



**Early Detection of
Bowel Cancer Study**

**Hunter Community Study
Researching Health & Lifestyle in the Hunter Region**



hunter community study

Researching Health and Lifestyle in the Hunter Region

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All of the questions in this survey are about bowel cancer. They ask about symptoms, visiting the doctor, family history of bowel cancer and screening tests.

Please circle the number or letter that best describes your answer to each question. Some questions will require you to record numbers.

Please answer every question.

There are no right or wrong answers. The survey will take around 15 minutes to complete.

When you have completed all sections of the survey, simply put the survey in the reply-paid envelope provided and post it back within the next 7 days. No postage stamp is needed.

The return of your completed questionnaire will be taken as an indication of your voluntary consent to participate in this study.

If you have any questions or concerns about the study please do not hesitate to contact Dr Chris Paul (Study co ordinator) by telephone on 02 49 138143 or by email chris.paul@newcastle.edu.au

THANKS FOR YOUR TIME

If you have any concerns or complaints about the conduct of the study, you may contact:

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Professional Officer

Hunter New England Human Research Ethics Committee

Hunter New England Health

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Q1. Have you ever been told that you have a bowel related condition e.g. Inflammatory bowel disease - Ulcerative colitis or Crohn's disease?	<ol style="list-style-type: none">1. Yes2. No
The following questions are about blood in your bowel motions	
Q2. Have you ever noticed blood in your bowel motions, in the toilet bowl or on the toilet paper?	<ol style="list-style-type: none">1. Yes ⇒ Go to Question 32. No ⇒ Go to Question 2a
Q2a. If you noticed blood or black material in a bowel motion how soon would you contact your doctor to make an appointment?	<ol style="list-style-type: none">1. Less than 1 week2. More than 1 week but less than 4 weeks3. More than 4 weeks but less than 8 weeks4. More than 8 weeks but less than 12 weeks5. More than 3 months but less than 12 months6. More than 12 months7. Never ⇒ Go to Question 15
Q3. Have you ever seen a doctor about blood in your bowel motions, in the toilet bowl or on the toilet paper?	<ol style="list-style-type: none">1. Yes ⇒ Go to Question 42. No ⇒ Go to Question 3a
Q3a. If you noticed blood or black material in a bowel motion ('sign of rectal bleeding') how soon would you contact your doctor to make an appointment?	<ol style="list-style-type: none">1. Less than 1 week2. More than 1 week but less than 4 weeks3. More than 4 weeks but less than 8 weeks4. More than 8 weeks but less than 12 weeks5. More than 3 months but less than 12 months6. More than 12 months7. Never ⇒ Go to Question 14
Q4. Did you first notice blood in your bowel motions, in the toilet bowl or on the toilet paper in the last 5 years?	<ol style="list-style-type: none">1. Yes ⇒ Go to Question 52. No ⇒ Go to Question 4a



