Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   Yes                           No
   Please continue with Question 2
   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?
   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below |
|-----------------------|-----|-------------------------------------|
| Did you have this symptom? | [x] | [ ] No |
| [ ] Please go to Section 2 |

| A | When did you first notice this? | [ ] 2 3 / 1 2 / 0 7 |
| B | When did you first tell your GP or nurse? |
| C | Put a cross here if you didn't tell your GP or nurse |

Estimate

'3 months ago' or 'June'

Version:- 2.1 08/01/2009
3. **Change in bowel habit**

   Did you have this symptom?

   A  When did you first notice this?

   B  When did you first tell your GP or nurse?

   OR

   C  Put a cross here if you didn't tell your GP or nurse

   Please complete A then B or C below

   Yes

   No

   Please go to Question 4

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

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   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

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   No

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   OR

   Yes

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   No

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   Yes

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   No

   Please go to Section 2

   OR

   Yes

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   No

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   OR

   Yes

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   No

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   Yes

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   No

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   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

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   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

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   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

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   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

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   Please go to Section 2

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   Yes

   Please complete A then B or C below

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   Please go to Section 2

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   Yes

   Please complete A then B or C below

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   Please go to Section 2

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   Yes

   Please complete A then B or C below

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   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2

   OR

   Yes

   Please complete A then B or C below

   No

   Please go to Section 2
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes  
No  

Please complete A then B or C below

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes  
No  

Please complete A then B or C below

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

**Please complete A then B or C below**

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

**Please go to Question 4**

---

4. **Feeling different 'in yourself' from usual**

Did you have this?

**Please complete A then B or C below**

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

**Please go to Question 5**

---

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

_______________________________________________________________
_______________________________________________________________

A  When did you first notice this?  
   ☐ ☐ ☐ ☐ OR

B  When did you first tell your GP or nurse?  
   ☐ ☐ ☐ ☐ OR

C  Put a cross here if you didn’t tell your GP or nurse
   ☐

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

_______________________________________________________________
_______________________________________________________________

A  When did you first notice this?  
   ☐ ☐ ☐ ☐ OR

B  When did you first tell your GP or nurse?  
   ☐ ☐ ☐ ☐ OR

C  Put a cross here if you didn’t tell your GP or nurse
   ☐

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                              | Yes | Not sure | No |
|----------------------------------|-----|----------|----|
| Blood test(s)                    |     |          |    |
| CT Scan                          |     |          |    |
| Ultrasound scan                  |     |          |    |
| Barium Enema                     |     |          |    |
| Sigmoidoscopy or colonoscopy     |     |          |    |
| (Looking at bowel with internal camera) | |  |  |
| X-ray                            |     |          |    |

Please go to Question 8
About you
The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home
   - Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None
   - Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11.

Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

**Please cross any that are applicable to you**

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. **About smoking**

**Please cross the appropriate statement**

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. **Do you think you were more at risk of getting cancer because of your family history?**

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm   |   |   |   |   |
| 2. I am tense    |   |   |   |   |
| 3. I feel upset  |   |   |   |   |
| 4. I am relaxed  |   |   |   |   |
| 5. I feel content|   |   |   |   |
| 6. I am worried  |   |   |   |   |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  Yes  No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  Yes  No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Looking At Your Symptoms Study

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Dear Patient

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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes

No

Please complete A then B or C below

A When did you first notice this? OR

B When did you first tell your GP or nurse? OR

C Put a cross here if you didn't tell your GP or nurse

Please go to Question 3

Please continue with Question 2

Please go to Section 2 on Page 5
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn’t tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn’t tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

Please go to Section 2
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

- [ ] Yes
- [x] No

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse


2. Unexplained weight loss

Did you have this?

- [ ] Yes
- [x] No

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse




3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

__________________________________________________________________________
__________________________________________________________________________

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

C Put a cross here if you didn't tell your GP or nurse

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6.

__________________________________________________________________________
__________________________________________________________________________

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

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If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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Please cross the appropriate boxes

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| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

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Other, please specify
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Please cross one box only

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  or
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    White Irish
    Other White background

Mixed
  or
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    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

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| Statement          | Not at all | Somewhat | Moderately | Very much |
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| 1. I feel calm     |            |          |            |           |
| 2. I am tense      |            |          |            |           |
| 3. I feel upset    |            |          |            |           |
| 4. I am relaxed    |            |          |            |           |
| 5. I feel content  |            |          |            |           |
| 6. I am worried    |            |          |            |           |

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Researcher - Post-completion Sheet

Date questionnaire completed: 

If not completed, give reason

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Did the patient ask for any help? 
Yes  No

If yes, please specify what help was requested

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For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? 
Yes  No

If yes, please specify which questions and what the difficulty was



Was the patient made anxious? 
Yes  No

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Section 1

About your symptoms

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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   - Yes
   - No

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes No

Please complete A then B or C below

A When did you first notice this? d d / m m / y y

OR

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7

OR

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**
   
   Did you have this?

   Yes  No

   Please complete A then B or C below

   Please go to Question 2

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**
   
   Did you have this?

   Yes  No

   Please complete A then B or C below

   Please go to Question 3

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

**Please try and describe what the feeling was**
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                             | Yes | Not sure | No  |
|--------------------------------------------------|-----|----------|-----|
| Blood test(s)                                    |     |          |     |
| CT Scan                                          |     |          |     |
| Ultrasound scan                                  |     |          |     |
| Barium Enema                                     |     |          |     |
| Sigmoidoscopy or colonoscopy                     |     |          |     |
| (Looking at bowel with internal camera)          |     |          |     |
| X-ray                                            |     |          |     |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. **How would you describe your ethnicity**

Please cross one box only

- **White**
  - White British
  - White Irish
  - Other White background

- **Mixed**
  - White & Black Carribean
  - White & Black African
  - White & Asian
  - Other mixed background

- **Black or Black British**
  - Carribean
  - African
  - Other Black background

- **Asian or Asian British**
  - Indian
  - Pakistani
  - Bangladeshi
  - Other Asian background

- **Chinese or other ethnic group**
  - Chinese
  - Other ethnic group

11. **Do you live alone?**

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes   No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □         | □        | □          | □         |
| 2. I am tense  | □         | □        | □          | □         |
| 3. I feel upset | □        | □        | □          | □         |
| 4. I am relaxed | □        | □        | □          | □         |
| 5. I feel content | □       | □        | □          | □         |
| 6. I am worried | □         | □        | □          | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time : :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes  ☐
Between 5 and 10 minutes  ☐
Between 11 and 15 minutes  ☐
Longer than 15 minutes  ☐

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  ☐ Yes  ☐ No
If yes, please specify what help was requested

________________________________________________________________________

please specify what help was given

________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  ☐ Yes  ☐ No
If yes, please specify which questions and what the difficulty was

________________________________________________________________________

________________________________________________________________________

Was the patient made anxious?  ☐ Yes  ☐ No
If yes, please give details

________________________________________________________________________

________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
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Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A When did you first notice this? d d m m y y

OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

2 3 1 2 0 7

OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn’t tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn’t tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

- A When did you first notice this?
- B When did you first tell your GP or nurse?
- OR
- C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 2

2. Unexplained weight loss

Did you have this?

- A When did you first notice this?
- B When did you first tell your GP or nurse?
- OR
- C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 3
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

__________________________________________________________________________
__________________________________________________________________________

A When did you first notice this?

__________________________________________________________________________

B When did you first tell your GP or nurse?

__________________________________________________________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

__________________________________________________________________________
__________________________________________________________________________

A When did you first notice this?

__________________________________________________________________________

B When did you first tell your GP or nurse?

__________________________________________________________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. **Were you sent for any of these?**

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
No

Please say who you live with below

(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?  

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking  

Please cross the appropriate statement

- Are you a current smoker?  
- Are you an ex-smoker?  
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☐        | ☐          | ☐         |
| 2. I am tense   | ☐         | ☐        | ☐          | ☐         |
| 3. I feel upset | ☐         | ☐        | ☐          | ☐         |
| 4. I am relaxed | ☐         | ☐        | ☐          | ☐         |
| 5. I feel content | ☐         | ☐        | ☐          | ☐         |
| 6. I am worried | ☐         | ☐        | ☐          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: __________ / __________ / __________
Date __________
Time __________:

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
Less than 5 minutes ☐
Between 5 and 10 minutes ☐
Between 11 and 15 minutes ☐
Longer than 15 minutes ☐

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? ☐ Yes ☐ No
If yes,
please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? ☐ Yes ☐ No
If yes,
please specify which questions and what the difficulty was

Was the patient made anxious? ☐ Yes ☐ No
If yes,
please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?  
   - Yes  
   - No  
   Please continue with Question 2

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite |
|----------------------|
| Did you have this symptom? | Yes | Please complete A then B or C below |
| No | Please go to Section 2 |

A When did you first notice this?  
   - Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?  
   - Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

   Please complete A then B or C below

   Please go to Question 2

2. Unexplained weight loss

   Did you have this?

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

   Please complete A then B or C below

   Please go to Question 3
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

Yes

No

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

Yes

No

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.  

__________________________________________________________________________

__________________________________________________________________________

A  When did you first notice this?  

☑ ☐ ☐ ☐ / ☐ ☐ ☐ ☐ OR ☐ ☐ ☐ ☐

B  When did you first tell your GP or nurse?  

☐ ☐ ☐ ☐ / ☐ ☐ ☐ ☐ OR ☐ ☐ ☐ ☐

OR

C  Put a cross here if you didn't tell your GP or nurse

☐

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.  

__________________________________________________________________________

__________________________________________________________________________

A  When did you first notice this?  

☑ ☐ ☐ ☐ / ☐ ☐ ☐ ☐ OR ☐ ☐ ☐ ☐

B  When did you first tell your GP or nurse?  

☐ ☐ ☐ ☐ / ☐ ☐ ☐ ☐ OR ☐ ☐ ☐ ☐

OR

C  Put a cross here if you didn't tell your GP or nurse

☐

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

|               | Yes | Not sure | No |
|---------------|-----|----------|----|
| Blood test(s) |     |          |    |
| CT Scan       |     |          |    |
| Ultrasound scan |   |        |    |
| Barium Enema  |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |   |        |    |
| X-ray         |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. **How would you describe your ethnicity**

*Please cross one box only*

- **White**
  - White British
  - White Irish
  - Other White background

- **Mixed**
  - White & Black Carribean
  - White & Black African
  - White & Asian
  - Other mixed background

- **Black or Black British**
  - Carribean
  - African
  - Other Black background

- **Asian or Asian British**
  - Indian
  - Pakistani
  - Bangladeshi
  - Other Asian background

- **Chinese or other ethnic group**
  - Chinese
  - Other ethnic group

---

11. **Do you live alone?**

- Yes **Please go to Question 12**
- No **Please say who you live with below**

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
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- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
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Please cross the appropriate statement

- Are you a current smoker?
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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm |            |          |            |           |
| 2. I am tense   |            |          |            |           |
| 3. I feel upset |            |          |            |           |
| 4. I am relaxed |            |          |            |           |
| 5. I feel content |            |          |            |           |
| 6. I am worried |            |          |            |           |

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date __/__/____  Time __:__

If not completed, give reason ____________________________

How long is it since the patient was told of his/her diagnosis? ____________________________

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes ☐
- Between 5 and 10 minutes ☐
- Between 11 and 15 minutes ☐
- Longer than 15 minutes ☐

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? ☐ Yes ☐ No

If yes, please specify what help was requested ____________________________

please specify what help was given ____________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? ☐ Yes ☐ No

If yes, please specify which questions and what the difficulty was ____________________________

Was the patient made anxious? ☐ Yes ☐ No

If yes, please give details ____________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other) ____________________________

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Yours sincerely

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Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A When did you first notice this? d o / m m / y y

OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

2 3 / 1 2 / 0 7

OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?  

C  Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?  

C  Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?
   - **Yes**
   - **No**

   Please complete A then B or C below

   **A** When did you **first notice** this?
   [ ] / [ ] / [ ] OR

   **B** When did you **first tell** your GP or nurse?
   [ ] / [ ] / [ ] OR

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?
   - **Yes**
   - **No**

   Please complete A then B or C below

   **A** When did you **first notice** this?
   [ ] / [ ] / [ ] OR

   **B** When did you **first tell** your GP or nurse?
   [ ] / [ ] / [ ] OR

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________

_____________________________

A When did you first notice this?

□□□ / □□□ / □□□ OR □□□

B When did you first tell your GP or nurse?

□□□ / □□□ / □□□ OR □□□

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________

_____________________________

A When did you first notice this?

□□□ / □□□ / □□□ OR □□□

B When did you first tell your GP or nurse?

□□□ / □□□ / □□□ OR □□□

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No  |
|-------------------------------------------|-----|----------|-----|
| Blood test(s)                             |     |          |     |
| CT Scan                                   |     |          |     |
| Ultrasound scan                           |     |          |     |
| Barium Enema                              |     |          |     |
| Sigmoidoscopy or colonoscopy              |     |          |     |
| (Looking at bowel with internal camera)   |     |          |     |
| X-ray                                     |     |          |     |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- ‘A’ level
- GCSE / ‘O’ level
- None

Other, please specify
10. How would you describe your ethnicity

**Please cross one box only**

**White**
- White British
- White Irish
- Other White background

**Mixed**
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

**Black or Black British**
- Carribean
- African
- Other Black background

**Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

**Chinese or other ethnic group**
- Chinese
- Other ethnic group

---

11. Do you live alone?

**Yes**
- Please go to Question 12

**No**
- Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker? [ ]
- Are you an ex-smoker? [ ]
- Are you a non-smoker (never smoked)? [ ]

14. Do you think you were more at risk of getting cancer because of your family history?

[ ] Yes  [ ] No
The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm |   |           |           |           |
| 2. I am tense |   |           |           |           |
| 3. I feel upset |   |           |           |           |
| 4. I am relaxed |   |           |           |           |
| 5. I feel content |   |           |           |           |
| 6. I am worried |   |           |           |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Researcher initials:

Date questionnaire completed:  
Date  /  /  Time : 

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes  
- Between 5 and 10 minutes  
- Between 11 and 15 minutes  
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  
- Yes  
- No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  
- Yes  
- No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  
- Yes  
- No

If yes, please give details

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes No

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit
Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage
Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - **A** When did you **first notice** this?
                 OR
   - **B** When did you **first tell** your GP or nurse?
                 OR
   - **C** Put a cross here if you **didn't tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   - **A** When did you **first notice** this?
                 OR
   - **B** When did you **first tell** your GP or nurse?
                 OR
   - **C** Put a cross here if you **didn't tell** your GP or nurse
3. **Feeling different 'in yourself' from usual**

Did you have this?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

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4. **Fatigue or tiredness that is unusual for you**

Did you have this?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

---

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________

A When did you first notice this? OR
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C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________

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C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                    | Yes | Not sure | No |
|-----------------------------------------|-----|----------|----|
| Blood test(s)                           |     |          |    |
| CT Scan                                 |     |          |    |
| Ultrasound scan                         |     |          |    |
| Barium Enema                            |     |          |    |
| Sigmoidoscopy or colonoscopy            |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                                   |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   
   Employed full-time
   Employed part-time
   Self employed full-time
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   Unemployed (seeking work)
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   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   
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   Diploma (or equivalent)
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   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
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  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

**Please cross any that are applicable to you**

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
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- Previous cancer
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13. **About smoking**

**Please cross the appropriate statement**

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. **Do you think you were more at risk of getting cancer because of your family history?**

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement       | Not at all | Somewhat | Moderately | Very much |
|-----------------|------------|----------|------------|-----------|
| I feel calm     |            |          |            |           |
| I am tense      |            |          |            |           |
| I feel upset    |            |          |            |           |
| I am relaxed    |            |          |            |           |
| I feel content  |            |          |            |           |
| I am worried    |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire.

Please give it to the research nurse.

The next page is for the Researcher to complete.
Date questionnaire completed: __________ / __________ / __________

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious? [ ] Yes [ ] No

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A  When did you first notice this?  d  d / m  m / y  y

B  When did you first tell your GP or nurse?  2  3 / 1  2 / 0  7  OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   Yes □  Please complete A then B or C below

   No □  Please go to Question 2

   A When did you first notice this?

   □ / □ / □ OR __________________________

   B When did you first tell your GP or nurse?

   □ / □ / □ OR __________________________

   OR

2. Unexplained weight loss

   Did you have this?

   Yes □  Please complete A then B or C below

   No □  Please go to Question 3

   A When did you first notice this?

   □ / □ / □ OR __________________________

   B When did you first tell your GP or nurse?

   □ / □ / □ OR __________________________

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Yes Please complete A then B or C below

No Please go to Question 4

Yes Please complete A then B or C below

No Please go to Question 5

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Version:- 2.1 08/01/2009
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________
   ____________________________________________________________

A  When did you first notice this?  ______ / ______ / ______ OR ______

B  When did you first tell your GP or nurse?  ______ / ______ / ______ OR ______

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

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6. ____________________________________________________________
   ____________________________________________________________

A  When did you first notice this?  ______ / ______ / ______ OR ______

B  When did you first tell your GP or nurse?  ______ / ______ / ______ OR ______

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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   Student
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   Temporarily sick/disabled
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   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   Degree (or equivalent)
   Diploma (or equivalent)
   ‘A’ level
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   Other, please specify
10. How would you describe your ethnicity
   Please cross one box only

   White
   or
   White British
   White Irish
   Other White background

   Mixed
   or
   White & Black Carribean
   White & Black African
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   Other mixed background

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   African
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   Asian or Asian British
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   Pakistani
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   Chinese or other ethnic group
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11. Do you live alone?

   Yes
   No
   Please go to Question 12
   Please say who you live with below

   Who do you live with?
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Please cross the appropriate statement

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No
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| Not at all | Somewhat | Moderately | Very much |
|------------|----------|------------|-----------|
| 1. I feel calm | ☐ | ☐ | ☐ | ☐ |
| 2. I am tense | ☐ | ☐ | ☐ | ☐ |
| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

Please make sure you have answered all the questions.
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Researcher - Post-completion Sheet

Date questionnaire completed: [Date] / [Day] / [Year] Time [Time]

If not completed, give reason

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How long did it take the patient to complete the questionnaire?
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If yes, please specify what help was requested

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Did the patient find any of the questions difficult?  [Yes]  [No]
If yes, please specify which questions and what the difficulty was

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Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   
   Yes □  Please continue with Question 2
   
   No □  Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?
   
   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes □  Please complete A then B or C below

No □  Please go to Section 2

A When did you first notice this? d d / m m / y y

OR Estimate '3 months ago' or 'June'

2 3 / 1 2 / 0 7

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   Please complete A then B or C below

   Please go to Question 2

   A When did you **first notice** this?

   B When did you **first tell** your GP or nurse?

   OR

   C Put a cross here if you **didn't tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   Please complete A then B or C below

   Please go to Question 3

   A When did you **first notice** this?

   B When did you **first tell** your GP or nurse?

