT)
- Routine blood test (blood count, blood tests for liver and kidney function)
- CEA test (specific blood test for bowel cancer)









Thinking about the future, the following questions ask about the arrangements for your follow-up care over the next 3 years. If you are unsure, please answer to the best of your ability.

**7. Have you been advised to see any Doctor for routine follow-up of your bowel cancer over the next three years? If yes, please indicate how frequently you have been advised to see them.**

*Please tick all that apply*

		Annually	Every 2 years	Every 3 years	Other ( <i>please specify</i> ):
GP	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				_____
Surgeon	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				_____
Gastroenterologist	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				_____
Radiation oncologist	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				_____
Medical oncologist	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				_____
Other ( <i>please specify</i> ): _____	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				_____

**8. Have you been advised to have any of the following tests or investigations in the next three years?**  
*Please tick all that apply*

		Annually	Every 2 years	Every 3 years	Other ( <i>please specify</i> ):
Colonoscopy	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				
Sigmoidoscopy	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				
CT scan of abdomen	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				
CT scan of chest	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				
Chest X-Ray	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				
Faecal Occult Blood Test (FOBT)	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				
Routine blood test (blood count, blood tests for liver and kidney function)	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				
CEA test (specific blood test for bowel cancer)	<input checked="" type="checkbox"/> Yes 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
	<input type="checkbox"/> No				
	<input type="checkbox"/> Not sure				

**9. Which of the following statements best describes your preference for your follow-up care?**  
*Please tick the box that most applies*

- I would have preferred more follow-up consultations with my Doctors
- I would have preferred more follow-up investigations and tests
- I am happy with the follow-up consultations and investigations I received
- I would have preferred fewer follow-up investigations and tests
- I would have preferred fewer follow-up consultations with my Doctors

**10. How would you rate the care you received from your follow-up care Doctor?**

1    2    3    4    5    6    7    8    9    10  
*Very poor* *Excellent*

11. Since your diagnosis with cancer, have you been advised to have regular screening tests for other cancers?

Please tick all that apply

- No
- Yes →
  - Bowel cancer
  - Skin cancer
  - Breast cancer
  - Cervical cancer
  - Prostate cancer
  - Other (please specify): \_\_\_\_\_

12. Since your diagnosis with cancer, has your doctor discussed the risk of cancer for other members of your family?

Please note most cancers are NOT genetic and only a small number of families have a greater risk of cancer because they carry a changed gene

- No
- Yes

13. Since completing your cancer treatment, do you know what symptoms or changes in your health you should look out for that could be due to bowel cancer?

- No
- Yes

14. Since completing your cancer treatment, how much focus have you put in with other aspects of your lifestyle?

Please tick any that apply

	Less Effort	Same	More Effort	Not Applicable
Healthy diet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Maintaining a healthy weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being physically active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limiting alcohol consumption	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stop smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sun protection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing stress or anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting enough sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pap tests and mammography (women only)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Since completing your cancer treatment, have you received assistance from a health professional (eg. doctor, nurse, dietician, counsellor) with any of the above?

- No
- Yes

If yes, please describe:

**16. Since completing your cancer treatment, would you like to have received more assistance, advice or support about general health or lifestyle issues?**

No

Yes

*If yes, which aspects of your lifestyle would you have liked more help with?*

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**17. Since your diagnosis with cancer, have you or your family members used any services or resources that support coping or emotional well-being?**

*Please tick all that apply*

No, I did not need this type of support

No, I did not know about these services

Yes



Saw a psychologist/counsellor

Attended a cancer support group

Used internet and computer resources (eg. websites, online communities, blogs & online support groups)

Used a telephone support helpline (eg. Cancer Council helpline)

Other(*please specify*): \_\_\_\_\_

**18. Did you have any comments or experiences that you would like to share?**

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***Thank you very much for your time***