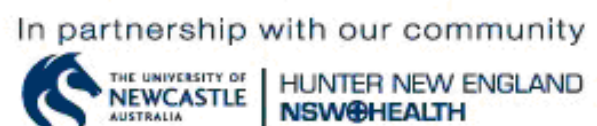


<p>Q4a. If you noticed blood or black material in a bowel motion ('sign of rectal bleeding') how soon would you contact your doctor to make an appointment?</p>	<ol style="list-style-type: none"> 1. Less than 1 week 2. More than 1 week but less than 4 weeks 3. More than 4 weeks but less than 8 weeks 4. More than 8 weeks but less than 12 weeks 5. More than 3 months but less than 12 months 6. More than 12 months 7. Never <p>⇒ Go to Question 15</p>
<p>Q5. How long ago did you notice blood in your bowel motions for the first time? <i>(Please specify the amount of time)</i></p>	<ol style="list-style-type: none"> a. _____ Days b. _____ Weeks c. _____ Months d. _____ Years
<p>Q5a. Did you see a doctor about it?</p>	<ol style="list-style-type: none"> 1. Yes 2. No ⇒ Go to Question 14
<p>Q6. How long after you first noticed blood in your bowel motions did you see a doctor about it? <i>(Please specify the amount of time)</i></p>	<ol style="list-style-type: none"> a. _____ Days b. _____ Weeks c. _____ Months d. _____ Years
<p>Q7. What is the main reason you did not seek medical advice about blood in your bowel motions sooner? <i>(Please circle only one response)</i></p>	<ol style="list-style-type: none"> 1. I consulted a doctor within one week 2. Thought it wasn't serious 3. Cleared up itself 4. Thought it was haemorrhoids/piles 5. Decided to wait and see 6. Seeing a doctor would be unpleasant / embarrassing 7. Worried or scared it might be serious 8. No faith in doctors / doctor couldn't do anything 9. Couldn't afford doctor visit 10. Did not want to waste doctor's time 11. Not confident in discussing symptom / doctor hard to talk to 12. No time/busy/other things to think about 13. Difficulty making an appointment or getting transport 14. Didn't want to worry family/friends 15. Can't remember 16. Other (please specify _____)





<p>Q8. Where did you notice this blood? <i>(Please circle all that apply)</i></p>	<p>a. Blood mixed with stool / poo b. Blood on toilet paper c. Blood in the toilet bowl</p>
<p>Q9. How would you describe the colour of the blood?</p>	<p>1. Bright red 2. Dark red 3. Black</p>
<p>Q10. How often was there blood in bowel motion?</p>	<p>1. Every time 2. More than half of the time but not all the time 3. About half of the time 4. Less than half the time but more than once 5. Only once 6. Not sure</p>
<p>Q11. How much did the amount of blood concern you?</p>	<p>1. High concern 2. Moderate concern 3. Minor concern 4. No concern at all</p>
<p>Q12. What in particular prompted you to consult a doctor about blood in your bowel motions? <i>(Please circle all that apply)</i></p>	<p>1. Thought the symptom was serious 2. Symptom didn't go away 3. Symptom was bad 4. Symptom got worse 5. Partner or family member suggested it 6. Advertisement about bowel cancer 7. Friend diagnosed with cancer 8. Family history of cancer 9. Opportunity to talk during doctor visit for other reason 10. Had check up or appointment already booked 11. Other (please specify_____)</p>





Q13. What did your doctor do when you mentioned the blood in your bowel movements?

(Please circle all that apply)

1. Discussed symptoms
2. Advised to make dietary change e.g. higher fibre diet
3. Told to 'wait and see'
4. Digital rectal examination (DRE)/Physical examination
5. Referral to bowel specialist for screening test e.g. colonoscopy/sigmoidoscopy
6. Sent for test to detect blood in stool/poo e.g. Faecal Occult Blood Test (FOBT)
7. Blood test
8. Diagnosed with haemorrhoids/piles
9. Diagnosed with bowel related condition e.g. Irritable bowel syndrome, no further action taken

⇒ Go to Question 15





Q14. What is the main reason you did not seek medical advice about blood in your bowel motions?
(Please circle only one response)

1. **Thought it wasn't serious** ⇒ Go to Question 14a
2. **Cleared up itself** ⇒ Go to question 14b
3. **Thought it was haemorrhoids/piles**
⇒ Go to Question 15
4. **Decided to wait and see**
⇒ Go to Question 15
5. **Seeing doctor would be unpleasant/embarrassing**
⇒ Go to Question 15
6. **Worried that the doctor might find something serious (scared)** ⇒ Go to Question 15
7. **Never see doctors/little faith in doctors**
⇒ Go to Question 15
8. **Thought doctor couldn't do anything**
⇒ Go to Question 15
9. **Couldn't afford doctor visit**
⇒ Go to Question 15
10. **Did not want to waste doctor's time**
⇒ Go to Question 15
11. **Not confident in discussing symptom**
⇒ Go to Question 15
12. **Doctor difficult to talk to**
⇒ Go to Question 15
13. **No time/busy/other things to worry about**
⇒ Go to Question 15
14. **Put it out of my mind – chose not to think about the symptom** ⇒ Go to Question 15
15. **Difficulty making an appointment**
⇒ Go to Question 15
16. **Didn't want to worry family/friends**
⇒ Go to Question 15
17. **Transport problems** ⇒ Go to Question 15
18. **Can't remember** ⇒ Go to Question 15
19. **Other (please specify _____)**