   OR

   C Put a cross here if you **didn't tell** your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

---

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

---

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. _____________________________
   _____________________________

A  When did you first notice this?  [ ] / [ ] / [ ] OR [ ]

B  When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR [ ]

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. _____________________________
   _____________________________

A  When did you first notice this?  [ ] / [ ] / [ ] OR [ ]

B  When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR [ ]

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
or
White British
White Irish
Other White background

Mixed
or
White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British
or
Carribean
African
Other Black background

Asian or Asian British
or
Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group
or
Chinese
Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☐        | ☐          | ☐         |
| 2. I am tense   | ☐         | ☐        | ☐          | ☐         |
| 3. I feel upset | ☐         | ☐        | ☐          | ☐         |
| 4. I am relaxed | ☐         | ☐        | ☐          | ☐         |
| 5. I feel content | ☐     | ☐        | ☐          | ☐         |
| 6. I am worried | ☐         | ☐        | ☐          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date  /  /  Time  :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes  □
- Between 5 and 10 minutes  □
- Between 11 and 15 minutes  □
- Longer than 15 minutes  □

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  □ Yes  □ No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  □ Yes  □ No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  □ Yes  □ No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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Yours sincerely

Dr Richard Neal
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Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes ☒  Please complete A then B or C below

No ☐  Please go to Section 2

A  When did you first notice this?  

B  When did you first tell your GP or nurse?  

OR

C  Put a cross here if you didn't tell your GP or nurse

Please go to Question 3
3. Change in bowel habit

Did you have this symptom?

**Please complete A then B or C below**

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

**Please complete A then B or C below**

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

### 1. Decrease in appetite

|   |   |   |
|---|---|---|
| Yes | Please complete A then B or C below |   |
| No | Please go to Question 2 |   |

A. When did you **first notice** this?

|   |   |   |
|---|---|---|
|   |   | OR |

B. When did you **first tell** your GP or nurse?

|   |   |   |
|---|---|---|
|   |   | OR |

C. Put a cross here if you **didn't tell** your GP or nurse

### 2. Unexplained weight loss

|   |   |   |
|---|---|---|
| Yes | Please complete A then B or C below |   |
| No | Please go to Question 3 |   |

A. When did you **first notice** this?

|   |   |   |
|---|---|---|
|   |   | OR |

B. When did you **first tell** your GP or nurse?

|   |   |   |
|---|---|---|
|   |   | OR |

C. Put a cross here if you **didn't tell** your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

__________________________________________________________
__________________________________________________________

A When did you first notice this?

__________________ / __________________ / __________________ OR

B When did you first tell your GP or nurse?

__________________ / __________________ / __________________ OR

OR

C Put a cross here if you didn't tell your GP or nurse



If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

__________________________________________________________
__________________________________________________________

A When did you first notice this?

__________________ / __________________ / __________________ OR

B When did you first tell your GP or nurse?

__________________ / __________________ / __________________ OR

OR

C Put a cross here if you didn't tell your GP or nurse



If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

### 7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   **Please cross one box only**

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?
   **Please cross one box only**

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes [ ] Please go to Question 12
No [ ] Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|        | Not at all | Somewhat | Moderately | Very much |
|--------|------------|----------|------------|-----------|
| 1. I feel calm |            |          |            |           |
| 2. I am tense   |            |          |            |           |
| 3. I feel upset |            |          |            |           |
| 4. I am relaxed |            |          |            |           |
| 5. I feel content |            |          |            |           |
| 6. I am worried |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed: ________________________________ Date __________ / __________ / ________ Time __________:__________

If not completed, give reason: ________________________________________________________________

How long is it since the patient was told of his/her diagnosis? _______________________________________

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? Yes __ No __

If yes, please specify what help was requested

______________________________________________________________

please specify what help was given

______________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? Yes __ No __

If yes, please specify which questions and what the difficulty was

______________________________________________________________

______________________________________________________________

Was the patient made anxious? Yes __ No __

If yes, please give details

______________________________________________________________

______________________________________________________________

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

______________________________________________________________

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No

Please complete A then B or C below

OR

Estimate

‘3 months ago’ or ‘June’

A When did you first notice this? d d / m m / y y

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7

C Put a cross here if you didn’t tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite
   
   Did you have this?
   
   Yes ☐
   No ☐

   Please complete A then B or C below

   Please go to Question 2

   A When did you first notice this?
   
   □ □ / □ □ / □ □ OR

   B When did you first tell your GP or nurse?
   
   □ □ / □ □ / □ □ OR

   OR

   C Put a cross here if you didn't tell your GP or nurse
   

2. Unexplained weight loss
   
   Did you have this?
   
   Yes ☐
   No ☐

   Please complete A then B or C below

   Please go to Question 3

   A When did you first notice this?
   
   □ □ / □ □ / □ □ OR

   B When did you first tell your GP or nurse?
   
   □ □ / □ □ / □ □ OR

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

**Yes**

**Please complete A then B or C below**

**No**

**Please go to Question 4**

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

**Yes**

**Please complete A then B or C below**

**No**

**Please go to Question 5**

Please try and describe what the feeling was

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  

\[\square/\square/\square\] OR

B When did you first tell your GP or nurse?  

\[\square/\square/\square\] OR

\[\square/\square/\square\] OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  

\[\square/\square/\square\] OR

B When did you first tell your GP or nurse?  

\[\square/\square/\square\] OR

\[\square/\square/\square\] OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

### 7. Were you sent for any of these?

| Test                                         | Yes | Not sure | No |
|----------------------------------------------|-----|----------|----|
| Blood test(s)                                |     |          |    |
| CT Scan                                      |     |          |    |
| Ultrasound scan                              |     |          |    |
| Barium Enema                                 |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | | | |
| X-ray                                        |     |          |    |

**Please go to Question 8**
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8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
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- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity
   Please cross one box only

   White
   or
      White British
      White Irish
      Other White background

   Mixed
   or
      White & Black Caribbean
      White & Black African
      White & Asian
      Other mixed background

   Black or Black British
   or
      Caribbean
      African
      Other Black background

   Asian or Asian British
   or
      Indian
      Pakistani
      Bangladeshi
      Other Asian background

   Chinese or other ethnic group
   or
      Chinese
      Other ethnic group

---

11. Do you live alone?

   Yes
   No
   Please go to Question 12
   Please say who you live with below

   Who do you live with?
   (e.g. wife, husband, partner, family member)
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Please cross any that are applicable to you

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- Anxiety or depression
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- Irritable bowel syndrome
- Peptic ulcer
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- Diabetes
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Please cross the appropriate statement

- Are you a current smoker?
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- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | [ ] | [ ] | [ ] | [ ] |
| 2. I am tense | [ ] | [ ] | [ ] | [ ] |
| 3. I feel upset | [ ] | [ ] | [ ] | [ ] |
| 4. I am relaxed | [ ] | [ ] | [ ] | [ ] |
| 5. I feel content | [ ] | [ ] | [ ] | [ ] |
| 6. I am worried | [ ] | [ ] | [ ] | [ ] |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / Time

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? ☐ Yes ☐ No

If yes, please specify what help was requested

________________________________________________________________________

please specify what help was given

________________________________________________________________________

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? ☐ Yes ☐ No

If yes, please specify which questions and what the difficulty was

________________________________________________________________________

________________________________________________________________________

Was the patient made anxious? ☐ Yes ☐ No

If yes, please give details

________________________________________________________________________

________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK

Confidential Questionnaire

GLAN CLWYD

GWYNEDD

MAELOR
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes [X] No

Please complete A then B or C below

A When did you first notice this? d d m m y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 1 2 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse

Please go to Question 3
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

- Yes
- No

Please complete A then B or C below

Please go to Question 2

- A When did you first notice this?
- B When did you first tell your GP or nurse?
- OR
- C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

- Yes
- No

Please complete A then B or C below

Please go to Question 3

- A When did you first notice this?
- B When did you first tell your GP or nurse?
- OR
- C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

---

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

---

**Please try and describe what the feeling was**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

---

---
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

[Text box for symptom description]

A When did you first notice this? [Date] / [Date] / [Date] OR

B When did you first tell your GP or nurse? [Date] / [Date] / [Date] OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

[Text box for symptom description]

A When did you first notice this? [Date] / [Date] / [Date] OR

B When did you first tell your GP or nurse? [Date] / [Date] / [Date] OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
**Did your GP send you for any tests?**

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

**7.** Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11.

Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm |   |   |   |   |
| 2. I am tense |   |   |   |   |
| 3. I feel upset |   |   |   |   |
| 4. I am relaxed |   |   |   |   |
| 5. I feel content |   |   |   |   |
| 6. I am worried |   |   |   |   |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [___] / [___] / [___] Time [___]:[___]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
Less than 5 minutes [___]  
Between 5 and 10 minutes [___]  
Between 11 and 15 minutes [___]  
Longer than 15 minutes [___]

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [___] Yes [___] No
If yes, please specify what help was requested
__________________________________________________________________________
__________________________________________________________________________
Please specify what help was given
__________________________________________________________________________
__________________________________________________________________________

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [___] Yes [___] No
If yes, please specify which questions and what the difficulty was
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Was the patient made anxious? [___] Yes [___] No
If yes, please give details
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)
__________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Looking At Your Symptoms Study

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Dear Patient

I am very grateful to you for agreeing to help us with this study.

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If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes [ ] Please continue with Question 2
   No [ ] Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? [ ] Yes [ ] No

Please complete A then B or C below

A When did you first notice this? OR Estimate
   d  d  /  m / m  /  y  y '3 months ago' or 'June'

B When did you first tell your GP or nurse? OR Estimate
   2  3 /  1 2 / 0 7

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

☐ Yes Please complete A then B or C below

☐ No Please go to Question 2

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

☐ Yes Please complete A then B or C below

☐ No Please go to Question 3

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

__________________________________________________________________________
__________________________________________________________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

6.

__________________________________________________________________________
__________________________________________________________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   
   Employed full-time
   Employed part-time
   Self employed full-time
   Self employed part-time
   Unemployed (seeking work)
   Unemployed (not seeking work)
   Retired
   Student
   Permanently sick/disabled
   Temporarily sick/disabled
   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   
   Degree (or equivalent)
   Diploma (or equivalent)
   ‘A’ level
   GCSE / ’O’ level
   None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectatis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

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Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

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|  | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐ | ☐ | ☐ | ☐ |
| 2. I am tense | ☐ | ☐ | ☐ | ☐ |
| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: □ □ / □ □ / □ □ Time □ : □ □

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

☐ Less than 5 minutes
☐ Between 5 and 10 minutes
☐ Between 11 and 15 minutes
☐ Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? □ Yes □ No
If yes,
please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? □ Yes □ No
If yes,
please specify which questions and what the difficulty was

Was the patient made anxious? □ Yes □ No
If yes,
please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have *any* symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | No |
|----------------------|-----|----|
| Did you have this symptom? | | |
| Please complete A then B or C below | | |

A When did you first notice this?  
B When did you first tell your GP or nurse?  
C Put a cross here if you didn't tell your GP or nurse  

Please go to Question 3
3. **Change in bowel habit**

Did you have this symptom?

A. **When did you first notice this?**

B. **When did you first tell your GP or nurse?**

C. **Put a cross here if you didn't tell your GP or nurse**

4. **Bleeding from back passage**

Did you have this symptom?

A. **When did you first notice this?**

B. **When did you first tell your GP or nurse?**

C. **Put a cross here if you didn't tell your GP or nurse**
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?
   - Yes
   - No

   **Please complete A then B or C below**

   **A** When did you first notice this?
   
   |   |   |   |   |   |
   |---|---|---|---|---|
   |   |   |   |   |   |
   |   |   |   |   |   |
   |   |   |   |   |   |
   OR

   **B** When did you first tell your GP or nurse?
   
   |   |   |   |   |   |
   |---|---|---|---|---|
   |   |   |   |   |   |
   |   |   |   |   |   |
   |   |   |   |   |   |
   OR

   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?
   - Yes
   - No

   **Please complete A then B or C below**

   **A** When did you first notice this?
   
   |   |   |   |   |   |
   |---|---|---|---|---|
   |   |   |   |   |   |
   |   |   |   |   |   |
   |   |   |   |   |   |
   OR

   **B** When did you first tell your GP or nurse?
   
   |   |   |   |   |   |
   |---|---|---|---|---|
   |   |   |   |   |   |
   |   |   |   |   |   |
   |   |   |   |   |   |
   OR

   **C** Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

**Please try and describe what the feeling was**

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________
   __________________________________________________________

   A  When did you first notice this?
   [ ] / [ ] / [ ] OR

   B  When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

   OR

   C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________
   __________________________________________________________

   A  When did you first notice this?
   [ ] / [ ] / [ ] OR

   B  When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

   OR

   C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

### 7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only

   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only

   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes  Please go to Question 12
No   Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?  
   **Please cross any that are applicable to you**
   - Asthma
   - Chronic Obstructive Pulmonary Disease (COPD)
   - Other lung disease (e.g. fibrosis, bronchiectasis etc)
   - Heart disease
   - Anxiety or depression
   - Inflammatory bowel disease
   - Irritable bowel syndrome
   - Peptic ulcer
   - Previous cancer
   - Diabetes
   - Arthritis

13. **About smoking**
   **Please cross the appropriate statement**
   - Are you a current smoker? ☐
   - Are you an ex-smoker? ☐
   - Are you a non-smoker (never smoked)? ☐

14. **Do you think you were more at risk of getting cancer because of your family history?**
   - Yes ☐
   - No ☐
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | [ ] | [ ] | [ ] | [ ] |
| 2. I am tense | [ ] | [ ] | [ ] | [ ] |
| 3. I feel upset | [ ] | [ ] | [ ] | [ ] |
| 4. I am relaxed | [ ] | [ ] | [ ] | [ ] |
| 5. I feel content | [ ] | [ ] | [ ] | [ ] |
| 6. I am worried | [ ] | [ ] | [ ] | [ ] |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials:  

Date questionnaire completed:  
Date  /  /  Time  :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
Less than 5 minutes   
Between 5 and 10 minutes   
Between 11 and 15 minutes   
Longer than 15 minutes   

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  
Yes  No  
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  
Yes  No  
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  
Yes  No  
If yes, please give details

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed? 

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? 

Yes [X] Please complete A then B or C below

No [ ] Please go to Section 2

Please go to Question 3

Please continue with Question 2

Please go to Section 2 on Page 5

Please go to Question 3

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   - Yes
   - No

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   - Yes
   - No

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
C Put a cross here if you didn’t tell your GP or nurse

4. Feeling different ’in yourself’ from usual

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
C Put a cross here if you didn’t tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________
   __________________________________________

A When did you first notice this?
B When did you first tell your GP or nurse?
   OR
C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________
   __________________________________________

A When did you first notice this?
B When did you first tell your GP or nurse?
   OR
C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No  |
|-------------------------------------------|-----|----------|-----|
| Blood test(s)                             |     |          |     |
| CT Scan                                   |     |          |     |
| Ultrasound scan                           |     |          |     |
| Barium Enema                              |     |          |     |
| Sigmoidoscopy or colonoscopy             |     |          |     |
| (Looking at bowel with internal camera)   |     |          |     |
| X-ray                                     |     |          |     |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

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- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker? 
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

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Yes ☐ No ☐
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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. | I feel calm | □        | □          | □         | □         |
| 2. | I am tense | □        | □          | □         | □         |
| 3. | I feel upset | □        | □          | □         | □         |
| 4. | I am relaxed | □        | □          | □         | □         |
| 5. | I feel content | □        | □          | □         | □         |
| 6. | I am worried | □        | □          | □         | □         |

Please make sure you have answered all the questions.
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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed: Date □ / □ / □ Time □ : □

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes □
- Between 5 and 10 minutes □
- Between 11 and 15 minutes □
- Longer than 15 minutes □

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? □ Yes □ No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? □ Yes □ No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? □ Yes □ No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Yours sincerely

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Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below |
|----------------------|-----|-------------------------------------|
| Did you have this symptom? | × | |

A When did you first notice this? d m y

B When did you first tell your GP or nurse? 23 12 07

C Put a cross here if you didn't tell your GP or nurse

Please go to Question 3
3. **Change in bowel habit**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes  □  Please complete A then B or C below

No  □  Please go to Question 2

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse

☐

2. Unexplained weight loss

Did you have this?

Yes  □  Please complete A then B or C below

No  □  Please go to Question 3

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse

☐
3. Featigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________
   ____________________________________________

A When did you first notice this? ___________ / _______/ _______/ OR

B When did you first tell your GP or nurse? ___________ / _______/ _______/ OR

   OR

C Put a cross here if you didn't tell your GP or nurse ___________

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________
   ____________________________________________

A When did you first notice this? ___________ / _______/ _______/ OR

B When did you first tell your GP or nurse? ___________ / _______/ _______/ OR

   OR

C Put a cross here if you didn't tell your GP or nurse ___________

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                           | Yes | Not sure | No |
|-----------------------------------------------|-----|----------|----|
| Blood test(s)                                 |     |          |    |
| CT Scan                                       |     |          |    |
| Ultrasound scan                               |     |          |    |
| Barium Enema                                  |     |          |    |
| Sigmoidoscopy or colonoscopy                 |     |          |    |
| (Looking at bowel with internal camera)       |     |          |    |
| X-ray                                         |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

Employed full-time
Employed part-time
Self employed full-time
Self employed part-time
Unemployed (seeking work)
Unemployed (not seeking work)
Retired
Student
Permanently sick/disabled
Temporarily sick/disabled
Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

Degree (or equivalent)
Diploma (or equivalent)
'A' level
GCSE / 'O' level
None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
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  or
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  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

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- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □        | □        | □          | □         |
| 2. I am tense   | □        | □        | □          | □         |
| 3. I feel upset | □        | □        | □          | □         |
| 4. I am relaxed | □        | □        | □          | □         |
| 5. I feel content | □    | □        | □          | □         |
| 6. I am worried  | □        | □        | □          | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason: ____________________________

How long is it since the patient was told of his/her diagnosis? ____________________________

How long did it take the patient to complete the questionnaire?

Less than 5 minutes [ ]
Between 5 and 10 minutes [ ]
Between 11 and 15 minutes [ ]
Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No

If yes, please specify what help was requested

____________________________________________________

Please specify what help was given

____________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No

If yes, please specify which questions and what the difficulty was

____________________________________________________

____________________________________________________

____________________________________________________

Was the patient made anxious? [ ] Yes [ ] No

If yes, please give details

____________________________________________________

____________________________________________________

____________________________________________________

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

____________________________________________________

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

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Cardiff University
Chief Investigator, Symptoms Study
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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes □ No □ Please complete A then B or C below

A When did you first notice this? Date

B When did you first tell your GP or nurse? Date

OR

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 2

A  When did you first notice this?

☐ / ☐ / ☐ OR

B  When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

☐

2. Unexplained weight loss

Did you have this?

Yes ☐ Please complete A then B or C below
No ☐ Please go to Question 3

A  When did you first notice this?

☐ / ☐ / ☐ OR

B  When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

☐
### 3. Fatigue or tiredness that is unusual for you

Did you have this?

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| Yes | Please complete A then B or C below |
| No | Please go to Question 4 |

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

### 4. Feeling different 'in yourself' from usual

Did you have this?

