

## AUSTRALASIAN COLORECTAL CANCER FAMILY STUDY FOLLOW-UP QUESTIONNAIRE

In **«InterviewDt»**, you completed a questionnaire for this study. We now want to update some of the information you gave us previously and also ask for some additional information, including your family history.

Some questions ask about the time since the date of your last interview, while other questions are not restricted to a specific time. If you are unsure about any answers, it would still help greatly if you give us your best estimate.

Should you wish to talk to someone about this questionnaire, contact the Study Coordinator Judi Maskiell on Free Call number 1800 060 660.

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### **SECTION 1: Personal Information**

To begin with, I'd like to confirm your details for our records.

**What is your full name?**

\_\_\_\_\_

First Name

\_\_\_\_\_

Middle Name

\_\_\_\_\_

Surname

**Have you ever used any other SURNAMES?**

\_\_\_\_\_  
\_\_\_\_\_

**Your Date of Birth is «DOB»? Write here if not correct,**

\_\_\_\_\_

#### **Office Use Only**

This page is to be removed and stored separately to protect individual privacy and confidentiality.

Short Version

In case we need to contact you in the future and you have moved may we please have the name of someone who is not living with you to whom we might write or call for your new address or phone number? If you agree, please write the details in the space below.

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*First Name*

*Middle Name*

*Last Name*

What is this person's relationship to you? (eg mother, aunt, friend) \_\_\_\_\_

What is their Address?

Street Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Postcode \_\_\_\_\_

What is their Phone number and Email Address?

Home \_\_\_\_\_ Mobile \_\_\_\_\_

Email Address \_\_\_\_\_

## AUSTRALASIAN COLORECTAL CANCER FAMILY STUDY - FOLLOW-UP QUESTIONNAIRE

Date of Birth «DOB»

Gender «Gender»

What date are you completing this questionnaire? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Day month year

**SECTION 2 – Personal Medical History****2a. BARIUM ENEMA**

Since «InterviewDt\_FUP», have you ever had a barium enema?

A barium enema is an x-ray examination of your colon. X-rays of the colon are taken following a barium enema. Preparation involves fluids, laxatives, and an enema to cleanse the bowel.

- Yes → continue  
 No → go to question 2b.  
 Don't Know → go to question 2b.

Since «InterviewDt\_FUP», how many separate occasions have you had a barium enema? \_\_\_\_\_ times

When did you have your most recent barium enema? \_\_\_\_\_ Age OR \_\_\_\_\_ Year

What were the reasons for the most recent barium enema (select all that apply)?

- To investigate a new problem  
 Family history of colorectal cancer  
 Routine exam or check-up  
 Follow-up of a previous problem  
 Follow-up of FOBT result  
 Other (specify) \_\_\_\_\_  
 Don't know

**2b. FAECAL OCCULT BLOOD TEST (FOBT)**

Since «InterviewDt\_FUP», have you had an FOBT?

This is a test using treated cards to detect blood in faeces? It is also called a smear or stool test, or hemoccult test. A FOBT is typically done at home using a kit containing 3 treated cards.

- Yes → continue  
 No → go to question 2c.  
 Don't Know → go to question 2c.

Since «InterviewDt\_FUP», how many separate occasions have you had an FOBT? \_\_\_\_\_ times

When did you have your most recent FOBT? \_\_\_\_\_ Age OR \_\_\_\_\_ Year

What were the reasons for the most recent FOBT (select all that apply)?

- To investigate a new problem  
 Family history of colorectal cancer  
 Routine exam or check-up  
 Follow-up of a previous problem  
 Follow-up of FOBT result  
 Other (specify) \_\_\_\_\_

Don't know

## 2c. SIGMOIDOSCOPIES

Since «InterviewDt\_FUP», have you had a sigmoidoscopy?

This is an examination limited to the lower colon and rectum and is usually done in a doctor's rooms without medication to relax you or make you sleepy. Preparation involves enemas and sometimes drinking fluids or taking pills to cleanse the bowel.

- Yes → continue  
 No → go to question 2d.  
 Don't Know → go to question 2d.

Since «InterviewDt\_FUP», how many separate occasions have you had a sigmoidoscopy? \_\_\_\_\_ times

When did you have your most recent sigmoidoscopy? \_\_\_\_\_ Age OR \_\_\_\_\_ Year

What were the reasons for the most recent sigmoidoscopy (select all that apply)?

- To investigate a new problem  
 Family history of colorectal cancer  
 Routine exam or check-up  
 Follow-up of a previous problem  
 Follow-up of FOBT result  
 Other (specify) \_\_\_\_\_  
 Don't know

## 2d. COLONOSCOPIES

Since «InterviewDt\_FUP», have you had a colonoscopy?

In a colonoscopy, the entire large bowel is examined and a medication is usually given intravenously to relax you or make you sleepy. Preparation involves drinking fluids or taking pills to cleanse the bowel.