Q14a. Which symptom(s) would be serious enough for you to see a doctor?
(Please circle all that apply)

- a. **Black blood**
- b. **Blood in the stool**
- c. **Blood every time I passed bowel movements**
- d. **Lots of blood**
⇒ Go to Question 15





Q14b. How long did it take to clear up?
(Please specify the amount of time)

- a. _____ Days
- b. _____ Weeks
- c. _____ Months
- d. _____ Years

The following questions are about a change in normal bowel habits

Q15. Have you ever noticed a persistent change in your normal bowel habits that lasted longer than two weeks? This may include looser bowel motion/ needing to go to the toilet more than usual (diarrhoea) or an inability to pass bowel motions (constipation).

- 1. **Yes** ⇒ Go to Question 16
- 2. **No** ⇒ Go to Question 15a

Q15a. If you noticed a persistent change in your bowel habits lasting longer than two weeks, how soon would you contact your doctor to make an appointment?

- 1. **Less than 1 week**
 - 2. **More than 1 week but less than 4 weeks**
 - 3. **More than 4 weeks but less than 8 weeks**
 - 4. **More than 8 weeks but less than 12 weeks**
 - 5. **More than 3 months but less than 12 months**
 - 6. **More than 12 months**
 - 7. **Never**
- ⇒ Go to Question 28

Q16. Have you ever seen a doctor about a persistent change in your normal bowel habits that lasted longer than two weeks?

- 1. **Yes** ⇒ Go to Question 17
- 2. **No** ⇒ Go to Question 16a

Q16a. If you noticed a persistent change in your bowel habits lasting longer than two weeks, how soon would you contact your doctor to make an appointment?

- 1. **Less than 1 week**
 - 2. **More than 1 week but less than 4 weeks**
 - 3. **More than 4 weeks but less than 8 weeks**
 - 4. **More than 8 weeks but less than 12 weeks**
 - 5. **More than 3 months but less than 12 months**
 - 6. **More than 12 months**
 - 7. **Never**
- ⇒ Go to Question 27

Q17. Did you first notice a persistent change in your bowel habits that lasted longer than two weeks in the last 5 years?

- 1. **Yes** ⇒ Go to Question 18
- 2. **No** ⇒ Go to Question 17a



<p>Q17a. If you noticed a persistent change in your bowel habits lasting longer than two weeks, how soon would you contact your doctor about it to make an appointment?</p>	<ol style="list-style-type: none"> 1. Less than 1 week 2. More than 1 week but less than 4 weeks 3. More than 4 weeks but less than 8 weeks 4. More than 8 weeks but less than 12 weeks 5. More than 3 months but less than 12 months 6. More than 12 months 7. Never ⇒ Go to Question 28
<p>Q18. How long ago did you notice a persistent change in your bowel habits for the first time? <i>(Please specify the amount of time)</i></p>	<ol style="list-style-type: none"> a. _____ Days b. _____ Weeks c. _____ Months d. _____ Years
<p>Q19. What type of irregular bowel movements did you experience? <i>(Please circle all that apply)</i></p>	<ol style="list-style-type: none"> a. Diarrhoea b. Constipation c. Other (please specify _____)
<p>Q19a. Did you see a doctor about it?</p>	<ol style="list-style-type: none"> 1. Yes 2. No ⇒ Go to Question 27
<p>Q20. How long after you first noticed a persistent change in your bowel habits did you see a doctor about it? <i>(Please specify the amount of time)</i></p>	<ol style="list-style-type: none"> a. _____ Days b. _____ Weeks c. _____ Months d. _____ Years