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| Yes | Please complete A then B or C below |
| No | Please go to Question 5 |

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________
________________________________________________________________________

A When did you first notice this?
   OR

B When did you first tell your GP or nurse?
   OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________
________________________________________________________________________

A When did you first notice this?
   OR

B When did you first tell your GP or nurse?
   OR

C Put a cross here if you didn't tell your GP or nurse

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Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                         | Yes | Not sure | No |
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| Blood test(s)                                |     |          |    |
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- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. **How would you describe your ethnicity**

*Please cross one box only*

**White**
- White British
- White Irish
- Other White background

**Mixed**
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

**Black or Black British**
- Carribean
- African
- Other Black background

**Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

**Chinese or other ethnic group**
- Chinese
- Other ethnic group

11. **Do you live alone?**

Yes
- Please go to Question 12

No
- Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | I feel calm | I am tense | I feel upset | I am relaxed | I feel content | I am worried |
|---|-------------|------------|--------------|--------------|---------------|-------------|
| 1 | Not at all  |            |              |              |               |             |
| 2 |             |            |              |              |               |             |
| 3 |             |            |              |              |               |             |
| 4 |             |            |              |              |               |             |
| 5 |             |            |              |              |               |             |
| 6 |             |            |              |              |               |             |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time : :
If not completed, give reason
How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? Yes No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? Yes No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes □ No □

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   [ ] Yes  Please complete A then B or C below
   [ ] No   Please go to Question 2

   A When did you first notice this?
   [ ] [ ] [ ] OR

   B When did you first tell your GP or nurse?
   [ ] [ ] [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   [ ] Yes  Please complete A then B or C below
   [ ] No   Please go to Question 3

   A When did you first notice this?
   [ ] [ ] [ ] OR

   B When did you first tell your GP or nurse?
   [ ] [ ] [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

____________________________________________________________________________

____________________________________________________________________________

A When did you first notice this?  

B When did you first tell your GP or nurse?  

C Put a cross here if you didn’t tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

____________________________________________________________________________

____________________________________________________________________________

A When did you first notice this?  

B When did you first tell your GP or nurse?  

C Put a cross here if you didn’t tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy        |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                               |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
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9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
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Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
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    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. **Are you suffering from, or have you suffered from, any of the following in the past 2 years?**

*Please cross any that are applicable to you*

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- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. **About smoking**

*Please cross the appropriate statement*

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. **Do you think you were more at risk of getting cancer because of your family history?**

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☑️       | ☐          | ☐         |
| 2. I am tense  | ☐         | ☐        | ☐          | ☑️        |
| 3. I feel upset| ☐         | ☐        | ☑️          | ☐         |
| 4. I am relaxed| ☐         | ☐        | ☑️          | ☐         |
| 5. I feel content| ☐       | ☐        | ☑️          | ☐         |
| 6. I am worried | ☐         | ☐        | ☑️          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials: [ ] [ ]

Date questionnaire completed: [ ] / [ ] / [ ]

Time [ ] : [ ]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?

[ ] Yes  [ ] No

If yes, please specify what help was requested

[ ]

Please specify what help was given

[ ]

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?

[ ] Yes  [ ] No

If yes, please specify which questions and what the difficulty was

[ ]

Was the patient made anxious?

[ ] Yes  [ ] No

If yes, please give details

[ ]

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

[ ]

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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

| Yes |
|-----|
| No  |

Please complete A then B or C below

A When did you first notice this?  

| d | d | m | m | y | y |

OR

Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?  

| 2 | 3 | 1 | 2 | 0 | 7 |

OR

Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

---

4. **Bleeding from back passage**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

- Yes
- No

Please complete A then B or C below

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

- Yes
- No

Please complete A then B or C below

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please try and describe what the feeling was

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

______________________________

______________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

______________________________

______________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test Type                                               | Yes | Not sure | No |
|---------------------------------------------------------|-----|----------|----|
| Blood test(s)                                           |     |          |    |
| CT Scan                                                 |     |          |    |
| Ultrasound scan                                         |     |          |    |
| Barium Enema                                            |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                                   |     |          |    |

Please go to Question 8
About you

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Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
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- None

Other, please specify
10. How would you describe your ethnicity

   Please cross one box only

White
   or
   White British
   White Irish
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   White & Asian
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Black or Black British
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   African
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Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?

   Yes
   Please go to Question 12
   No
   Please say who you live with below

   Who do you live with?
   (e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

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Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

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- Yes
- No
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|   | Not at all | Somewhat | Moderately | Very much |
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| 1. I feel calm | ☐         | ☐        | ☐          | ☐         |
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| 5. I feel content | ☐       | ☐        | ☐          | ☐         |
| 6. I am worried | ☐         | ☐        | ☐          | ☐         |

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If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials: [ ] [ ]

Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason
________________________________________

How long is it since the patient was told of his/her diagnosis?
________________________________________

How long did it take the patient to complete the questionnaire?

Less than 5 minutes [ ]
Between 5 and 10 minutes [ ]
Between 11 and 15 minutes [ ]
Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested
________________________________________

please specify what help was given
________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was
________________________________________
________________________________________
________________________________________

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details
________________________________________
________________________________________
________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other
________________________________________

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Yours sincerely

[Signature]

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Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes  

No

Please complete A then B or C below

A When did you first notice this?  

B When did you first tell your GP or nurse?  

OR

C Put a cross here if you didn't tell your GP or nurse

| Date | Yes | No | Please complete A then B or C below | Please go to Question 3 |
|------|-----|----|-------------------------------------|-------------------------|
| 2 3 1 2 0 7 | Yes | No | Estimate '3 months ago' or 'June' | Please go to Section 2 |
3. **Change in bowel habit**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   Yes [ ] No [ ]

   Please complete A then B or C below

   Please go to Question 2

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   Yes [ ] No [ ]

   Please complete A then B or C below

   Please go to Question 3

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

4. Feeling different ‘in yourself’ from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________

________________________________________________________

A  When did you first notice this?

☐ / ☐ / ☐ OR

☐ / ☐ / ☐ OR

B  When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

☐ / ☐ / ☐ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

☐

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________

________________________________________________________

A  When did you first notice this?

☐ / ☐ / ☐ OR

☐ / ☐ / ☐ OR

B  When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

☐ / ☐ / ☐ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

☐

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Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                    | Yes | Not sure | No |
|-----------------------------------------|-----|----------|----|
| Blood test(s)                           |     |          |    |
| CT Scan                                 |     |          |    |
| Ultrasound scan                         |     |          |    |
| Barium Enema                            |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                   |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home
- Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None
- Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11.

Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectatis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Not at all | Somewhat | Moderately | Very much |
|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire
Please give it to the research nurse
The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date ___/___/___ Time ___:___

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  Yes  No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  Yes  No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No

If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes  Please continue with Question 2
   No   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  Yes  Please complete A then B or C below

   No   Please go to Section 2

A  When did you first notice this?  d  m  y

   OR  Estimate

   '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  2  3  1  2  0  7

   OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

Yes ☐ No ☐

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

OR

B

OR

C

4. Bleeding from back passage

Did you have this symptom?

Yes ☐ No ☐

Please complete A then B or C below

Please go to Section 2

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

OR

B

OR

C
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - **Yes**
     - Please complete A then B or C below
   - **No**
     - Please go to Question 2

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   - **Yes**
     - Please complete A then B or C below
   - **No**
     - Please go to Question 3

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Version:- 2.1 08/01/2009
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

__________________________________________________________

__________________________________________________________

A  When did you first notice this?  

/  /  OR  

B  When did you first tell your GP or nurse?  

/  /  OR  

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

__________________________________________________________

__________________________________________________________

A  When did you first notice this?  

/  /  OR  

B  When did you first tell your GP or nurse?  

/  /  OR  

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

| 7. Were you sent for any of these?                      | Yes | Not sure | No |
|---------------------------------------------------------|-----|----------|----|
| Blood test(s)                                           |     |          |    |
| CT Scan                                                 |     |          |    |
| Ultrasound scan                                         |     |          |    |
| Barium Enema                                            |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                                   |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- ‘A’ level
- GCSE / ‘O’ level
- None

Other, please specify
10. How would you describe your ethnicity
   Please cross one box only

   White
   or
   White British
   White Irish
   Other White background

   Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

   Black or Black British
   or
   Carribean
   African
   Other Black background

   Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

   Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?
   
   Yes
   No
   Please go to Question 12
   Please say who you live with below

   Who do you live with?
   (e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

**Please cross any that are applicable to you**

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
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- Inflammatory bowel disease
- Irritable bowel syndrome
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- Previous cancer
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13. About smoking

**Please cross the appropriate statement**

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement         | Not at all | Somewhat | Moderately | Very much |
|-------------------|------------|----------|------------|-----------|
| 1. I feel calm    |            |          |            |           |
| 2. I am tense     |            |          |            |           |
| 3. I feel upset   |            |          |            |           |
| 4. I am relaxed   |            |          |            |           |
| 5. I feel content |            |          |            |           |
| 6. I am worried   |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed:

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  Yes  No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  Yes  No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Yours sincerely

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Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?  
   - [ ] Yes  
   - [X] No  
   *Please continue with Question 2*

2. What was the first symptom that made you think something might be wrong?

   *Please go to Question 3*

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom?  
- [ ] Yes  
- [X] No  
*Please complete A then B or C below*

A. When did you first notice this?  
   [ ] 23/12/07  
   OR  
   Estimate  
   '3 months ago' or 'June'

B. When did you first tell your GP or nurse?  
   [ ] 23/12/07  
   OR  
   Estimate

C. Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse
Section 2

Did you have any of the following?

1. Decrease in appetite

Did you have this?

A When did you first notice this?  

B When did you first tell your GP or nurse?  

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

A When did you first notice this?  

B When did you first tell your GP or nurse?  

OR

C Put a cross here if you didn't tell your GP or nurse

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different ‘in yourself’ from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ___________________________________________________________
   ___________________________________________________________
   ___________________________________________________________

   A When did you first notice this?  OR
   B When did you first tell your GP or nurse?  OR
   C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ___________________________________________________________
   ___________________________________________________________
   ___________________________________________________________

   A When did you first notice this?  OR
   B When did you first tell your GP or nurse?  OR
   C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
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- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
Please go to Question 12

No
Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
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Please cross any that are applicable to you

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Please cross the appropriate statement

- Are you a current smoker?
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|       | Not at all | Somewhat | Moderately | Very much |
|-------|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials: 

Date questionnaire completed:   Date   /   /   Time   :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
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- Between 11 and 15 minutes
- Longer than 15 minutes

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Did the patient ask for any help?  Yes  No

If yes, please specify what help was requested

please specify what help was given

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Did the patient find any of the questions difficult?  Yes  No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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Version: 2.1  08/01/2009  Page 14 of 14
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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Yes  Please complete A then B or C below
No   Please go to Section 2

| A  | When did you first notice this? | OR | Estimate     |
|----|---------------------------------|----|--------------|
|    |                                 |    | '3 months ago' or 'June' |

| B  | When did you first tell your GP or nurse? |
|----|------------------------------------------|
|    | 2 3 / 1 2 / 0 7                          |

| C  | Put a cross here if you didn't tell your GP or nurse |
|----|----------------------------------------------------|
3. Change in bowel habit

Did you have this symptom?

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| **A** | When did you **first notice** this? |   |   |   |   |
| **B** | When did you **first tell** your GP or nurse? |   |   |   |   |
| **C** | Put a cross here if you **didn't tell** your GP or nurse |   |   |   |   |

4. Bleeding from back passage

Did you have this symptom?

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| **A** | When did you **first notice** this? |   |   |   |   |
| **B** | When did you **first tell** your GP or nurse? |   |   |   |   |
| **C** | Put a cross here if you **didn't tell** your GP or nurse |   |   |   |   |
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   ![Choice](Please complete A then B or C below)

   **Please go to Question 2**

   **A** When did you first notice this?

   ![Choice](Please complete A then B or C below)

   **OR**

   **B** When did you first tell your GP or nurse?

   ![Choice](Please complete A then B or C below)

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   ![Choice](Please complete A then B or C below)

   **Please go to Question 3**

   **A** When did you first notice this?

   ![Choice](Please complete A then B or C below)

   **OR**

   **B** When did you first tell your GP or nurse?

   ![Choice](Please complete A then B or C below)

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Please complete A then B or C below

A. When did you first notice this?

B. When did you first tell your GP or nurse?

OR

C. Put a cross here if you didn't tell your GP or nurse

4. Feeling different ‘in yourself’ from usual

Did you have this?

Please complete A then B or C below

A. When did you first notice this?

B. When did you first tell your GP or nurse?

OR

C. Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

__________________________________________________________________________

__________________________________________________________________________

A  When did you first notice this?

OR

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

__________________________________________________________________________

__________________________________________________________________________

A  When did you first notice this?

OR

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

   Please cross one box only

   Employed full-time
   Employed part-time
   Self employed full-time
   Self employed part-time
   Unemployed (seeking work)
   Unemployed (not seeking work)
   Retired
   Student
   Permanently sick/disabled
   Temporarily sick/disabled
   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?

   Please cross one box only

   Degree (or equivalent)
   Diploma (or equivalent)
   'A' level
   GCSE / 'O' level
   None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?  
- Are you an ex-smoker?  
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|                                      | Not at all | Somewhat | Moderately | Very much |
|--------------------------------------|------------|----------|------------|-----------|
| 1. I feel calm                        |            |          |            |           |
| 2. I am tense                         |            |          |            |           |
| 3. I feel upset                       |            |          |            |           |
| 4. I am relaxed                       |            |          |            |           |
| 5. I feel content                     |            |          |            |           |
| 6. I am worried                       |            |          |            |           |

Please make sure you have answered all the questions.
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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed:  
Date ___/___/___  
Time ___:___

If not completed, give reason:  

How long is it since the patient was told of his/her diagnosis?  

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- Less than 5 minutes  
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Did the patient ask for any help?  
- Yes  
- No

If yes, please specify what help was requested  
__________________________________________________________________________

please specify what help was given  
__________________________________________________________________________
__________________________________________________________________________

For the patient selected for the researcher-administered questionnaire  
Did the patient find any of the questions difficult?  
- Yes  
- No

If yes, please specify which questions and what the difficulty was  
__________________________________________________________________________

Was the patient made anxious?  
- Yes  
- No

If yes, please give details  
__________________________________________________________________________

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

__________________________________________________________________________

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Yours sincerely

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Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   - Yes
   - No

2. What was the first symptom that made you think something might be wrong?

  Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom?  

- Yes  
- No

Please complete A then B or C below

A When did you first notice this?  

- Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

- Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

**Did you have any of the following?**

1. **Decrease in appetite**

   Did you have this?
   
   Yes  
   No

   Please complete A then B or C below

   A When did you **first notice** this?

   B When did you **first tell** your GP or nurse?

   OR

   C Put a cross here if you didn't **tell** your GP or nurse

   [ ]

2. **Unexplained weight loss**

   Did you have this?
   
   Yes  
   No

   Please complete A then B or C below

   A When did you **first notice** this?

   B When did you **first tell** your GP or nurse?

   OR

   C Put a cross here if you didn't **tell** your GP or nurse

   [ ]
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ______________________________________________________

   ______________________________________________________

A When did you first notice this?  

   [ ] / [ ] / [ ] OR [ ]

B When did you first tell your GP or nurse?

   [ ] / [ ] / [ ] OR [ ]

OR

C Put a cross here if you didn't tell your GP or nurse

   [ ]

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Please describe the symptom here and complete A then B or C below

6. ______________________________________________________

   ______________________________________________________

A When did you first notice this?

   [ ] / [ ] / [ ] OR [ ]

B When did you first tell your GP or nurse?

   [ ] / [ ] / [ ] OR [ ]

OR

C Put a cross here if you didn't tell your GP or nurse

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Please cross the appropriate boxes

7. Were you sent for any of these?

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|----------------------------------------------|-----|----------|-----|
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| CT Scan                                      |     |          |     |
| Ultrasound scan                              |     |          |     |
| Barium Enema                                 |     |          |     |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |     |
| X-ray                                        |     |          |     |

Please go to Question 8
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Please cross one box only

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  Other White background

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  or
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  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
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  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

[ ] Yes
[ ] No

Please go to Question 12

Please say who you live with below

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| Statement               | Not at all | Somewhat | Moderately | Very much |
|-------------------------|------------|----------|------------|-----------|
| 1. I feel calm          |            |          |            |           |
| 2. I am tense           |            |          |            |           |
| 3. I feel upset         |            |          |            |           |
| 4. I am relaxed         |            |          |            |           |
| 5. I feel content       |            |          |            |           |
| 6. I am worried         |            |          |            |           |

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: 
Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes  
Between 5 and 10 minutes  
Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  
Yes  No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  
Yes  No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  
Yes  No

If yes, please give details

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?

Yes ☒ No

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   
   | Yes | No |
   |-----|----|
   |     |    |

   Please complete A then B or C below

   A When did you first notice this?
   
   |       |       |       |
   |       |       |       | OR |
   |       |       |       |

   B When did you first tell your GP or nurse? OR
   
   |       |       |       |
   |       |       |       | OR |
   |       |       |       |

   C Put a cross here if you didn't tell your GP or nurse
   
   

2. Unexplained weight loss

   Did you have this?
   
   | Yes | No |
   |-----|----|
   |     |    |

   Please complete A then B or C below

   A When did you first notice this?
   
   |       |       |       |
   |       |       |       | OR |
   |       |       |       |

   B When did you first tell your GP or nurse? OR
   
   |       |       |       |
   |       |       |       | OR |
   |       |       |       |

   C Put a cross here if you didn't tell your GP or nurse
   
   

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3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A. When did you **first notice** this?

B. When did you **first tell** your GP or nurse?

C. Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

A. When did you **first notice** this?

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C. Put a cross here if you didn't tell your GP or nurse

---

**Please try and describe what the feeling was**

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

__________________________________________________________________________
__________________________________________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

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Please describe the symptom here and complete A then B or C below

6.