- Yes → continue  
 No → go to question 2e.  
 Don't Know → go to question 2e.

Since «InterviewDt\_FUP», how many separate occasions have you had a colonoscopy? \_\_\_\_\_ times

When did you have your most recent colonoscopy? \_\_\_\_\_ Age OR \_\_\_\_\_ Year

What were the reasons for the most recent colonoscopy (select all that apply)?

- To investigate a new problem  
 Family history of colorectal cancer  
 Routine exam or check-up  
 Follow-up of a previous problem  
 Follow-up of FOBT result  
 Other (specify) \_\_\_\_\_  
 Don't know

**2e. COLONOGRAPH OR VIRTUAL COLONOSCOPY (VC)**

Since «InterviewDt\_FUP», have you ever had a CT Colonograph or Virtual Colonoscopy (this is not a regular colonoscopy)?

A CT Colonograph is a procedure done using x-rays with you lying on a table that is slid through a large circular scanner or a tunnel. Typically a tube is inserted to inflate the rectum with air. Preparation may include drinking fluid or taking laxatives to cleanse the bowel. You are not given medications to relax you or make you sleep. This procedure may also be referred to as a Virtual Colonoscopy (VC).

- Yes → continue
- No → go to question 2f.
- Don't Know → go to question 2f.

Since «InterviewDt\_FUP», how many separate occasions have you had a virtual colonoscopy? \_\_\_\_\_ times

When did you have your most recent virtual colonoscopy? \_\_\_\_\_ Age OR \_\_\_\_\_ Year

What were the reasons for the most recent virtual colonoscopy (select all that apply)?

- To investigate a new problem
- Family history of colorectal cancer
- Routine exam or check-up
- Follow-up of a previous problem
- Follow-up of FOBT result
- Other (specify) \_\_\_\_\_
- Don't know

**2f. POLYPS**

Since «InterviewDt\_FUP», has a doctor told you that you had polyps in your colon or rectum? Be sure to include all polyps that were found during any of the procedures discussed above that you have had since your last interview and not just polyps that may have been found during your most recent procedure.

- Yes → continue
- No → go to question 2g.
- Don't Know → go to question 2g.

If yes, since «InterviewDt\_FUP», have you had any of these polyps removed (usually done during colonoscopy)?

- Yes → go to question 2g.
- No → go to question 2g.
- Don't Know → go to question 2g.

**2g. COLORECTAL SURGERY**

Since «InterviewDt\_FUP», have you had surgery to remove any of your colon or rectum? Please do not include any surgery where only polyps were removed.

- Yes → go to question 2h.
- No → go to question 2h.
- Don't Know → go to question 2h.

**2h. GYNAECOLOGICAL SURGERY**

Since «InterviewDt\_FUP», have you had any surgeries on your ovaries and/or uterus?

- Yes → go to SECTION 3
- No → go to SECTION 3
- Don't Know → go to SECTION 3

**SECTION 3 – Cancer**

3a. Since «InterviewDt\_FUP», has a doctor ever told you that you had any type of cancer, such as leukaemia, lymphoma or a malignant tumour?

- Yes → go to SECTION 4
- No → go to SECTION 4
- Don't Know → go to SECTION 4

**SECTION 4 – Genetic Testing**

4a. Have you ever participated in any other genetic or family-based cancer studies other than this study?

- Yes, please  
specify name of study or clinic \_\_\_\_\_ → continue
- No → continue
- Don't Know → continue

4.b Have you had a blood test to look for genes for bowel cancer? You may have had such a test when attending a genetic clinic or service? Do not include blood tests you have had as part of this study.

- Yes → go to SECTION 5 (Office Use Only  Expansion Not Required)
- No → go to SECTION 5
- Don't Know → go to SECTION 5

**SECTION 5 – New Adults**

This question asks about any of your children, brothers, sisters, nieces or nephews who may have turned 18 years old since your last interview.

Since «InterviewDt\_FUP», have there been any of your children, brothers, sisters, nieces or nephews that have turned 18 years old?

- Yes → please write details below
- No → go to SECTION 6
- Don't Know → go to SECTION 6

Relative	Male or Female?	Relationship to you?	Year they turned 18
1			
2			
3			
4			
5			

**FOLLOW UP 2**

FAMILY ID «FamilyID»

ID Number

«IDNumber»

6			
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**SECTION 6 – Your Family Cancer History**

This section asks about cancer in your biological (blood) relatives since «InterviewDt\_FUP»

**6a. Since «InterviewDt\_FUP», have any of your relatives had cancer?**

- Yes → please write details below
- No
- Don't Know

Relative	Male or Female?	What is their Relationship to you?	What type of cancer did they have?
1			
2			
3			
4			
5			
6			

**6b. Since «InterviewDt\_FUP», have any of your relatives died?**

- Yes → please write details below
- No
- Don't Know

Relative	Male or Female?	What is their Relationship to you?	What was the cause of their death?
1			
2			
3			
4			
5			
6			

**THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE**