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Q21. What is the main reason you did not seek medical advice about a persistent change in your bowel habits sooner?
(Please circle only one response)

- 1. I consulted a doctor within one week**
⇒ Go to Question 22
- 2. Thought it wasn't serious** ⇒ Go to Question 22
- 3. Cleared up itself** ⇒ Go to Question 21a
- 4. Thought it was haemorrhoids/piles**
⇒ Go to Question 22
- 5. Decided to wait and see** ⇒ Go to Question 22
- 6. Seeing doctor would be unpleasant/embarrassing**
⇒ Go to Question 22
- 7. Worried or scared it might be serious**
⇒ Go to Question 22
- 8. No faith in doctors/doctor couldn't do anything**
⇒ Go to Question 22
- 9. Couldn't afford doctor visit**
⇒ Go to Question 22
- 10. Did not want to waste doctor's time**
⇒ Go to Question 22
- 11. Not confident in discussing symptom/doctor hard to talk to** ⇒ Go to Question 22
- 12. No time/busy/other things to think about**
⇒ Go to Question 22
- 13. Difficulty making an appointment or getting transport** ⇒ Go to Question 22
- 14. Didn't want to worry family/friends**
⇒ Go to Question 22
- 15. Can't remember** ⇒ Go to Question 22
- 16. Other (please specify _____)**
⇒ Go to Question 22

Q21a. How long did it take to clear up?
(Please specify the amount of time)

- a. _____ Days
- b. _____ Weeks
- c. _____ Months
- d. _____ Years

Q22. How long did the change in bowel habits persist?
(Please specify the amount of time)

- a. _____ Days
- b. _____ Weeks
- c. _____ Months
- d. _____ Years





<p>Q23. Please rate how uncomfortable or painful this diarrhoea/ constipation was?</p>	<ol style="list-style-type: none"> 1. No discomfort 2. Mild discomfort 3. Mild pain 4. Moderate pain 5. Intense pain
<p>Q24. How often did you experience diarrhoea/ constipation when passing bowel motion?</p>	<ol style="list-style-type: none"> 1. Every time 2. More than half of the time but not all the time 3. About half of the time 4. Less than half the time but more than once 5. Only once 6. Not sure
<p>Q25. What in particular prompted you to consult a doctor about a persistent change in your bowel habits? <i>(Please circle all that apply)</i></p>	<ol style="list-style-type: none"> 1. Thought the symptom was serious 2. Symptom didn't go away 3. Symptom was bad 4. Symptom got worse 5. Partner or family member suggested it 6. Advertisement about bowel cancer 7. Friend diagnosed with cancer 8. Family history of cancer 9. Opportunity to talk during doctor visit for other reason 10. Had check up or appointment already booked 11. Other (please specify _____)
<p>Q26. What did your doctor do when you mentioned a persistent change in your bowel habits? <i>(Please circle all that apply)</i></p>	<ol style="list-style-type: none"> a. Discussed symptoms b. Advised to make dietary change e.g. higher fibre diet c. Told to 'wait and see' d. Digital rectal examination (DRE)/Physical Examination e. Referral to bowel specialist for screening test e.g. colonoscopy/sigmoidoscopy f. Sent for test to detect blood in stool/poo e.g. Faecal Occult Blood Test (FOBT) g. Blood test h. Diagnosed with Haemorrhoids/piles i. Diagnosed with bowel related condition e.g. Irritable bowel syndrome, no further action taken. <p>⇒ Go to Question 28</p>





Q27. What is the main reason you did not seek medical advice about a persistent change in your bowel habits?
(Please circle only one response)