__________________________________________________________________________
__________________________________________________________________________

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Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
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Please cross one box only

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  or
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  or
    White & Black Carribean
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No

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|   | Not at all | Somewhat | Moderately | Very much |
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Between 11 and 15 minutes  
Longer than 15 minutes  
For the patient selected to complete the questionnaire on their own  
Did the patient ask for any help?  
If yes, please specify what help was requested  
please specify what help was given  
For the patient selected for the researcher-administered questionnaire  
Did the patient find any of the questions difficult?  
If yes, please specify which questions and what the difficulty was  
Was the patient made anxious?  
If yes, please give details  
Where did the patient complete the questionnaire?  
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Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A When did you first notice this? d d m m y y

OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 1 2 0 7

OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes □ No □

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes □ No □

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
OR
C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
OR
C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please try and describe what the feeling was
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ________________________________
   ________________________________

A When did you first notice this?
   □□□ / □□□ / □□ □ OR

B When did you first tell your GP or nurse?
   □□□ / □□□ / □□ □ OR

OR

C Put a cross here if you didn't tell your GP or nurse
   □

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ________________________________
   ________________________________

A When did you first notice this?
   □□□ / □□□ / □□ □ OR

B When did you first tell your GP or nurse?
   □□□ / □□□ / □□ □ OR

OR

C Put a cross here if you didn't tell your GP or nurse
   □

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes

Please go to Question 12

No

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes ☐
No ☐
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|               | Not at all | Somewhat | Moderately | Very much |
|---------------|------------|----------|------------|-----------|
| I feel calm   | ☐          | ☐        | ☐          | ☐         |
| I am tense    | ☐          | ☐        | ☐          | ☐         |
| I feel upset  | ☐          | ☐        | ☐          | ☐         |
| I am relaxed  | ☐          | ☐        | ☐          | ☐         |
| I feel content| ☐          | ☐        | ☐          | ☐         |
| I am worried  | ☐          | ☐        | ☐          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed:  
If not completed, give reason

How long was it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  
If yes, please specify what help was requested

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
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Dear Patient

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I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes ☒ Please continue with Question 2
   No ☐ Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒

Please complete A then B or C below

No ☐

Please go to Section 2

A When did you first notice this? d d / m m / y y OR

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR

OR

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 2

2. Unexplained weight loss

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 3
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

**Please try and describe what the feeling was**

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

____________________________________________________________________________________
____________________________________________________________________________________

A When did you first notice this?  OR

B When did you first tell your GP or nurse?  OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

____________________________________________________________________________________
____________________________________________________________________________________

A When did you first notice this?  OR

B When did you first tell your GP or nurse?  OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                          | Yes | Not sure | No |
|-------------------------------|-----|----------|----|
| Blood test(s)                 |     |          |    |
| CT Scan                       |     |          |    |
| Ultrasound scan               |     |          |    |
| Barium Enema                  |     |          |    |
| Sigmoidoscopy or colonoscopy  |     |          |    |
| (Looking at bowel with internal camera) | | | |
| X-ray                         |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

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   Please cross one box only
   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home
   - Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None
   - Other, please specify
10. How would you describe your ethnicity

Please cross one box only

**White**
- White British
- White Irish
- Other White background

**Mixed**
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

**Black or Black British**
- Carribean
- African
- Other Black background

**Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

**Chinese or other ethnic group**
- Chinese
- Other ethnic group

11. Do you live alone?

Yes  [ ]  Please go to Question 12
No  [ ]  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement                  | Not at all | Somewhat | Moderately | Very much |
|----------------------------|------------|----------|------------|-----------|
| 1. I feel calm             |            |          |            |           |
| 2. I am tense              |            |          |            |           |
| 3. I feel upset            |            |          |            |           |
| 4. I am relaxed            |            |          |            |           |
| 5. I feel content          |            |          |            |           |
| 6. I am worried            |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials: [ ] [ ]

Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
  - Less than 5 minutes [ ]
  - Between 5 and 10 minutes [ ]
  - Between 11 and 15 minutes [ ]
  - Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own
  Did the patient ask for any help? [ ] Yes [ ] No
  If yes, please specify what help was requested
  
  please specify what help was given

For the patient selected for the researcher-administered questionnaire
  Did the patient find any of the questions difficult? [ ] Yes [ ] No
  If yes, please specify which questions and what the difficulty was
  
  
  
  
  Was the patient made anxious?
  [ ] Yes [ ] No
  If yes, please give details
  
  
  Where did the patient complete the questionnaire?
  (Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)
  

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Yours sincerely

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Cardiff University
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About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes  

No

Please complete A then B or C below

A  When did you first notice this?  

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

OR  

OR

Estimate

'3 months ago' or 'June'
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn’t tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn’t tell your GP or nurse

Please complete A then B or C below

Please go to Section 2
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - Yes
   - No

   **Please complete A then B or C below**

   **Please go to Question 2**

   A When did you **first notice** this?

   [ ] / [ ] / [ ] OR

   B When did you **first tell** your GP or nurse?

   [ ] / [ ] / [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   - Yes
   - No

   **Please complete A then B or C below**

   **Please go to Question 3**

   A When did you **first notice** this?

   [ ] / [ ] / [ ] OR

   B When did you **first tell** your GP or nurse?

   [ ] / [ ] / [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________
________________________________________________________________________

A  When did you first notice this?  

  / /  OR

B  When did you first tell your GP or nurse?  

  / /  OR

OR

C  Put a cross here if you didn't tell your GP or nurse


If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________
________________________________________________________________________

A  When did you first notice this?  

  / /  OR

B  When did you first tell your GP or nurse?  

  / /  OR

OR

C  Put a cross here if you didn't tell your GP or nurse


If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
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Looking after family/home

Other, please describe

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Other, please specify
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  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

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Heart disease
Anxiety or depression
Inflammatory bowel disease
Irritable bowel syndrome
Peptic ulcer
Previous cancer
Diabetes
Arthritis

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Please cross the appropriate statement

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Are you a non-smoker (never smoked)?

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No
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| Statement            | Not at all | Somewhat | Moderately | Very much |
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| 1. I feel calm       |            |          |            |           |
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| 3. I feel upset      |            |          |            |           |
| 4. I am relaxed      |            |          |            |           |
| 5. I feel content    |            |          |            |           |
| 6. I am worried      |            |          |            |           |

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date ______/_____/______ Time ______:______

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes  ☐

Between 5 and 10 minutes  ☐

Between 11 and 15 minutes  ☐

Longer than 15 minutes  ☐

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  ☐ Yes  ☐ No

If yes, please specify what help was requested

________________________________________

________________________________________

________________________________________

please specify what help was given

________________________________________

________________________________________

________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  ☐ Yes  ☐ No

If yes, please specify which questions and what the difficulty was

________________________________________

________________________________________

________________________________________

Was the patient made anxious?  ☐ Yes  ☐ No

If yes, please give details

________________________________________

________________________________________

________________________________________

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

________________________________________

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These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   - [ ] Yes
   - [ ] No
   - [ ] Please continue with Question 2
   - [ ] Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?
   - Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?
   - [ ] Yes
   - [ ] No
   - [ ] Please complete A then B or C below

A  When did you first notice this? [ ] d [ ] m [ ] m [ ] y

B  When did you first tell your GP or nurse? [ ] 2 [ ] 3 [ ] 1 [ ] 2 [ ] 0 [ ] 7

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

---

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   - Yes
   - No

   Please complete A then B or C below
   Please go to Question 2

   A When did you first notice this?
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   - Yes
   - No

   Please complete A then B or C below
   Please go to Question 3

   A When did you first notice this?
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________

A When did you first notice this? ________________________ ________________________

OR

B When did you first tell your GP or nurse? ________________________ ________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________

A When did you first notice this? ________________________ ________________________

OR

B When did you first tell your GP or nurse? ________________________ ________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. **How would you describe your ethnicity**

Please cross one box only

**White**
- White British
- White Irish
- Other White background

**Mixed**
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

**Black or Black British**
- Carribean
- African
- Other Black background

**Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

**Chinese or other ethnic group**
- Chinese
- Other ethnic group

11. **Do you live alone?**

*Yes*  Please go to Question 12
*No*  Please say who you live with below

Who do you live with?  
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm |           |          |            |           |
| 2. I am tense   |           |          |            |           |
| 3. I feel upset |           |          |            |           |
| 4. I am relaxed |           |          |            |           |
| 5. I feel content |          |          |            |           |
| 6. I am worried |           |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed:   Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?    Yes  No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?    Yes  No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?    Yes  No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.

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Page 14 of 14
Confidential Questionnaire

Looking At Your Symptoms Study

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Dear Patient

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I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes
   No

   Please continue with Question 2
   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? 

Yes

No

Please complete A then B or C below

A When did you first notice this? d d / m m / y y

OR

Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7

OR

Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 4

A  When did you first notice this?

☐ / ☐ / ☐ OR ☐

B  When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR ☐

OR

C  Put a cross here if you didn’t tell your GP or nurse

☐

4. Bleeding from back passage

Did you have this symptom?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Section 2

A  When did you first notice this?

☐ / ☐ / ☐ OR ☐

B  When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR ☐

OR

C  Put a cross here if you didn’t tell your GP or nurse

☐
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   Yes  Please complete A then B or C below

   No   Please go to Question 2

   A When did you first notice this?

   / / OR

   B When did you first tell your GP or nurse?

   / / OR

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?

   Yes  Please complete A then B or C below

   No   Please go to Question 3

   A When did you first notice this?

   / / OR

   B When did you first tell your GP or nurse?

   / / OR

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes  Please complete A then B or C below
No   Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes  Please complete A then B or C below
No   Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

________________________________________________________________________
________________________________________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

________________________________________________________________________
________________________________________________________________________

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Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                           | Yes | Not sure | No |
|-------------------------------|-----|----------|----|
| Blood test(s)                 |     |          |    |
| CT Scan                       |     |          |    |
| Ultrasound scan               |     |          |    |
| Barium Enema                  |     |          |    |
| Sigmoidoscopy or colonoscopy  |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                         |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

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Please cross one box only

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- Self employed part-time
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- Unemployed (not seeking work)
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- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes  Please go to Question 12
No   Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

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- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □         | □        | □          | □         |
| 2. I am tense   | □         | □        | □          | □         |
| 3. I feel upset | □         | □        | □          | □         |
| 4. I am relaxed | □         | □        | □          | □         |
| 5. I feel content | □       | □        | □          | □         |
| 6. I am worried  | □         | □        | □          | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire.

Please give it to the research nurse.

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Researcher initials: 

Date questionnaire completed: 

Date / Time 

If not completed, give reason 

How long is it since the patient was told of his/her diagnosis? 

How long did it take the patient to complete the questionnaire? 

Less than 5 minutes 

Between 5 and 10 minutes 

Between 11 and 15 minutes 

Longer than 15 minutes 

For the patient selected to complete the questionnaire on their own 

Did the patient ask for any help? 

Yes No 

If yes, please specify what help was requested 

please specify what help was given 

For the patient selected for the researcher-administered questionnaire 

Did the patient find any of the questions difficult? 

Yes No 

If yes, please specify which questions and what the difficulty was 

Was the patient made anxious? 

Yes No 

If yes, please give details 

Where did the patient complete the questionnaire? 

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other) 

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided. 

Version: 2.1 08/01/2009
Confidential Questionnaire

Looking At Your Symptoms Study

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Dear Patient

I am very grateful to you for agreeing to help us with this study.

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If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes [ ] Please continue with Question 2
   No [ ] Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? [ ]

No [ ] Please go to Section 2

A When did you first notice this? [d] [d] [m] [m] [y] [y]  OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? [23] [12] [07]  OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

**Did you have any of the following?**

### 1. Decrease in appetite

| Did you have this? | Yes | Please complete A then B or C below |
|--------------------|-----|------------------------------------|
|                    | No  | **Please go to Question 2**        |

**A** When did you **first notice** this?

|        | /   | /   | OR |   |
|--------|-----|-----|----|---|

**B** When did you **first tell** your GP or nurse?

|        | /   | /   | OR |   |
|--------|-----|-----|----|---|

**OR**

**C** Put a cross here if you **didn't tell** your GP or nurse

### 2. Unexplained weight loss

| Did you have this? | Yes | Please complete A then B or C below |
|--------------------|-----|------------------------------------|
|                    | No  | **Please go to Question 3**        |

**A** When did you **first notice** this?

|        | /   | /   | OR |   |
|--------|-----|-----|----|---|

**B** When did you **first tell** your GP or nurse?

|        | /   | /   | OR |   |
|--------|-----|-----|----|---|

**OR**

**C** Put a cross here if you **didn't tell** your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

OR

OR

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?  __/__/ OR __________________________________

B  When did you first tell your GP or nurse?  __/__/ OR __________________________________

OR

C  Put a cross here if you didn't tell your GP or nurse



If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?  __/__/ OR __________________________________

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If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

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| Test                                      | Yes | Not sure | No |
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| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
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Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only

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   - Retired
   - Student
   - Permanently sick/disabled
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   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only

   - Degree (or equivalent)
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   - 'A' level
   - GCSE / 'O' level
   - None

   Other, please specify
10. **How would you describe your ethnicity**

*Please cross one box only*

- **White**
  - White British
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  - Other White background

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  - Other Black background

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  - Indian
  - Pakistani
  - Bangladeshi
  - Other Asian background

- **Chinese or other ethnic group**
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  - Other ethnic group

11. **Do you live alone?**

- [ ] Yes  **Please go to Question 12**
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Yes  No
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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☐        | ☐          | ☐         |
| 2. I am tense  | ☐         | ☐        | ☐          | ☐         |
| 3. I feel upset| ☐         | ☐        | ☐          | ☐         |
| 4. I am relaxed| ☐         | ☐        | ☐          | ☐         |
| 5. I feel content| ☐       | ☐        | ☐          | ☐         |
| 6. I am worried| ☐         | ☐        | ☐          | ☐         |

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: 

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

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If yes, please specify what help was requested

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Did the patient find any of the questions difficult?  
- Yes  
- No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  
- Yes  
- No

If yes, please give details

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes No

Please complete A then B or C below

A When did you first notice this? d d / m m / y y

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7

OR

C Put a cross here if you didn't tell your GP or nurse

Please go to Question 3

Please continue with Question 2

Please go to Section 2 on Page 5

Version:- 2.1 08/01/2009
3. **Change in bowel habit**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - Yes
   - No

   Please complete A then B or C below

   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   
   OR

   C Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   - Yes
   - No

   Please complete A then B or C below

   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   
   OR

   C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________
   ____________________________

A When did you first notice this?
   □ □ / □ □ / □ □ OR  ____________________________

B When did you first tell your GP or nurse?
   □ □ / □ □ / □ □ OR  ____________________________

OR

C Put a cross here if you didn't tell your GP or nurse
   □

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________
   ____________________________

A When did you first notice this?
   □ □ / □ □ / □ □ OR  ____________________________

B When did you first tell your GP or nurse?
   □ □ / □ □ / □ □ OR  ____________________________

OR

C Put a cross here if you didn't tell your GP or nurse
   □

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

7. **Were you sent for any of these?**

|                                | Yes | Not sure | No |
|--------------------------------|-----|----------|----|
| Blood test(s)                  |     |          |    |
| CT Scan                        |     |          |    |
| Ultrasound scan                |     |          |    |
| Barium Enema                   |     |          |    |
| Sigmoidoscopy or colonoscopy   |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                          |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

**Please cross one box only**

**White**
- White British
- White Irish
- Other White background

**Mixed**
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

**Black or Black British**
- Carribean
- African
- Other Black background

**Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

**Chinese or other ethnic group**
- Chinese
- Other ethnic group

11. Do you live alone?

**Yes**
- Please go to Question 12

**No**
- Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectatis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time : :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  Yes  No
If yes,
please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  Yes  No
If yes,
please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No
If yes,
please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse

Please go to Question 3
3. **Change in bowel habit**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse

| Yes | Please complete A then B or C below |
|-----|-----------------------------------|
| No  | Please go to Question 4           |

| Yes | Please complete A then B or C below |
|-----|-----------------------------------|
| No  | Please go to Section 2            |

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse

| Yes | Please complete A then B or C below |
|-----|-----------------------------------|
| No  | Please go to Section 2            |
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   - Yes
   - No

   Please complete A then B or C below

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   - Yes
   - No

   Please complete A then B or C below

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

---

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________
______________________________________________________________

A When did you first notice this?  [ ] / [ ] / [ ] OR _______________________

B When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR _______________________

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________________________
______________________________________________________________

A When did you first notice this?  [ ] / [ ] / [ ] OR _______________________

B When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR _______________________

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

- Blood test(s)
- CT Scan
- Ultrasound scan
- Barium Enema
- Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera)
- X-ray

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

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Other, please describe

9. What is your highest level of qualification?

Please cross one box only

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Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes  Please go to Question 12
No  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

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- Irritable bowel syndrome
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- Previous cancer
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13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  ☐  No  ☐
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement          | Not at all | Somewhat | Moderately | Very much |
|--------------------|------------|----------|------------|-----------|
| 1. I feel calm     |            |          |            |           |
| 2. I am tense      |            |          |            |           |
| 3. I feel upset    |            |          |            |           |
| 4. I am relaxed    |            |          |            |           |
| 5. I feel content  |            |          |            |           |
| 6. I am worried    |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: 

If not completed, give reason: 

How long is it since the patient was told of his/her diagnosis? 

How long did it take the patient to complete the questionnaire? 
- Less than 5 minutes 
- Between 5 and 10 minutes 
- Between 11 and 15 minutes 
- Longer than 15 minutes 

For the patient selected to complete the questionnaire on their own: 
Did the patient ask for any help? 
- Yes 
- No 
If yes, please specify what help was requested. 

Please specify what help was given. 

For the patient selected for the researcher-administered questionnaire: 
Did the patient find any of the questions difficult? 
- Yes 
- No 
If yes, please specify which questions and what the difficulty was. 

Was the patient made anxious? 
- Yes 
- No 
If yes, please give details. 

Where did the patient complete the questionnaire? 
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other. 

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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes [ ]  Please continue with Question 2
   No [ ]  Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  
[ ] Yes  [ ] No  
Please complete A then B or C below  

A  When did you first notice this?  
   [ ] 2 [ ] 3 [ ] 1 [ ] 2 [ ] 0 [ ] 7  OR  
   Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  
   OR

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

**OR**

C  Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

**OR**

C  Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   
   Yes □  Please complete A then B or C below
   No □  Please go to Question 2

   A When did you first notice this?
   
   □ / □ / □ OR □

   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   
   Yes □  Please complete A then B or C below
   No □  Please go to Question 3

   A When did you first notice this?
   
   □ / □ / □ OR □

   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ________________________________________________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ________________________________________________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                          | Yes | Not sure | No |
|-----------------------------------------------|-----|----------|----|
| Blood test(s)                                 | □   |          | □  |
| CT Scan                                       | □   |          | □  |
| Ultrasound scan                               | □   |          | □  |
| Barium Enema                                  | □   |          | □  |
| Sigmoidoscopy or colonoscopy                  | □   |          | □  |
| (Looking at bowel with internal camera)       |     |          |    |
| X-ray                                         | □   |          | □  |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. **Which best describes your employment status?**
   **Please cross one box only**
   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home

   Other, please describe

9. **What is your highest level of qualification?**
   **Please cross one box only**
   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12
No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
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*Please cross the appropriate statement*

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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm |            |          |            |           |
| 2. I am tense |            |          |            |           |
| 3. I feel upset |            |          |            |           |
| 4. I am relaxed |            |          |            |           |
| 5. I feel content |            |          |            |           |
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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?

Yes No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?

Yes No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?

Yes No

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below |
|----------------------|-----|--------------------------------------|
| Did you have this symptom? | ☒ | |
| No | Please go to Section 2 |

| A | When did you first notice this? | Estimate '3 months ago' or 'June' |
|---|---------------------------------|-------------------------------|
|  | d d / m m / y y | |

| B | When did you first tell your GP or nurse? | Estimate |
|---|------------------------------------------|----------|
|  | 2 3 / 1 2 / 0 7 | |

| C | Put a cross here if you didn't tell your GP or nurse | |
|---|------------------------------------------------------|
3. **Change in bowel habit**

Did you have this symptom?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

OR

C. Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

OR

C. Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

| Did you have this? | Please complete A then B or C below | Please go to Question 2 |
|--------------------|-------------------------------------|------------------------|
| Yes                |                                     |                        |
| No                 |                                     |                        |

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

| Did you have this? | Please complete A then B or C below | Please go to Question 3 |
|--------------------|-------------------------------------|------------------------|
| Yes                |                                     |                        |
| No                 |                                     |                        |

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

**Please describe the symptom here and complete A then B or C below**

5. __________________________________________________________________________
_____________________________________________________________________________

A When did you first notice this?  [□/□/□] OR
_____________________________________________________________________

B When did you first tell your GP or nurse?  [□/□/□] OR
_____________________________________________________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

**Please describe the symptom here and complete A then B or C below**

6. __________________________________________________________________________
_____________________________________________________________________________

A When did you first notice this?  [□/□/□] OR
_____________________________________________________________________

B When did you first tell your GP or nurse?  [□/□/□] OR
_____________________________________________________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

**7. Were you sent for any of these?**

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | | | |
| X-ray                                     |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   
   Employed full-time
   Employed part-time
   Self employed full-time
   Self employed part-time
   Unemployed (seeking work)
   Unemployed (not seeking work)
   Retired
   Student
   Permanently sick/disabled
   Temporarily sick/disabled
   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   
   Degree (or equivalent)
   Diploma (or equivalent)
   'A' level
   GCSE / 'O' level
   None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
   Please go to Question 12

No
   Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?
   Please cross any that are applicable to you
   - Asthma
   - Chronic Obstructive Pulmonary Disease (COPD)
   - Other lung disease (e.g. fibrosis, bronchiectasis etc)
   - Heart disease
   - Anxiety or depression
   - Inflammatory bowel disease
   - Irritable bowel syndrome
   - Peptic ulcer
   - Previous cancer
   - Diabetes
   - Arthritis

13. About smoking
   Please cross the appropriate statement
   - Are you a current smoker?
   - Are you an ex-smoker?
   - Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?
   Yes   No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☑        | ☐          | ☐         |
| 2. I am tense  | ☐         | ☑        | ☐          | ☐         |
| 3. I feel upset| ☐         | ☑        | ☐          | ☐         |
| 4. I am relaxed| ☐         | ☑        | ☐          | ☐         |
| 5. I feel content| ☐       | ☑        | ☐          | ☐         |
| 6. I am worried | ☐         | ☑        | ☐          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials: [ ]

Date questionnaire completed: [ ] / [ ] / [ ] Time [ ]:

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No

If yes, please specify what help was requested

________________________________________________________________________

please specify what help was given

________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No

If yes, please specify which questions and what the difficulty was

________________________________________________________________________

________________________________________________________________________

Was the patient made anxious? [ ] Yes [ ] No

If yes, please give details

________________________________________________________________________

________________________________________________________________________

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

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Please put a cross in the appropriate box, or write an answer as required.

**Looking back...**

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below | No | Please go to Section 2 |
|-----------------------|-----|-------------------------------------|----|------------------------|

**A** When did you first notice this? [dd/mm/yyyy] OR Estimate '3 months ago' or 'June'

**B** When did you first tell your GP or nurse? [dd/mm/yyyy] OR Estimate

**C** Put a cross here if you didn’t tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

[ ] / [ ] / [ ] OR [ ]

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR [ ]

OR

C Put a cross here if you didn't tell your GP or nurse

[ ]

2. Unexplained weight loss

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

[ ] / [ ] / [ ] OR [ ]

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR [ ]

OR

C Put a cross here if you didn't tell your GP or nurse

[ ]
3. Fatigue or tiredness that is unusual for you

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

_________________________________________

_________________________________________

A When did you first notice this?  

/ / / OR

B When did you first tell your GP or nurse?  

/ / / OR

OR

C Put a cross here if you didn't tell your GP or nurse



If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

_________________________________________

_________________________________________

A When did you first notice this?  

/ / / OR

B When did you first tell your GP or nurse?  

/ / / OR

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Please cross the appropriate boxes

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| Test                                      | Yes | Not sure | No |
|--------------------------------------------|-----|----------|----|
| Blood test(s)                              |     |          |    |
| CT Scan                                    |     |          |    |
| Ultrasound scan                            |     |          |    |
| Barium Enema                               |     |          |    |
| Sigmoidoscopy or colonoscopy               |     |          |    |
| (Looking at bowel with internal camera)    |     |          |    |
| X-ray                                      |     |          |    |

Please go to Question 8
About you

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   - Self employed full-time
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   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home
   - Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None
   - Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
   or
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   White Irish
   Other White background

Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

Black or Black British
   or
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   African
   Other Black background

Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

**Please cross any that are applicable to you**

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. **About smoking**

**Please cross the appropriate statement**

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. **Do you think you were more at risk of getting cancer because of your family history?**

- Yes
- No
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|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐ | ☐ | ☐ | ☐ |
| 2. I am tense | ☐ | ☐ | ☐ | ☐ |
| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [ ] [ ] [ ]
Date [ ] [ ] [ ] Time [ ] [ ]

If not completed, give reason


How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes  
No

Please complete A then B or C below

A  When did you first notice this?  

2  3  1  2  0  7

OR

Estimate

'3 months ago' or 'June'

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

- **A** When did you **first notice** this?
- **B** When did you **first tell** your GP or nurse?
- **C** Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

- **A** When did you **first notice** this?
- **B** When did you **first tell** your GP or nurse?
- **C** Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 2

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 3

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.  

__________________________________________________________________________  
__________________________________________________________________________  
__________________________________________________________________________  

A  When did you first notice this?  
[ ] / [ ] / [ ]  OR  
__________________________________________________________________________  

B  When did you first tell your GP or nurse?  
[ ] / [ ] / [ ]  OR  
__________________________________________________________________________  

OR  

C  Put a cross here if you didn't tell your GP or nurse  
[ ]

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.  

__________________________________________________________________________  
__________________________________________________________________________  
__________________________________________________________________________  

A  When did you first notice this?  
[ ] / [ ] / [ ]  OR  
__________________________________________________________________________  

B  When did you first tell your GP or nurse?  
[ ] / [ ] / [ ]  OR  
__________________________________________________________________________  

OR  

C  Put a cross here if you didn't tell your GP or nurse  
[ ]

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

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**Please cross the appropriate boxes**

7. Were you sent for any of these?

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy        |     |          |    |
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| X-ray                               |     |          |    |

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- Unemployed (seeking work)
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- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
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- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
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Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
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Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
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   - Anxiety or depression
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   - Peptic ulcer
   - Previous cancer
   - Diabetes
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   Please cross the appropriate statement
   - Are you a current smoker?
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   - Yes
   - No
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| Statement                  | Not at all | Somewhat | Moderately | Very much |
|----------------------------|------------|----------|------------|-----------|
| 1. I feel calm             |            |          |            |           |
| 2. I am tense              |            |          |            |           |
| 3. I feel upset            |            |          |            |           |
| 4. I am relaxed            |            |          |            |           |
| 5. I feel content          |            |          |            |           |
| 6. I am worried            |            |          |            |           |

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Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: 
Date __/__/__ Time __:__:

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested _____________________________

please specify what help was given _____________________________

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was
______________________________
______________________________
______________________________

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details _____________________________
______________________________
______________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)
______________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   - Yes  Please continue with Question 2
   - No  Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  Yes  Please complete A then B or C below
   - No  Please go to Section 2

A When did you first notice this?  Estimate '3 months ago' or 'June'
   | d | d | m | m | y | y
   | 3 | 1 | 2 | 0 | 7

B When did you first tell your GP or nurse?
   OR

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse

---

4. **Bleeding from back passage**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   **Yes**  
   Please complete A then B or C below

   **No**  
   Please go to Question 2

   **A** When did you first notice this?

   **B** When did you first tell your GP or nurse?  
   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   **Yes**  
   Please complete A then B or C below

   **No**  
   Please go to Question 3

   **A** When did you first notice this?

   **B** When did you first tell your GP or nurse?  
   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?  □□□ / □□□ / □□□ OR

B  When did you first tell your GP or nurse?  □□□ / □□□ / □□□ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?  □□□ / □□□ / □□□ OR

B  When did you first tell your GP or nurse?  □□□ / □□□ / □□□ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|---------|----|
| Blood test(s)                             |     |         |    |
| CT Scan                                   |     |         |    |
| Ultrasound scan                           |     |         |    |
| Barium Enema                              |     |         |    |
| Sigmoidoscopy or colonoscopy              |     |         |    |
| (Looking at bowel with internal camera)   |     |         |    |
| X-ray                                     |     |         |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectatis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement                  | Not at all | Somewhat | Moderately | Very much |
|----------------------------|------------|----------|------------|-----------|
| 1. I feel calm             |            |          |            |           |
| 2. I am tense              |            |          |            |           |
| 3. I feel upset            |            |          |            |           |
| 4. I am relaxed            |            |          |            |           |
| 5. I feel content          |            |          |            |           |
| 6. I am worried            |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? Yes No

If yes, please specify what help was requested

Please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? Yes No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
## About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

**Please put a cross in the appropriate box, or write an answer as required.**

### Looking back...

1. Did you have **any** symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the **first** symptom that made you think something might be wrong?

---

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

**Please give an **exact** date if you can. Otherwise give your best **estimate**. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.**

**Here is an example question:**

| Decrease in appetite | Yes | Please complete A then B or C below |
|-----------------------|-----|-------------------------------------|
| Did you have this symptom? | ☒ | |
| No | | Please go to Section 2 |

**A** When did you **first notice** this? 

| d | d | m | m | y | y |
|---|---|---|---|---|---|

**OR**

| Estimate | '3 months ago' or 'June' |
|----------|------------------------|

**B** When did you first tell your GP or nurse?

| 2 | 3 | 1 | 2 | 0 | 7 |
|---|---|---|---|---|---|

**OR**

| Estimate |
|----------|

**C** Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   Yes [ ]

   No [ ]

   Please complete A then B or C below

   Please go to Question 2

A When did you **first notice** this?

   [ ] / [ ] / [ ] OR

B When did you **first tell** your GP or nurse?

   OR

C Put a cross here if you didn't **tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   Yes [ ]

   No [ ]

   Please complete A then B or C below

   Please go to Question 3

A When did you **first notice** this?

   [ ] / [ ] / [ ] OR

B When did you **first tell** your GP or nurse?

   OR

C Put a cross here if you didn't **tell** your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?

OR

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?

OR

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No   |
|-------------------------------------------|-----|----------|------|
| Blood test(s)                             |     |          |      |
| CT Scan                                   |     |          |      |
| Ultrasound scan                           |     |          |      |
| Barium Enema                              |     |          |      |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |      |
| X-ray                                     |     |          |      |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity
   Please cross one box only

   White
   or
   White British
   White Irish
   Other White background

   Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

   Black or Black British
   or
   Carribean
   African
   Other Black background

   Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

   Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?

   Yes
   Please go to Question 12

   No
   Please say who you live with below

   Who do you live with?
   (e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □         | □        | □          | □         |
| 2. I am tense  | □         | □        | □          | □         |
| 3. I feel upset | □         | □        | □          | □         |
| 4. I am relaxed | □         | □        | □          | □         |
| 5. I feel content | □         | □        | □          | □         |
| 6. I am worried  | □         | □        | □          | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials: 

Date questionnaire completed: 

If not completed, give reason 

How long is it since the patient was told of his/her diagnosis? 

How long did it take the patient to complete the questionnaire? 

Less than 5 minutes 
Between 5 and 10 minutes 
Between 11 and 15 minutes 
Longer than 15 minutes 

For the patient selected to complete the questionnaire on their own 

Did the patient ask for any help? 

If yes, please specify what help was requested 

Please specify what help was given 

For the patient selected for the researcher-administered questionnaire 

Did the patient find any of the questions difficult? 

If yes, please specify which questions and what the difficulty was 

Was the patient made anxious? 

If yes, please give details 

Where did the patient complete the questionnaire? 

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other) 

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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes ☒ Please complete A then B or C below

No

Please go to Section 2

A When did you first notice this?  

Estimate '3 months ago' or 'June'

OR

B When did you first tell your GP or nurse?  

2 3 1 2 0 7

OR

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Section 2

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes [ ]

No [ ]

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse



2. Unexplained weight loss

Did you have this?

Yes [ ]

No [ ]

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

No

Please go to Question 4

OR

OR

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

No

Please go to Question 5

OR

OR

Please try and describe what the feeling was

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  OR
B  When did you first tell your GP or nurse?  OR
C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  OR
B  When did you first tell your GP or nurse?  OR
C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy        |     |          |    |
| (Looking at bowel with internal camera) |    |          |    |
| X-ray                               |     |          |    |

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Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
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- 'A' level
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Other, please specify
10. How would you describe your ethnicity
   Please cross one box only

   White
   or
   White British
   White Irish
   Other White background

   Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

   Black or Black British
   or
   Carribean
   African
   Other Black background

   Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

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   or
   Chinese
   Other ethnic group

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- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

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Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes ☐  No ☐
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐ | ☐ | ☐ | ☐ |
| 2. I am tense | ☐ | ☐ | ☐ | ☐ |
| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes  
Between 5 and 10 minutes  
Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  Yes  No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  Yes  No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
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Dear Patient

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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A When did you first notice this? 

B When did you first tell your GP or nurse? 

C Put a cross here if you didn't tell your GP or nurse

Please go to Section 2 on Page 5

Please continue with Question 2
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Yes

No

Please complete A then B or C below

Please go to Question 4

Please go to Section 2
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - A When did you first notice this?
   - B When did you first tell your GP or nurse?
   - OR
   - C Put a cross here if you didn't tell your GP or nurse

   Please complete A then B or C below

2. **Unexplained weight loss**

   Did you have this?

   - A When did you first notice this?
   - B When did you first tell your GP or nurse?
   - OR
   - C Put a cross here if you didn't tell your GP or nurse

   Please complete A then B or C below
3. Fatigue or tiredness that is unusual for you

Did you have this?

A  When did you *first notice* this?

B  When did you *first tell* your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A  When did you *first notice* this?

B  When did you *first tell* your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

[Blank space for symptom description]

A When did you first notice this? 

[Blank spaces for date and time]

OR

B When did you first tell your GP or nurse? 

[Blank spaces for date and time]

OR

C Put a cross here if you didn’t tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

[Blank space for symptom description]

A When did you first notice this? 

[Blank spaces for date and time]

OR

B When did you first tell your GP or nurse? 

[Blank spaces for date and time]

OR

C Put a cross here if you didn’t tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                          | Yes | Not sure | No |
|-----------------------------------------------|-----|----------|----|
| Blood test(s)                                 |     |          |    |
| CT Scan                                       |     |          |    |
| Ultrasound scan                               |     |          |    |
| Barium Enema                                  |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                         |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12
No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes ☐ No ☐
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☐        | ☐          | ☐         |
| 2. I am tense  | ☐         | ☐        | ☐          | ☐         |
| 3. I feel upset| ☐         | ☐        | ☐          | ☐         |
| 4. I am relaxed| ☐         | ☐        | ☐          | ☐         |
| 5. I feel content| ☐       | ☐        | ☐          | ☐         |
| 6. I am worried | ☐         | ☐        | ☐          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed:  

If not completed, give reason  

How long is it since the patient was told of his/her diagnosis?  

How long did it take the patient to complete the questionnaire?  

- Less than 5 minutes  
- Between 5 and 10 minutes  
- Between 11 and 15 minutes  
- Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own  

Did the patient ask for any help?  

- Yes  
- No  

If yes, please specify what help was requested  

please specify what help was given  

For the patient selected for the researcher-administered questionnaire  

Did the patient find any of the questions difficult?  

- Yes  
- No  

If yes, please specify which questions and what the difficulty was  

Was the patient made anxious?  

- Yes  
- No  

If yes, please give details  

Where did the patient complete the questionnaire?  

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)  

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Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes [X] No

Please complete A then B or C below

A When did you first notice this? OR

B When did you first tell your GP or nurse? OR

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   
   Yes
   No
   Please complete A then B or C below

   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   
   Yes
   No
   Please go to Question 2

   Please complete A then B or C below

   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

   Did you have this?

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **C** Put a cross here if you didn't tell your GP or nurse

---

4. **Feeling different 'in yourself' from usual**

   Did you have this?

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **C** Put a cross here if you didn't tell your GP or nurse

---

Please try and describe what the feeling was:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________

A When did you first notice this?

   / / / OR

   / / / OR

B When did you first tell your GP or nurse?

   / / / OR

   / / / OR

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________

A When did you first notice this?

   / / / OR

   / / / OR

B When did you first tell your GP or nurse?

   / / / OR

   / / / OR

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?  

|                          | Yes | Not sure | No |
|--------------------------|-----|----------|----|
| Blood test(s)            |     |          |    |
| CT Scan                  |     |          |    |
| Ultrasound scan          |     |          |    |
| Barium Enema             |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | | | |
| X-ray                    |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

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Please cross one box only

- Employed full-time
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- Unemployed (seeking work)
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- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes
- Please go to Question 12

No
- Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years? 

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
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- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
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|                                | Not at all | Somewhat | Moderately | Very much |
|--------------------------------|------------|----------|------------|-----------|
| 1. I feel calm                 |            |          |            |           |
| 2. I am tense                  |            |          |            |           |
| 3. I feel upset                |            |          |            |           |
| 4. I am relaxed                |            |          |            |           |
| 5. I feel content              |            |          |            |           |
| 6. I am worried                |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

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The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

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- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  Yes  No

If yes, please specify what help was requested




please specify what help was given



For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  Yes  No

If yes, please specify which questions and what the difficulty was




Was the patient made anxious?  Yes  No

If yes, please give details




Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)




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Yours sincerely

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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom?  

Yes [X] Please complete A then B or C below  

No [ ] Please go to Section 2

A  When did you first notice this?  

[ ] d  [ ] m  [ ] m / y  

OR  Estimate  

'3 months ago' or 'June'

B  When did you first tell your GP or nurse?  

[ ] 2  [ ] 3  [ ] 1  [ ] 2  [ ] 0  [ ] 7  

OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse  

[ ]
3. Change in bowel habit

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse

   Please complete A then B or C below

   Yes
   [ ]

   No
   [ ]

   Please go to Question 2

   [ ] / [ ] / [ ] OR

2. **Unexplained weight loss**

   Did you have this?

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse

   Please complete A then B or C below

   Yes
   [ ]

   No
   [ ]

   Please go to Question 3

   [ ] / [ ] / [ ] OR

   [ ] / [ ] / [ ] OR

   [ ]
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

C. Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

4. **Feeling different 'in yourself' from usual**

Did you have this?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

C. Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

____________________________________________________________________

____________________________________________________________________

A  When did you first notice this?    OR

B  When did you first tell your GP or nurse?    OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

____________________________________________________________________

____________________________________________________________________

A  When did you first notice this?    OR

B  When did you first tell your GP or nurse?    OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

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The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

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No

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- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. | I feel calm | □        | □          | □         | □         |
| 2. | I am tense  | □        | □          | □         | □         |
| 3. | I feel upset| □        | □          | □         | □         |
| 4. | I am relaxed| □        | □          | □         | □         |
| 5. | I feel content| □      | □          | □         | □         |
| 6. | I am worried | □       | □          | □         | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? Yes No
If yes,
please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? Yes No
If yes,
please specify which questions and what the difficulty was

Was the patient made anxious? Yes No
If yes,
please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below |
|-----------------------|-----|-------------------------------------|
| Did you have this symptom? | ☒ | Please go to Section 2 |

A When did you first notice this? [ ] [ ] [ ] [ ] [ ] [ ] OR Estimate ‘3 months ago’ or ‘June’

B When did you first tell your GP or nurse? 2 [ ] [ ] [ ] 3 [ ] [ ] [ ] 0 [ ] [ ] [ ] 7 OR Estimate

C Put a cross here if you didn’t tell your GP or nurse

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3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**
   
   Did you have this?
   
   Yes  
   No  

   **Please complete A then B or C below**

   **Please go to Question 2**

   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse

   

2. **Unexplained weight loss**

   Did you have this?