1. **Thought it wasn't serious** ⇒ Go to Question 28
2. **Cleared up itself** ⇒ Go to Question 27a
3. **Thought it was haemorrhoids/piles**
⇒ Go to Question 28
4. **Decided to wait and see** ⇒ Go to Question 28
5. **Seeing doctor would be unpleasant/embarrassing** ⇒
Go to Question 28
6. **Worried that the doctor might find something serious (scared)** ⇒ Go to Question 28
7. **Never see doctors/little faith in doctors**
⇒ Go to Question 28
8. **Thought doctor couldn't do anything**
⇒ Go to Question 28
9. **Couldn't afford doctor visit** ⇒ Go to Question 28
10. **Did not want to waste doctor's time**
⇒ Go to Question 28
11. **Not confident in discussing symptom**
⇒ Go to Question 28
12. **Doctor difficult to talk to** ⇒ Go to Question 28
13. **No time/busy/other things to worry about** ⇒ Go to
Question 28
14. **Put it out of my mind – chose not to think about the symptom** ⇒ Go to Question 28
15. **Difficulty making an appointment** ⇒ Go to Question 28
16. **Didn't want to worry family/friends**
⇒ Go to Question 28
17. **Transport problems** ⇒ Go to Question 28
18. **Can't remember** ⇒ Go to Question 28
19. **Other (please specify _____)**

Q27a. How long did it take to clear up?
(Please specify the amount of time)

- a. _____ Days
- b. _____ Weeks
- c. _____ Months
- d. _____ Years



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Q28. If you noticed any of the following, how soon would you contact your doctor to make an appointment?
Record the answer to each question that best applies to you by circling:

	Less than a week	More than 1 week but less than 4 weeks	More than 4 weeks but less than 8 weeks	More than 8 weeks but less than 12 weeks	More than 3 months but less than 12 months	More than 12 months	Never
a. Unexplained weight loss	1	2	3	4	5	6	7
b. Unexplained tiredness or weakness	1	2	3	4	5	6	7
c. Abdominal pain	1	2	3	4	5	6	7
d. Loss of Appetite	1	2	3	4	5	6	7

The following questions are about appropriate bowel cancer screening

The following questions are about whether any of your relatives have been diagnosed with bowel cancer. Bowel cancer, also called colorectal cancer, is cancer in the large bowel or large intestine, it includes both colon and rectal cancer but not anal cancer.

Q29. How many of your close relatives (mother, father, brother, sister or child) have ever been diagnosed with bowel cancer?

- a. **None** ⇒ Go to Question 31
- b. **One**
- c. **Two**
- d. **Three or more**

Q30. How many of these relative(s) were diagnosed at the following ages?
(Please write number of relatives diagnosed in each age category)

- 1. ___ **50 or less**
- 2. ___ **Between 51 and 55**
- 3. ___ **56 or over**
- 4. ___ **Don't know**



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Q31. Have any of your second-degree relatives (grandparents, uncles, aunts, nephews, nieces or half-siblings) ever been diagnosed with bowel cancer? This includes only biological/blood-relatives, not those related to you through marriage.
(Please select all that apply)

- a. None of these relatives have ever been diagnosed with bowel cancer** ⇒ Go to Question 33
- b. Yes, mother's mother**
 - c. Yes, father's mother**
 - d. Yes, mother's father**
 - e. Yes, father's father**
 - f. Yes, mother's sister**
 - g. Yes, father's sister**
 - h. Yes, mother's brother**
 - i. Yes, father's brother**
 - j. Yes, nephew**
 - k. Yes, niece**
 - l. Yes, grandchild**
 - m. Yes, half-sibling (mother's side)**
 - n. Yes, half-sibling (father's side)**

Q32. How many of these relative(s) were diagnosed at the following ages?
(Please write number of relatives diagnosed in each age category)

- 1. ___ 50 or less**
- 2. ___ Between 51 and 55**
- 3. ___ 56 or over**
- 4. ___ Don't know**

Q33. Has your mother, father, brother, sister, child, grandparent, uncle, aunt, nephew, niece or half-sibling ever been diagnosed with any of the following cancers: endometrium, ovary, stomach, renal pelvis, ureter, biliary tract or brain.

- 1. Yes**
- 2. No**
- 3. Don't know**

The next questions are about *screening tests* you may have had for bowel cancer.