   Yes  
   No  

   **Please complete A then B or C below**

   **Please go to Question 3**

   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

**A** When did you **first notice** this?

**B** When did you **first tell** your GP or nurse?

**OR**

**C** Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

**A** When did you **first notice** this?

**B** When did you **first tell** your GP or nurse?

**OR**

**C** Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________

|   |   |   | OR |
|---|---|---|----|
| A | When did you first notice this? |
| B | When did you first tell your GP or nurse? |
| C | Put a cross here if you didn't tell your GP or nurse |

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________________________

|   |   |   | OR |
|---|---|---|----|
| A | When did you first notice this? |
| B | When did you first tell your GP or nurse? |
| C | Put a cross here if you didn't tell your GP or nurse |

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?  

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None

   Other, please specify
10. How would you describe your ethnicity
Please cross one box only

White
or
White British
White Irish
Other White background

Mixed
or
White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British
or
Carribean
African
Other Black background

Asian or Asian British
or
Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group
or
Chinese
Other ethnic group

11. Do you live alone?

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

**Please cross any that are applicable to you**

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

**Please cross the appropriate statement**

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.

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Confidential Questionnaire

Looking At Your Symptoms Study
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

Yes  [ ]  Please continue with Question 2

No  [ ]  Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  Yes  [X]  Please complete A then B or C below

No  [ ]  Please go to Section 2

A  When did you first notice this?  dd/mm/yyyy  OR  Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  23/12/07  OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

**Did you have any of the following?**

1. **Decrease in appetite**

   Did you have this?

   Yes
   No
   Please complete A then B or C below

   Please go to Question 2

   | A | When did you **first notice** this? |
   |---|----------------------------------|
   |   | **/ / OR**                        |

   | B | When did you **first tell** your GP or nurse? |
   |---|-----------------------------------------------|
   |   | **/ / OR**                                   |

   | C | Put a cross here if you didn't **tell** your GP or nurse |
   |---|--------------------------------------------------------|
   |   |                                                        |

2. **Unexplained weight loss**

   Did you have this?

   Yes
   No
   Please complete A then B or C below

   Please go to Question 3

   | A | When did you **first notice** this? |
   |---|----------------------------------|
   |   | **/ / OR**                        |

   | B | When did you **first tell** your GP or nurse? |
   |---|-----------------------------------------------|
   |   | **/ / OR**                                   |

   | C | Put a cross here if you didn't **tell** your GP or nurse |
   |---|--------------------------------------------------------|
   |   |                                                        |
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________

________________________________________

A  When did you first notice this?

   / / OR

B  When did you first tell your GP or nurse?

   / / OR

   OR

C  Put a cross here if you didn't tell your GP or nurse


If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________

________________________________________

A  When did you first notice this?

   / / OR

B  When did you first tell your GP or nurse?

   / / OR

   OR

C  Put a cross here if you didn't tell your GP or nurse


If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

| 7. Were you sent for any of these?                | Yes | Not sure | No |
|------------------------------------------------|-----|----------|----|
| Blood test(s)                                   |     |          |    |
| CT Scan                                         |     |          |    |
| Ultrasound scan                                 |     |          |    |
| Barium Enema                                    |     |          |    |
| Sigmoidoscopy or colonoscopy                    |     |          |    |
| (Looking at bowel with internal camera)         |     |          |    |
| X-ray                                           |     |          |    |

Please go to Question 8
**About you**

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. **Which best describes your employment status?**

   Please cross one box only

   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home
   - Other, please describe

9. **What is your highest level of qualification?**

   Please cross one box only

   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None
   - Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes

Please go to Question 12

No

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes ☐ No ☐
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement               | Not at all | Somewhat | Moderately | Very much |
|-------------------------|------------|----------|------------|-----------|
| 1. I feel calm          |            |          |            |           |
| 2. I am tense           |            |          |            |           |
| 3. I feel upset         |            |          |            |           |
| 4. I am relaxed         |            |          |            |           |
| 5. I feel content       |            |          |            |           |
| 6. I am worried         |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
| Question                                                                 | Response          |
|------------------------------------------------------------------------|-------------------|
| Date questionnaire completed:                                          |                   |
| If not completed, give reason                                          |                   |
| How long is it since the patient was told of his/her diagnosis?         |                   |
| How long did it take the patient to complete the questionnaire?         |                   |
| Less than 5 minutes                                                    | [ ]              |
| Between 5 and 10 minutes                                               | [ ]              |
| Between 11 and 15 minutes                                              | [ ]              |
| Longer than 15 minutes                                                 | [ ]              |
| For the patient selected to complete the questionnaire on their own    |                   |
| Did the patient ask for any help?                                      | [ ] Yes [ ] No   |
| If yes, please specify what help was requested                         |                   |
| please specify what help was given                                     |                   |
| For the patient selected for the researcher-administered questionnaire |                   |
| Did the patient find any of the questions difficult?                   | [ ] Yes [ ] No   |
| If yes, please specify which questions and what the difficulty was     |                   |
| Was the patient made anxious?                                          | [ ] Yes [ ] No   |
| If yes, please give details                                            |                   |
| Where did the patient complete the questionnaire?                       |                   |
| (Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other) |                   |

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes [ ] Please continue with Question 2
   No [ ] Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom? [ ]

Yes [ ] Please complete A then B or C below

No [ ] Please go to Section 2

A When did you first notice this? [ ]

OR

B When did you first tell your GP or nurse? [ ]

OR

C Put a cross here if you didn't tell your GP or nurse

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Page 3 of 14
3. **Change in bowel habit**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

---

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

---

Yes  Please complete A then B or C below
No   Please go to Question 4

---

Yes  Please complete A then B or C below
No   Please go to Section 2

---
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   Yes  [ ] Please complete A then B or C below

   No [ ] Please go to Question 2

   **A** When did you first notice this?

   **B** When did you first tell your GP or nurse?

   OR

   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   Yes  [ ] Please complete A then B or C below

   No [ ] Please go to Question 3

   **A** When did you first notice this?

   **B** When did you first tell your GP or nurse?

   OR

   **C** Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ________________________________________________________
   ________________________________________________________

A When did you first notice this?  □ □ □ / □ □ □ OR

B When did you first tell your GP or nurse?  □ □ □ / □ □ □ OR

C Put a cross here if you didn’t tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ________________________________________________________
   ________________________________________________________

A When did you first notice this?  □ □ □ / □ □ □ OR

B When did you first tell your GP or nurse?  □ □ □ / □ □ □ OR

C Put a cross here if you didn’t tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             | ![Yes](false) | ![Not sure](false) | ![No](false) |
| CT Scan                                   | ![Yes](false) | ![Not sure](false) | ![No](false) |
| Ultrasound scan                           | ![Yes](false) | ![Not sure](false) | ![No](false) |
| Barium Enema                              | ![Yes](false) | ![Not sure](false) | ![No](false) |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | ![Yes](false) | ![Not sure](false) | ![No](false) |
| X-ray                                     | ![Yes](false) | ![Not sure](false) | ![No](false) |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
or
White British
White Irish
Other White background

Mixed
or
White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British
or
Carribean
African
Other Black background

Asian or Asian British
or
Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group
or
Chinese
Other ethnic group

11. Do you live alone?

Yes Please go to Question 12
No Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. | I feel calm | [ ] | [ ] | [ ] | [ ] |
| 2. | I am tense | [ ] | [ ] | [ ] | [ ] |
| 3. | I feel upset | [ ] | [ ] | [ ] | [ ] |
| 4. | I am relaxed | [ ] | [ ] | [ ] | [ ] |
| 5. | I feel content | [ ] | [ ] | [ ] | [ ] |
| 6. | I am worried | [ ] | [ ] | [ ] | [ ] |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed:  

If not completed, give reason:  

How long is it since the patient was told of his/her diagnosis?  

How long did it take the patient to complete the questionnaire?  
Less than 5 minutes  
Between 5 and 10 minutes  
Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own  
Did the patient ask for any help?  
Yes  No  
If yes, please specify what help was requested  

please specify what help was given  

For the patient selected for the researcher-administered questionnaire  
Did the patient find any of the questions difficult?  
Yes  No  
If yes, please specify which questions and what the difficulty was  

Was the patient made anxious?  
Yes  No  
If yes, please give details  

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other  

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed? 

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

---

Decrease in appetite

Did you have this symptom? Yes  No

Please complete A then B or C below

A  When did you first notice this?  d  d  m  m  y  y

OR  Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  2  3  1  2  0  7

OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse

---

Version:- 2.1  08/01/2009
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

Please go to Section 2
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   
   Yes □  Please complete A then B or C below
   No   □  Please go to Question 2

   A When did you first notice this?
   
   □ / □ / □ OR

   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?

   Yes □  Please complete A then B or C below
   No   □  Please go to Question 3

   A When did you first notice this?
   
   □ / □ / □ OR

   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

---

**Please try and describe what the feeling was**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________
________________________________________________________

A When did you first notice this?  [ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR

C Or put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________
________________________________________________________

A When did you first notice this?  [ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR

C Or put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

7. **Were you sent for any of these?**

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy        |     |          |    |
| (Looking at bowel with internal camera) |    |          |    |
| X-ray                               |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

**Please cross one box only**

**White**
- White British
- White Irish
- Other White background

**Mixed**
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

**Black or Black British**
- Carribean
- African
- Other Black background

**Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

**Chinese or other ethnic group**
- Chinese
- Other ethnic group

11. Do you live alone?

Yes  Please go to Question 12
No  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed:   Date   /   /   Time   :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?  

How long did it take the patient to complete the questionnaire?  

Less than 5 minutes  
Between 5 and 10 minutes  
Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?   Yes  No
If yes, 
please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?   Yes  No
If yes, 
please specify which questions and what the difficulty was

Was the patient made anxious?   Yes  No
If yes, 
please give details

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes  No

   Please continue with Question 2

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  Yes  No

Please complete A then B or C below

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| 2 | 3 | 1 | 2 | 0 | 7 |

OR

 Estimate

'3 months ago' or 'June'

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

**A** When did you **first notice** this?

**B** When did you **first tell** your GP or nurse?

**C** Put a cross here if you **didn't tell** your GP or nurse

---

**4. Bleeding from back passage**

Did you have this symptom?

**A** When did you **first notice** this?

**B** When did you **first tell** your GP or nurse?

**C** Put a cross here if you **didn't tell** your GP or nurse

---
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   Yes
   No

   Please complete A then B or C below

   Please go to Question 2

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?

   Yes
   No

   Please complete A then B or C below

   Please go to Question 3

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

____________________________________________________________________
____________________________________________________________________

A When did you first notice this?

[] / [] / [] OR

B When did you first tell your GP or nurse?

[] / [] / [] OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

____________________________________________________________________
____________________________________________________________________

A When did you first notice this?

[] / [] / [] OR

B When did you first tell your GP or nurse?

[] / [] / [] OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.

Version:- 2.1 08/01/2009
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

| 7. Were you sent for any of these? | Yes | Not sure | No |
|-----------------------------------|-----|----------|----|
| Blood test(s)                     |     |          |    |
| CT Scan                           |     |          |    |
| Ultrasound scan                   |     |          |    |
| Barium Enema                      |     |          |    |
| Sigmoidoscopy or colonoscopy      |     |          |    |
| (Looking at bowel with internal camera) | |        |    |
| X-ray                             |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

**Please cross one box only**

- Employed full-time
- Employed part-time
- Self employed full-time
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- Unemployed (seeking work)
- Unemployed (not seeking work)
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- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

**Please cross one box only**

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity
   Please cross one box only

   White
      or
      White British
      White Irish
      Other White background

   Mixed
      or
      White & Black Carribean
      White & Black African
      White & Asian
      Other mixed background

   Black or Black British
      or
      Carribean
      African
      Other Black background

   Asian or Asian British
      or
      Indian
      Pakistani
      Bangladeshi
      Other Asian background

   Chinese or other ethnic group
      or
      Chinese
      Other ethnic group

11. Do you live alone?
   Yes
      Please go to Question 12
   No
      Please say who you live with below

   Who do you live with?
   (e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?
   Please cross any that are applicable to you

   - Asthma
   - Chronic Obstructive Pulmonary Disease (COPD)
   - Other lung disease (e.g. fibrosis, bronchiectasis etc)
   - Heart disease
   - Anxiety or depression
   - Inflammatory bowel disease
   - Irritable bowel syndrome
   - Peptic ulcer
   - Previous cancer
   - Diabetes
   - Arthritis

13. About smoking
   Please cross the appropriate statement

   - Are you a current smoker?
   - Are you an ex-smoker?
   - Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?
   Yes
   No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement              | Not at all | Somewhat | Moderately | Very much |
|------------------------|------------|----------|------------|-----------|
| I feel calm            |            |          |            |           |
| I am tense             |            |          |            |           |
| I feel upset           |            |          |            |           |
| I am relaxed           |            |          |            |           |
| I feel content         |            |          |            |           |
| I am worried           |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Researcher initials: [ ] [ ]

Date questionnaire completed: Date [ ] / [ ] / [ ] Time [ ]:[ ]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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Version: 2.1 08/01/2009 Page 14 of 14
Confidential Questionnaire

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Cardiff University
Chief Investigator, Symptoms Study
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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes  

No  

Please complete A then B or C below

A  When did you first notice this?  

2 3 / 1 2 / 0 7  

OR  

Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  

OR  

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?

   A When did you first notice this?

   B When did you first tell your GP or nurse?

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

4. Feeling different ‘in yourself’ from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________
   ____________________________________________

A  When did you first notice this?  
   / / / OR
B  When did you first tell your GP or nurse?  
   / / / OR
C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________
   ____________________________________________

A  When did you first notice this?  
   / / / OR
B  When did you first tell your GP or nurse?  
   / / / OR
C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

### 7. Were you sent for any of these?

| Test                           | Yes | Not sure | No |
|-------------------------------|-----|----------|----|
| Blood test(s)                 |     |          |    |
| CT Scan                       |     |          |    |
| Ultrasound scan               |     |          |    |
| Barium Enema                  |     |          |    |
| Sigmoidoscopy or colonoscopy  |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                         |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement                  | Not at all | Somewhat | Moderately | Very much |
|----------------------------|------------|----------|------------|-----------|
| 1. I feel calm             |            |          |            |           |
| 2. I am tense              |            |          |            |           |
| 3. I feel upset            |            |          |            |           |
| 4. I am relaxed            |            |          |            |           |
| 5. I feel content          |            |          |            |           |
| 6. I am worried            |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Researcher initials: [ ] [ ]

Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason:

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested

Please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.

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Confidential Questionnaire

Looking At Your Symptoms Study

This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   [ ] Yes  Please continue with Question 2
   [ ] No     Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

---

**Decrease in appetite**

Did you have this symptom?  

[ ] Yes  Please complete A then B or C below

[ ] No  Please go to Section 2

A  When did you first notice this?  

[ ] Estimate  '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  

[ ] Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?
   - Yes
   - No

   Please complete A then B or C below
   Please go to Question 2

   A When did you **first notice** this?
   
   OR

   B When did you **first tell** your GP or nurse?
   
   OR

   C Put a cross here if you didn't **tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?
   - Yes
   - No

   Please complete A then B or C below
   Please go to Question 3

   A When did you **first notice** this?
   
   OR

   B When did you **first tell** your GP or nurse?
   
   OR

   C Put a cross here if you didn't **tell** your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

---

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

---

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________
________________________________________________________________________

A When did you first notice this?

[ ] [ ] [ ] OR

B When did you first tell your GP or nurse?

[ ] [ ] [ ] OR

C Put a cross here if you didn’t tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________
________________________________________________________________________

A When did you first notice this?

[ ] [ ] [ ] OR

B When did you first tell your GP or nurse?

[ ] [ ] [ ] OR

C Put a cross here if you didn’t tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only

   Employed full-time
   Employed part-time
   Self employed full-time
   Self employed part-time
   Unemployed (seeking work)
   Unemployed (not seeking work)
   Retired
   Student
   Permanently sick/disabled
   Temporarily sick/disabled
   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only

   Degree (or equivalent)
   Diploma (or equivalent)
   'A' level
   GCSE / 'O' level
   None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
or
White British
White Irish
Other White background

Mixed
or
White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British
or
Carribean
African
Other Black background

Asian or Asian British
or
Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group
or
Chinese
Other ethnic group

11. Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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- Irritable bowel syndrome
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- Previous cancer
- Diabetes
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13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   |   |   |   |   |
|---|---|---|---|---|
|   | Not at all | Somewhat | Moderately | Very much |
| 1. | I feel calm | □ | □ | □ | □ |
| 2. | I am tense | □ | □ | □ | □ |
| 3. | I feel upset | □ | □ | □ | □ |
| 4. | I am relaxed | □ | □ | □ | □ |
| 5. | I feel content | □ | □ | □ | □ |
| 6. | I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: 

If not completed, give reason:

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? 

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? 

If yes, please specify which questions and what the difficulty was

Was the patient made anxious? 

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Looking At Your Symptoms Study
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below |
|----------------------|-----|------------------------------------|
| Did you have this symptom? | No | Please go to Section 2 |

A  When did you first notice this?  

B  When did you first tell your GP or nurse?  

C  Put a cross here if you didn't tell your GP or nurse  

OR  

Estimate  

'3 months ago' or 'June'  

Estimate
3. **Change in bowel habit**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

**Did you have any of the following?**

1. **Decrease in appetite**
   - Did you have this?
     - Yes
     - No
   - Please complete A then B or C below
   - **Please go to Question 2**
     - A When did you **first notice** this?
     - B When did you **first tell** your GP or nurse?
     - OR
     - C Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**
   - Did you have this?
     - Yes
     - No
   - Please complete A then B or C below
   - **Please go to Question 3**
     - A When did you **first notice** this?
     - B When did you **first tell** your GP or nurse?
     - OR
     - C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

   Did you have this?

   - **A** When did you **first notice** this?
   - **B** When did you **first tell** your GP or nurse?
   - **C** Put a cross here if you didn't tell your GP or nurse

   Please complete A then B or C below

   Please go to Question 4

4. **Feeling different 'in yourself' from usual**

   Did you have this?

   - **A** When did you **first notice** this?
   - **B** When did you **first tell** your GP or nurse?
   - **C** Put a cross here if you didn't tell your GP or nurse

   Please complete A then B or C below

   Please go to Question 5

---

**Please try and describe what the feeling was**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ........................................................................................................................................
........................................................................................................................................

A When did you first notice this? .............................................. OR ..............................................

B When did you first tell your GP or nurse? .............................................. OR ..............................................

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ........................................................................................................................................
........................................................................................................................................

A When did you first notice this? .............................................. OR ..............................................

B When did you first tell your GP or nurse? .............................................. OR ..............................................

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

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Please cross one box only

- Employed full-time
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- Unemployed (not seeking work)
- Retired
- Student
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Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. **How would you describe your ethnicity**

*Please cross one box only*

**White**
- White British
- White Irish
- Other White background

**Mixed**
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

**Black or Black British**
- Carribean
- African
- Other Black background

**Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

**Chinese or other ethnic group**
- Chinese
- Other ethnic group

11. **Do you live alone?**

*Yes*
*No*

*Please go to Question 12*

*Please say who you live with below*

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
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- Irritable bowel syndrome
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Please cross the appropriate statement

- Are you a current smoker?
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14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

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| Statement           | Not at all | Somewhat | Moderately | Very much |
|---------------------|------------|----------|------------|-----------|
| 1. I feel calm      |            |          |            |           |
| 2. I am tense       |            |          |            |           |
| 3. I feel upset     |            |          |            |           |
| 4. I am relaxed     |            |          |            |           |
| 5. I feel content   |            |          |            |           |
| 6. I am worried     |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed:  
Date / Time

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
  Less than 5 minutes
  Between 5 and 10 minutes
  Between 11 and 15 minutes
  Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  
Yes  No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  
Yes  No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  
Yes  No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   - Yes
   - No

   Please continue with Question 2

   OR

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below |
|----------------------|-----|------------------------------------|
|                      | No  | Please go to Section 2             |

A  When did you first notice this?  d d / m m / y y  OR  Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  2 3 / 1 2 / 0 7  OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

Please complete A then B or C below

Please go to Section 2
#### Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   |   |   | Yes | Please complete A then B or C below |
   |---|---|---|-------------------------------------|
   |   |   | No | Please go to Question 2 |

   **A** When did you first notice this?

   **B** When did you first tell your GP or nurse?

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   |   |   | Yes | Please complete A then B or C below |
   |---|---|---|-------------------------------------|
   |   |   | No | Please go to Question 3 |

   **A** When did you first notice this?

   **B** When did you first tell your GP or nurse?

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse? OR
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse? OR
- **C** Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  

   /   /   OR

B When did you first tell your GP or nurse?  

   /   /   OR

   

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  

   /   /   OR

B When did you first tell your GP or nurse?  

   /   /   OR

   

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before your diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

| 7. Were you sent for any of these? | Yes | Not sure | No |
|-----------------------------------|-----|----------|----|
| Blood test(s)                     |     |          |    |
| CT Scan                           |     |          |    |
| Ultrasound scan                   |     |          |    |
| Barium Enema                      |     |          |    |
| Sigmoidoscopy or colonoscopy      |     |          |    |
| (Looking at bowel with internal camera) | |       |    |
| X-ray                             |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Question               | Not at all | Somewhat | Moderately | Very much |
|------------------------|------------|----------|------------|-----------|
| 1. I feel calm         |            |          |            |           |
| 2. I am tense          |            |          |            |           |
| 3. I feel upset        |            |          |            |           |
| 4. I am relaxed        |            |          |            |           |
| 5. I feel content      |            |          |            |           |
| 6. I am worried        |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? Yes No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? Yes No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?  
   Yes  
   No  
   Please continue with Question 2  
   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  
Yes X  
No  
Please complete A then B or C below  
Please go to Section 2

A When did you first notice this?  
B When did you first tell your GP or nurse?  
C Put a cross here if you didn't tell your GP or nurse  

Estimate  
'3 months ago' or 'June'  
Estimate
3. **Change in bowel habit**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   
   Yes [ ] No [ ]
   
   Please complete A then B or C below
   
   Please go to Question 2

   A When did you first notice this?
   
   [ ] / [ ] / [ ] OR

   B When did you first tell your GP or nurse?
   
   [ ] / [ ] / [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   
   Yes [ ] No [ ]
   
   Please complete A then B or C below
   
   Please go to Question 3

   A When did you first notice this?
   
   [ ] / [ ] / [ ] OR

   B When did you first tell your GP or nurse?
   
   [ ] / [ ] / [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________
   ____________________________________________________________
   
   A  When did you first notice this?  OR
   B  When did you first tell your GP or nurse?  OR
   C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________________________
   ____________________________________________________________
   
   A  When did you first notice this?  OR
   B  When did you first tell your GP or nurse?  OR
   C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                         |   |   |   |
|----------------------------------------------|---|---|---|
| Blood test(s)                                |☐ |☐ |☐ |
| CT Scan                                      |☐ |☐ |☐ |
| Ultrasound scan                              |☐ |☐ |☐ |
| Barium Enema                                 |☐ |☐ |☐ |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |☐ |☐ |☐ |
| X-ray                                        |☐ |☐ |☐ |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

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- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☐        | ☐          | ☐         |
| 2. I am tense  | ☐         | ☐        | ☐          | ☐         |
| 3. I feel upset | ☐        | ☐        | ☐          | ☐         |
| 4. I am relaxed | ☐       | ☐        | ☐          | ☐         |
| 5. I feel content | ☐      | ☐        | ☐          | ☐         |
| 6. I am worried | ☐        | ☐        | ☐          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes □
- Between 5 and 10 minutes □
- Between 11 and 15 minutes □
- Longer than 15 minutes □

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? ☐ Yes ☐ No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? ☐ Yes ☐ No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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Yours sincerely

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Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐ Please complete A then B or C below

A  When did you first notice this?  ☐ ☐ / mm / y y OR Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  2 3 / 1 2 / 0 7 OR Estimate

C  Put a cross here if you didn't tell your GP or nurse ☐
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   |   | Yes | Please complete A then B or C below |
   |----|-----|-------------------------------------|
   | No |     |                                     |

   **A** When did you first notice this?

   |   |   |   | OR |
   |---|---|---|----|

   **B** When did you first tell your GP or nurse? OR

   |   |   |   | OR |
   |---|---|---|----|

   **C** Put a cross here if you didn't tell your GP or nurse

   [ ]

2. **Unexplained weight loss**

   Did you have this?

   |   | Yes | Please complete A then B or C below |
   |----|-----|-------------------------------------|
   | No |     |                                     |

   **A** When did you first notice this?

   |   |   |   | OR |
   |---|---|---|----|

   **B** When did you first tell your GP or nurse? OR

   |   |   |   | OR |
   |---|---|---|----|

   **C** Put a cross here if you didn't tell your GP or nurse

   [ ]
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                           | Yes | Not sure | No  |
|------------------------------------------------|-----|----------|-----|
| Blood test(s)                                  |     |          |     |
| CT Scan                                        |     |          |     |
| Ultrasound scan                                |     |          |     |
| Barium Enema                                   |     |          |     |
| Sigmoidoscopy or colonoscopy                    |     |          |     |
| (Looking at bowel with internal camera)        |     |          |     |
| X-ray                                          |     |          |     |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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- Inflammatory bowel disease
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Please cross the appropriate statement

- Are you a current smoker?
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- No
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| Statement         | Not at all | Somewhat | Moderately | Very much |
|-------------------|------------|----------|------------|-----------|
| 1. I feel calm    |            |          |            |           |
| 2. I am tense     |            |          |            |           |
| 3. I feel upset   |            |          |            |           |
| 4. I am relaxed   |            |          |            |           |
| 5. I feel content |            |          |            |           |
| 6. I am worried   |            |          |            |           |

Please make sure you have answered all the questions.
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If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed:   Date   /   /   Time   :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?   Yes   No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?   Yes   No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious?   Yes   No

If yes, please give details

Where did the patient complete the questionnaire?
*(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Confidential Questionnaire

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes [ ] Please continue with Question 2
   No [ ] Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   [ ]

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? [ ] Yes [ ] No

Yes [ ] Please complete A then B or C below
No [ ] Please go to Section 2

A When did you first notice this? [ ]

   OR

   Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

   [ ]

   OR

   Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

   Did you have this symptom?

   **A** When did you *first notice* this?

   **B** When did you *first tell* your GP or nurse?

   **C** Put a cross here if you *didn't tell* your GP or nurse

   Please complete A then B or C below

   Please go to Question 4

---

4. **Bleeding from back passage**

   Did you have this symptom?

   **A** When did you *first notice* this?

   **B** When did you *first tell* your GP or nurse?

   **C** Put a cross here if you *didn't tell* your GP or nurse

   Please complete A then B or C below

   Please go to Section 2
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - **A** When did you first notice this?
   - **B** When did you first tell your GP or nurse?
   - **OR**
   - **C** Put a cross here if you didn't tell your GP or nurse

   - Please complete A then B or C below
   - Please go to Question 2

   OR

2. **Unexplained weight loss**

   Did you have this?

   - **A** When did you first notice this?
   - **B** When did you first tell your GP or nurse?
   - **OR**
   - **C** Put a cross here if you didn't tell your GP or nurse

   - Please complete A then B or C below
   - Please go to Question 3
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes [ ]  Please complete A then B or C below
No [ ]  Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes [ ]  Please complete A then B or C below
No [ ]  Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

______________________________

______________________________

A When did you first notice this?

______________________________

______________________________

OR

B When did you first tell your GP or nurse?

______________________________

______________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

______________________________

______________________________

A When did you first notice this?

______________________________

______________________________

OR

B When did you first tell your GP or nurse?

______________________________

______________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | | | |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White

or

White British
White Irish
Other White background

Mixed

or

White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British

or

Carribean
African
Other Black background

Asian or Asian British

or

Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group

or

Chinese
Other ethnic group

11. Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | [ ] | [ ] | [ ] | [ ] |
| 2. I am tense | [ ] | [ ] | [ ] | [ ] |
| 3. I feel upset | [ ] | [ ] | [ ] | [ ] |
| 4. I am relaxed | [ ] | [ ] | [ ] | [ ] |
| 5. I feel content | [ ] | [ ] | [ ] | [ ] |
| 6. I am worried | [ ] | [ ] | [ ] | [ ] |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason: [ ]

How long is it since the patient was told of his/her diagnosis?: [ ]

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes: [ ]
- Between 5 and 10 minutes: [ ]
- Between 11 and 15 minutes: [ ]
- Longer than 15 minutes: [ ]

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested:
________________________________________________________________________
________________________________________________________________________

Please specify what help was given:
________________________________________________________________________
________________________________________________________________________

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)
________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK

Version: 2.1 08/01/2009  Page 1 of 14
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite                   | Yes | Please complete A then B or C below |
|----------------------------------------|-----|-----------------------------------|
| Did you have this symptom?            |     |                                   |

Please complete A then B or C below

A When did you first notice this? d d m m y y

B When did you first tell your GP or nurse? 2 3 1 2 0 7

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

   Did you have this symptom?
   
   **A** When did you first notice this?
   **B** When did you first tell your GP or nurse?
   **C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

   Did you have this symptom?
   
   **A** When did you first notice this?
   **B** When did you first tell your GP or nurse?
   **C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

[]

2. Unexplained weight loss

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

[]
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________
   __________________________________________

A When did you first notice this?  [ ] [ ] [ ] OR

B When did you first tell your GP or nurse?  [ ] [ ] [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________
   __________________________________________

A When did you first notice this?  [ ] [ ] [ ] OR

B When did you first tell your GP or nurse?  [ ] [ ] [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7.  Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | | | |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

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Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
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- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes  Please go to Question 12
No  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement                | Not at all | Somewhat | Moderately | Very much |
|--------------------------|------------|----------|------------|-----------|
| 1. I feel calm           |            | ❑        |            | ❑         |
| 2. I am tense            | ❑          |          | ❑          | ❑         |
| 3. I feel upset          | ❑          | ❑        | ❑          | ❑         |
| 4. I am relaxed          | ❑          | ❑        | ❑          | ❑         |
| 5. I feel content        | ❑          | ❑        | ❑          | ❑         |
| 6. I am worried          | ❑          | ❑        | ❑          | ❑         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: ____________________________

Date ______ / ______ / ______ Time ______:____

If not completed, give reason: ______________________________________________________

How long is it since the patient was told of his/her diagnosis? ___________________________

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes ☐
- Between 5 and 10 minutes ☐
- Between 11 and 15 minutes ☐
- Longer than 15 minutes ☐

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? ☐ Yes ☐ No

If yes, please specify what help was requested:
________________________________________________________________________________
________________________________________________________________________________

please specify what help was given:
________________________________________________________________________________
________________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? ☐ Yes ☐ No

If yes, please specify which questions and what the difficulty was:
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Was the patient made anxious? ☐ Yes ☐ No

If yes, please give details:
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other
________________________________________________________________________________

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Looking At Your Symptoms Study
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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

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Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below | No |
|----------------------|-----|------------------------------------|----|
| Did you have this symptom? | ☒ | | |
| Please go to Question 3 |

A When did you first notice this? [dd/mm/yyyy]

OR

B When did you first tell your GP or nurse? [dd/mm/yyyy]

OR

C Put a cross here if you didn't tell your GP or nurse

Please go to Section 2 on Page 5
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Yes

No

Please complete A then B or C below

Please go to Question 4

Please complete A then B or C below

Please go to Section 2
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?
   
   Yes ☐  Please complete A then B or C below
   
   No ☐  Please go to Question 2
   
   A  When did you **first notice** this?
   
   B  When did you **first tell** your GP or nurse?  
   OR
   
   C  Put a cross here if you **didn't tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?
   
   Yes ☐  Please complete A then B or C below
   
   No ☐  Please go to Question 3
   
   A  When did you **first notice** this?
   
   B  When did you **first tell** your GP or nurse?  
   OR
   
   C  Put a cross here if you **didn't tell** your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

| Question | Description |
|----------|-------------|
| 5.       |             |

A. When did you first notice this?  
   OR  
B. When did you first tell your GP or nurse?  
   OR  
C. Put a cross here if you didn’t tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

| Question | Description |
|----------|-------------|
| 6.       |             |

A. When did you first notice this?  
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   OR  
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Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                         | Yes | Not sure | No |
|----------------------------------------------|-----|----------|----|
| Blood test(s)                                |     |          |    |
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| Ultrasound scan                              |     |          |    |
| Barium Enema                                 |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                        |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home
   - Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None
   - Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes
- Please go to Question 12

No
- Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

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Please cross the appropriate statement

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No
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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm |   |   |   |   |
| 2. I am tense |   |   |   |   |
| 3. I feel upset |   |   |   |   |
| 4. I am relaxed |   |   |   |   |
| 5. I feel content |   |   |   |   |
| 6. I am worried |   |   |   |   |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: ________________________________ Date __________ / __________ / ________ Time __________:__________

If not completed, give reason: __________________________________________________________

How long is it since the patient was told of his/her diagnosis? ________________________________

How long did it take the patient to complete the questionnaire?

Less than 5 minutes [ ]
Between 5 and 10 minutes [ ]
Between 11 and 15 minutes [ ]
Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No

If yes, please specify what help was requested: ____________________________________________

please specify what help was given: ____________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No

If yes, please specify which questions and what the difficulty was: _________________________

__________________________

__________________________

Was the patient made anxious? [ ] Yes [ ] No

If yes, please give details: ____________________________________________________________

__________________________

__________________________

__________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

__________________________________________________________________________________

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These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes ☐  No ☐

   Please continue with Question 2

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom? ☒

Yes ☐  No ☐

Please complete A then B or C below

Please go to Section 2

A  When did you first notice this?  d  d / m  m / y  y  OR  Estimate

   '3 months ago' or 'June'

B  When did you first tell your GP or nurse?

   2  3 / 1 2 / 0 7  OR  Estimate

OR

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse? **OR**

C  Put a cross here if you **didn’t tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse? **OR**

C  Put a cross here if you **didn’t tell** your GP or nurse

---

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Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - **Yes**
     - Please complete A then B or C below
   - **No**
     - Please go to Question 2

   **A** When did you **first notice** this?
   
   **B** When did you **first tell** your GP or nurse?
   
   **OR**
   
   **C** Put a cross here if you **didn't tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   - **Yes**
     - Please complete A then B or C below
   - **No**
     - Please go to Question 3

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________
__________________________________________________________
__________________________________________________________
__________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________
   ____________________________________________

A  When did you first notice this?  
   [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?  
   [ ] / [ ] / [ ] OR

OR

C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________
   ____________________________________________

A  When did you first notice this?  
   [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?  
   [ ] / [ ] / [ ] OR

OR

C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

**Please cross any that are applicable to you**

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. **About smoking**

**Please cross the appropriate statement**

- Are you a current smoker?  
- Are you an ex-smoker?  
- Are you a non-smoker (never smoked)?

14. **Do you think you were more at risk of getting cancer because of your family history?**

Yes  
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement       | Not at all | Somewhat | Moderately | Very much |
|-----------------|------------|----------|------------|-----------|
| 1. I feel calm  |            |           |            |           |
| 2. I am tense   |            |           |            |           |
| 3. I feel upset |            |           |            |           |
| 4. I am relaxed |            |           |            |           |
| 5. I feel content |          |           |            |           |
| 6. I am worried |            |           |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? Yes No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? Yes No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No

If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes  No

   Please continue with Question 2  Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  Yes  No

Please complete A then B or C below

A When did you first notice this?  OR

B When did you first tell your GP or nurse?  OR

C Put a cross here if you didn't tell your GP or nurse

Please go to Section 2

Estimate '3 months ago' or 'June'

Estimate
3. **Change in bowel habit**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

---

Please complete A then B or C below

Please go to Question 4

Please complete A then B or C below

Please go to Section 2
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   [ ] Yes  [ ] No

   Please complete A then B or C below

   A When did you first notice this?
   [ ] / [ ] / [ ] OR

   B When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   [ ] Yes  [ ] No

   Please complete A then B or C below

   A When did you first notice this?
   [ ] / [ ] / [ ] OR

   B When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

   OR

   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?  

B When did you first tell your GP or nurse?  

C OR Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 5

A When did you first notice this?  

B When did you first tell your GP or nurse?  

C OR Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

__________________________________________________________________________
__________________________________________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

__________________________________________________________________________
__________________________________________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

|                          | Yes | Not sure | No |
|--------------------------|-----|----------|----|
| Blood test(s)            |     |          |    |
| CT Scan                  |     |          |    |
| Ultrasound scan          |     |          |    |
| Barium Enema             |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                    |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   
   Please cross one box only

   - Employed full-time
   - Employed part-time
   - Self employed full-time
   - Self employed part-time
   - Unemployed (seeking work)
   - Unemployed (not seeking work)
   - Retired
   - Student
   - Permanently sick/disabled
   - Temporarily sick/disabled
   - Looking after family/home

   Other, please describe

9. What is your highest level of qualification?

   Please cross one box only

   - Degree (or equivalent)
   - Diploma (or equivalent)
   - 'A' level
   - GCSE / 'O' level
   - None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes  Please go to Question 12
No  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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- Inflammatory bowel disease
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- Previous cancer
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13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked?)

14. Do you think you were more at risk of getting cancer because of your family history?

Yes ☐ No ☐
15. The following questions are about how completing the questionnaire made you feel.

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|-------------------------|------------|----------|------------|-----------|
| 1. I feel calm          |            |          |            |           |
| 2. I am tense           |            |          |            |           |
| 3. I feel upset         |            |          |            |           |
| 4. I am relaxed         |            |          |            |           |
| 5. I feel content       |            |          |            |           |
| 6. I am worried         |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [Date] / [Date] / [Date] Time [Time]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  [Yes] [No]
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  [Yes] [No]
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  [Yes] [No]
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes
   No

   Please continue with Question 2

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?

Yes
   No

   Please complete A then B or C below

   Please go to Section 2

A When did you first notice this?

   d d / m m / y y

   OR

   Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

   2 3 / 1 2 / 0 7

   OR

   Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   
   Yes  No
   Please complete A then B or C below
   Please go to Question 2

   A When did you first notice this?
   OR
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?
   