Q34. Have you ever had an FOBT, FIT or iFOBT? These tests faecal occult blood test (FOBT), faecal immunochemical test (FIT) and immunochemical faecal occult blood test (iFOBT) involve you providing samples of faeces or poo. The samples would have been sent to a laboratory to test for tiny amounts of blood.

- 1. Yes**
- 2. No** ⇒ Go to Question 37
- 3. Not Sure** ⇒ Go to Question 37



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<p>Q35. How long ago was your last FOBT, FIT or iFOBT?</p>	<ol style="list-style-type: none"> 1. Less than a month ago 2. One month to less than twelve months ago 3. Twelve months to less than two years ago 4. Two years to less than five years ago 5. Five years or longer ago 6. Don't know/not sure
<p>Q36. Did you have your last FOBT, FIT or iFOBT because you had a symptom?</p>	<ol style="list-style-type: none"> 1. Yes 2. No
<p>Q37. Have you ever had a colonoscopy? This is usually a day procedure in hospital where the inside of your colon is examined while you are sedated.</p>	<ol style="list-style-type: none"> 1. Yes 2. No ⇒ Go to Question 40 3. Not Sure ⇒ Go to Question 40
<p>Q38. How long ago was your most recent colonoscopy?</p>	<ol style="list-style-type: none"> 1. Less than a month ago 2. One month to less than twelve months ago 3. Twelve months to less than two years ago 4. Two years to less than five years ago 5. Five years or longer ago 6. Don't know/not sure
<p>Q39. Did you have your most recent colonoscopy because you had a symptom?</p>	<ol style="list-style-type: none"> 1. Yes 2. No
<p>Q40. Have you ever had a sigmoidoscopy? In this procedure only the rectum and lower part of the colon are examined. This is a short procedure which lasts about 5-10 minutes. Sedation is not usually required and you can usually go home straight after the procedure.</p>	<ol style="list-style-type: none"> 1. Yes 2. No ⇒ Go to Question 43 3. Not Sure ⇒ Go to Question 43
<p>Q41. How long ago was your most recent sigmoidoscopy?</p>	<ol style="list-style-type: none"> 1. Less than a month ago 2. One month to less than twelve months ago 3. Twelve months to less than two years ago 4. Two years to less than five years ago 5. Five years or longer ago
<p>Q42. Did you have your most recent sigmoidoscopy because you had a symptom?</p>	<ol style="list-style-type: none"> 1. Yes 2. No



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The following questions ask about risk

You may or may not be aware that an individual's risk of developing bowel cancer increases with the number of relatives diagnosed in a family. Sometimes doctors may ask questions about your family history of colorectal cancer and give advice on screening for you and your relatives.

<p>Q43. Has any health professional e.g. your doctor, ever asked if you have a family history of bowel cancer?</p>	<p>1. Yes 2. No ⇒ Go to Question 45</p>
<p>Q44. Did this person discuss whether there was a possible 'increased risk' of bowel cancer for you or your family members?</p>	<p>1. Yes 2. No</p>
<p>Q45. Has any health professional suggested that you or your relatives should do any of the following: <i>Please choose all that apply.</i></p>	<p>a. Start having screening tests for bowel cancer b. Talk to their doctor about screening tests c. No advice has ever been given d. Take other action related to bowel cancer (please specify _____)</p>

The following questions ask about internet use

We are interested in finding out whether people of various ages would be interested in answering surveys over the internet.

<p>Q46. Do you use the internet? <i>(Please circle all that apply)</i></p>	<p>a. Yes, at home b. Yes, at work c. Yes, at library or café d. No, not at all</p>
<p>Q47. Do you have access to email? <i>(Please circle all that apply)</i></p>	<p>a. Yes, at home b. Yes, at work c. Yes, at library or café d. No, not at all</p>

If you have any questions, concerns or worries about cancer after doing this survey, we encourage you to discuss matters with your doctor or contact the Cancer Council Helpline, on 13 11 20.

**You have now finished this survey.
Thank you for your time.
Please return the completed questionnaire to the Hunter Community Study
in the reply-paid envelope provided.**