   Yes  No
   Please complete A then B or C below
   Please go to Question 3

   A When did you first notice this?
   OR
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please go to Question 4

Please complete A then B or C below

Please complete A then B or C below

Please go to Question 5
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________
   ____________________________________________

A When did you first notice this?                        OR
   □ □ □ / □ □ □ / □ □ □ 

B When did you first tell your GP or nurse?             OR
   □ □ □ / □ □ □ / □ □ □ 

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________
   ____________________________________________

A When did you first notice this?                        OR
   □ □ □ / □ □ □ / □ □ □ 

B When did you first tell your GP or nurse?             OR
   □ □ □ / □ □ □ / □ □ □ 

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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| Test                                      | Yes | Not sure | No |
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| CT Scan                                   |     |          |    |
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| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
|   (Looking at bowel with internal camera) |     |          |    |
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- Unemployed (not seeking work)
- Retired
- Student
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- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?
Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
   or
   White British
   White Irish
   Other White background

Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

Black or Black British
   or
   Carribean
   African
   Other Black background

Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?

Yes
   Please go to Question 12
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   Please say who you live with below

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Please cross the appropriate statement

- Are you a current smoker?
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[ ] No
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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐ | ☐ | ☐ | ☐ |
| 2. I am tense | ☐ | ☐ | ☐ | ☐ |
| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

Please make sure you have answered all the questions.
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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
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- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? Yes No

If yes, please specify what help was requested

_________________________________________________________________________

please specify what help was given

_________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? Yes No

If yes, please specify which questions and what the difficulty was

_________________________________________________________________________

_________________________________________________________________________

Was the patient made anxious? Yes No

If yes, please give details

_________________________________________________________________________

_________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   [ ] Yes
   [ ] No

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?



Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom? [ ] Yes [ ] No

Please complete A then B or C below

A When did you first notice this? [d] [d] [m] [m] [y] [y] OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? [2] [3] [1] [2] [0] [7] OR Estimate

OR

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

### 1. Decrease in appetite

Did you have this?

- **[ ] Yes**  
- **[ ] No**

Please complete A then B or C below

**A** When did you **first notice** this?

[ ] / [ ] / [ ] OR

**B** When did you **first tell** your GP or nurse?

[ ] / [ ] / [ ] OR

**OR**

**C** Put a cross here if you didn't **tell** your GP or nurse

### 2. Unexplained weight loss

Did you have this?

- **[ ] Yes**  
- **[ ] No**

Please complete A then B or C below

**A** When did you **first notice** this?

[ ] / [ ] / [ ] OR

**B** When did you **first tell** your GP or nurse?

[ ] / [ ] / [ ] OR

**OR**

**C** Put a cross here if you didn't **tell** your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

---

**Please try and describe what the feeling was**

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________
______________________________
______________________________

A When did you first notice this?  
______________________________  OR  
______________________________

B When did you first tell your GP or nurse?  
______________________________  OR  
______________________________

C Put a cross here if you didn't tell your GP or nurse
[ ]

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________
______________________________
______________________________

A When did you first notice this?  
______________________________  OR  
______________________________

B When did you first tell your GP or nurse?  
______________________________  OR  
______________________________

C Put a cross here if you didn't tell your GP or nurse
[ ]

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

### 7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

**Please cross one box only**

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

**Please go to Question 12**

Yes

No

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. | I feel calm | ☐        | ☐          | ☐         | ☐         |
| 2. | I am tense | ☐        | ☐          | ☐         | ☐         |
| 3. | I feel upset | ☐      | ☐          | ☐         | ☐         |
| 4. | I am relaxed | ☐      | ☐          | ☐         | ☐         |
| 5. | I feel content | ☐    | ☐          | ☐         | ☐         |
| 6. | I am worried | ☐       | ☐          | ☐         | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [ ] / [ ] / [ ] Time [ ]:

If not completed, give reason:

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

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Yours sincerely

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Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes No

Please complete A then B or C below

Please go to Section 2

A When did you first notice this? OR

Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? OR

Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?
   [ ] Yes  [ ] No
   Please complete A then B or C below
   Please go to Question 2

   A When did you first notice this?
   [ ] / [ ] / [ ] OR [ ]

   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse
   [ ]

2. Unexplained weight loss

   Did you have this?
   [ ] Yes  [ ] No
   Please complete A then B or C below
   Please go to Question 3

   A When did you first notice this?
   [ ] / [ ] / [ ] OR [ ]

   B When did you first tell your GP or nurse?
   OR

   C Put a cross here if you didn't tell your GP or nurse
   [ ]
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________
   ____________________________________________________________

A When did you first notice this?  
   [] / [] / [] OR ___________________________________________________________________

B When did you first tell your GP or nurse?  
   [] / [] / [] OR ___________________________________________________________________

C Put a cross here if you didn't tell your GP or nurse
   [x]

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

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6. ____________________________________________________________
   ____________________________________________________________

A When did you first notice this?  
   [] / [] / [] OR ___________________________________________________________________

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   [] / [] / [] OR ___________________________________________________________________

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If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

### 7. Were you sent for any of these?

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy        |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                               |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

   Please cross one box only

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   Employed part-time
   Self employed full-time
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   Unemployed (seeking work)
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   Student
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   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?

   Please cross one box only

   Degree (or equivalent)
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   Other, please specify
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Please cross one box only

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11. Do you live alone?

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Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
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- Anxiety or depression
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Please cross the appropriate statement

- Are you a current smoker?
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| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / Time

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
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- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  Yes  No
If yes,
please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  Yes  No
If yes,
please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No
If yes,
please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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About your symptoms

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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes ☐ No ☐

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes ☐ No ☐

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

OR

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ___________________________________________________________  ___________________________________________________________

A  When did you first notice this?  

B  When did you first tell your GP or nurse?  

C  Put a cross here if you didn't tell your GP or nurse

_________________________  ____________________________  ____________________________

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Please describe the symptom here and complete A then B or C below

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A  When did you first notice this?  

B  When did you first tell your GP or nurse?  

C  Put a cross here if you didn't tell your GP or nurse

_________________________  ____________________________  ____________________________

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                              | Yes | Not sure | No |
|---------------------------------------------------|-----|---------|----|
| Blood test(s)                                     |     |         |    |
| CT Scan                                           |     |         |    |
| Ultrasound scan                                   |     |         |    |
| Barium Enema                                      |     |         |    |
| Sigmoidoscopy or colonoscopy                      |     |         |    |
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| X-ray                                             |     |         |    |

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   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   
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  or
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  African
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Chinese or other ethnic group
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No

Please go to Question 12

Please say who you live with below

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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐ | ☐ | ☐ | ☐ |
| 2. I am tense | ☐ | ☐ | ☐ | ☐ |
| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

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Date questionnaire completed: Date / Time

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- Between 5 and 10 minutes
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Did the patient ask for any help? Yes No

If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? Yes No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes ☐

   No ☐

   Please continue with Question 2

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite |
|----------------------|
| Did you have this symptom? | Yes ☒ |
| No ☐ | Please complete A then B or C below |
| Please go to Section 2 |

A  When did you first notice this?  
   day / month / year OR  
   Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  
   day / month / year OR  
   Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes □ No □

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes □ No □

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.  

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  

[ ] [ ] [ ] OR

B When did you first tell your GP or nurse?  

[ ] [ ] [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.  

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  

[ ] [ ] [ ] OR

B When did you first tell your GP or nurse?  

[ ] [ ] [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. **Were you sent for any of these?**

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                               |     |          |    |

Please go to Question 8
The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes
- Please go to Question 12

No
- Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes   No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|                      | Not at all | Somewhat | Moderately | Very much |
|----------------------|------------|----------|------------|-----------|
| 1. I feel calm        |           |          |            |           |
| 2. I am tense         |           |          |            |           |
| 3. I feel upset       |           |          |            |           |
| 4. I am relaxed       |           |          |            |           |
| 5. I feel content     |           |          |            |           |
| 6. I am worried       |           |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time : :
If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? Yes No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? Yes No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom? [ ] Yes [ ] No

Please complete A then B or C below

A  When did you first notice this? [d] [d] / [m] / [y] OR Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse? [2] [3] / [1] [2] / [0] [7] OR Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

OR

C Put a cross here if you **didn't tell** your GP or nurse

---

4. **Bleeding from back passage**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

OR

C Put a cross here if you **didn't tell** your GP or nurse

---
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   Yes
   No

   Please complete A then B or C below

   Please go to Question 2

   A  When did you **first notice** this?

   B  When did you **first tell** your GP or nurse?

   OR

   C  Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

   Did you have this?

   Yes
   No

   Please complete A then B or C below

   Please go to Question 3

   A  When did you **first notice** this?

   B  When did you **first tell** your GP or nurse?

   OR

   C  Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________

   ____________________________________________

A When did you first notice this?

   / / OR

B When did you first tell your GP or nurse?

   / / OR

   OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________

   ____________________________________________

A When did you first notice this?

   / / OR

B When did you first tell your GP or nurse?

   / / OR

   OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

|                             | Yes | Not sure | No |
|-----------------------------|-----|----------|----|
| Blood test(s)               |     |          |    |
| CT Scan                     |     |          |    |
| Ultrasound scan             |     |          |    |
| Barium Enema                |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                       |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

**Please cross one box only**

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

**Please cross one box only**

- Degree (or equivalent)
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Other, please specify
10. How would you describe your ethnicity

Please cross one box only

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  or
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  White & Black African
  White & Asian
  Other mixed background

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Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

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- Previous cancer
- Diabetes
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Please cross the appropriate statement

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14. Do you think you were more at risk of getting cancer because of your family history?

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No
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| Number | Statement             | Not at all | Somewhat | Moderately | Very much |
|--------|-----------------------|------------|----------|------------|-----------|
| 1.     | I feel calm           |            |          |            |           |
| 2.     | I am tense            |            |          |            |           |
| 3.     | I feel upset          |            |          |            |           |
| 4.     | I am relaxed          |            |          |            |           |
| 5.     | I feel content        |            |          |            |           |
| 6.     | I am worried          |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

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Date questionnaire completed:  
If not completed, give reason:  
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Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own  
Did the patient ask for any help?  
Yes  
No  
If yes, please specify what help was requested  

please specify what help was given  

For the patient selected for the researcher-administered questionnaire  
Did the patient find any of the questions difficult?  
Yes  
No  
If yes, please specify which questions and what the difficulty was  



Was the patient made anxious?  
Yes  
No  
If yes, please give details  

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other  


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About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes
   No

   Please continue with Question 2
   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example, approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom?  

Yes  
No

Please complete A then B or C below

**A** When did you first notice this?  
\[ \text{d} \text{d} / \text{m} \text{m} / \text{y} \text{y} \]  
OR  
Estimate  
'3 months ago' or 'June'

**B** When did you first tell your GP or nurse?  
\[ 23 / 12 / 07 \]  
OR  
Estimate

**C** Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

4. **Bleeding from back passage**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes

No

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes

No

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

___________________________________________________________________________
___________________________________________________________________________

A When did you first notice this? __________ / __________ / __________ OR __________

B When did you first tell your GP or nurse? __________ / __________ / __________ OR __________

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

___________________________________________________________________________
___________________________________________________________________________

A When did you first notice this? __________ / __________ / __________ OR __________

B When did you first tell your GP or nurse? __________ / __________ / __________ OR __________

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   
   Employed full-time
   Employed part-time
   Self employed full-time
   Self employed part-time
   Unemployed (seeking work)
   Unemployed (not seeking work)
   Retired
   Student
   Permanently sick/disabled
   Temporarily sick/disabled
   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
   
   Degree (or equivalent)
   Diploma (or equivalent)
   'A' level
   GCSE / 'O' level
   None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White

or

White British
White Irish
Other White background

Mixed

or

White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British

or

Carribean
African
Other Black background

Asian or Asian British

or

Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group

or

Chinese
Other ethnic group

11. Do you live alone?

Yes

Please go to Question 12

No

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?  
**Please cross any that are applicable to you**

Asthma  
Chronic Obstructive Pulmonary Disease (COPD)  
Other lung disease (e.g. fibrosis, bronchiectasis etc)  
Heart disease  
Anxiety or depression  
Inflammatory bowel disease  
Irritable bowel syndrome  
Peptic ulcer  
Previous cancer  
Diabetes  
Arthritis

13. About smoking  
**Please cross the appropriate statement**

Are you a current smoker?  
Are you an ex-smoker?  
Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □         | □        | □          | □         |
| 2. I am tense  | □         | □        | □          | □         |
| 3. I feel upset | □         | □        | □          | □         |
| 4. I am relaxed | □         | □        | □          | □         |
| 5. I feel content | □         | □        | □          | □         |
| 6. I am worried | □         | □        | □          | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  Yes  No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  Yes  No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious?  Yes  No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.

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Confidential Questionnaire

Looking At Your Symptoms Study

This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decay in appetite

Did you have this symptom?

Yes [X]  Please complete A then B or C below

No  Please go to Section 2

A When did you first notice this?  d d  m m  y y  OR  Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

2 3  1 2  0 7  OR  Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite
   
   Did you have this?
   
   Please complete A then B or C below
   
   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   
   OR
   
   C Put a cross here if you didn't tell your GP or nurse
   
   Please go to Question 2

2. Unexplained weight loss
   
   Did you have this?
   
   Please complete A then B or C below
   
   A When did you first notice this?
   
   B When did you first tell your GP or nurse?
   
   OR
   
   C Put a cross here if you didn't tell your GP or nurse
   
   Please go to Question 3
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

________________________________________________________________________

________________________________________________________________________

A When did you **first notice** this?  

B When did you **first tell** your GP or nurse?  

C Put a cross here if you **didn't tell** your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

________________________________________________________________________

________________________________________________________________________

A When did you **first notice** this?  

B When did you **first tell** your GP or nurse?  

C Put a cross here if you **didn't tell** your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did yourGP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                          | Yes | Not sure | No |
|-------------------------------|-----|----------|----|
| Blood test(s)                 |     |          |    |
| CT Scan                       |     |          |    |
| Ultrasound scan               |     |          |    |
| Barium Enema                  |     |          |    |
| Sigmoidoscopy or colonoscopy  |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                         |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel **right now, at the moment**. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement          | Not at all | Somewhat | Moderately | Very much |
|--------------------|------------|----------|------------|-----------|
| 1. I feel calm     |            |          |            |           |
| 2. I am tense      |            |          |            |           |
| 3. I feel upset    |            |          |            |           |
| 4. I am relaxed    |            |          |            |           |
| 5. I feel content  |            |          |            |           |
| 6. I am worried    |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: 
If not completed, give reason: 
How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own:
Did the patient ask for any help? 
Yes  No
If yes, please specify what help was requested:

please specify what help was given:

For the patient selected for the researcher-administered questionnaire:
Did the patient find any of the questions difficult? 
Yes  No
If yes, please specify which questions and what the difficulty was:

Was the patient made anxious? 
Yes  No
If yes, please give details:

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?  
   - Yes  
   - No

   Please continue with Question 2

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

- Yes
- No

Please complete A then B or C below

A When did you first notice this?  

OR

B When did you first tell your GP or nurse?  

23/12/07

OR

C Put a cross here if you didn’t tell your GP or nurse

Please go to Section 2
3. **Change in bowel habit**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse?

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

---

**Please try and describe what the feeling was**

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________
________________________________________________________________________

A  When did you first notice this?  

☐ / ☐ / ☐ OR

B  When did you first tell your GP or nurse?  

☐ / ☐ / ☐ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________
________________________________________________________________________

A  When did you first notice this?  

☐ / ☐ / ☐ OR

B  When did you first tell your GP or nurse?  

☐ / ☐ / ☐ OR

OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

7. **Were you sent for any of these?**

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | |          |    |
| X-ray                                     |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
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9. What is your highest level of qualification?

Please cross one box only

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- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

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|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: __________ / __________ / __________ Time __________:__

If not completed, give reason: ____________________________________________________________

How long is it since the patient was told of his/her diagnosis? ____________________________________

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes  ☐
- Between 5 and 10 minutes ☐
- Between 11 and 15 minutes ☐
- Longer than 15 minutes ☐

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? ☐ Yes ☐ No
If yes, please specify what help was requested
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

please specify what help was given
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? ☐ Yes ☐ No
If yes, please specify which questions and what the difficulty was
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

Was the patient made anxious? ☐ Yes ☐ No
If yes, please give details
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes ☒  Please complete A then B or C below

No ☐  Please go to Section 2

A When did you first notice this?  

B When did you first tell your GP or nurse?  

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

|   | A | B | C |
|---|---|---|---|
| Yes |  |  |  |
| No |  |  |  |

Please complete A then B or C below

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

|   | A | B | C |
|---|---|---|---|
| Yes |  |  |  |
| No |  |  |  |

Please complete A then B or C below

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes ☐  Please complete A then B or C below

No ☐  Please go to Question 2

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes ☐  Please complete A then B or C below

No ☐  Please go to Question 3

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you *didn't tell* your GP or nurse

[ ] Yes **Please complete A then B or C below**

[ ] No **Please go to Question 4**

**OR**

[ ] / [ ] / [ ] OR

[ ] / [ ] / [ ] OR


4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you *first notice* this?
- **B** When did you *first tell* your GP or nurse?
- **C** Put a cross here if you *didn't tell* your GP or nurse

[ ] Yes **Please complete A then B or C below**

[ ] No **Please go to Question 5**

**OR**

[ ] / [ ] / [ ] OR

[ ] / [ ] / [ ] OR


Please try and describe what the feeling was

____________________________________

____________________________________

____________________________________

____________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?
   [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?
   [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

7. **Were you sent for any of these?**

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
or
  White British
  White Irish
  Other White background

Mixed
or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
or
  Carribean
  African
  Other Black background

Asian or Asian British
or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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- Other lung disease (e.g. fibrosis, bronchiectasis etc)
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- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
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|                      | Not at all | Somewhat | Moderately | Very much |
|----------------------|------------|----------|------------|-----------|
| 1. I feel calm        |            |          |            |           |
| 2. I am tense         |            |          |            |           |
| 3. I feel upset       |            |          |            |           |
| 4. I am relaxed       |            |          |            |           |
| 5. I feel content     |            |          |            |           |
| 6. I am worried       |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: [ ] / [ ] / [ ] Time [ ]: [ ]

If not completed, give reason: [ ]

How long is it since the patient was told of his/her diagnosis?: [ ]

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own:
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested:
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

please specify what help was given:
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

For the patient selected for the researcher-administered questionnaire:
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was:
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details:
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)
_________________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
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Dear Patient

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I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?  OR

C  Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?  OR

C  Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

- [ ] Yes  Please complete A then B or C below
- [ ] No  Please go to Question 2

|   |   |   | OR |   |
|---|---|---|----|---|
| A | When did you first notice this? |   |    |   |
| B | When did you first tell your GP or nurse? |   |    |   |
| OR |   |   |    |   |
| C | Put a cross here if you didn't tell your GP or nurse |   |    |   |

2. Unexplained weight loss

Did you have this?

- [ ] Yes  Please complete A then B or C below
- [ ] No  Please go to Question 3

|   |   |   | OR |   |
|---|---|---|----|---|
| A | When did you first notice this? |   |    |   |
| B | When did you first tell your GP or nurse? |   |    |   |
| OR |   |   |    |   |
| C | Put a cross here if you didn't tell your GP or nurse |   |    |   |
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?  

   /  /  OR

B  When did you first tell your GP or nurse?  

   /  /  OR

OR

C  Put a cross here if you didn't tell your GP or nurse


If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

________________________________________________________________________

________________________________________________________________________

A  When did you first notice this?  

   /  /  OR

B  When did you first tell your GP or nurse?  

   /  /  OR

OR

C  Put a cross here if you didn't tell your GP or nurse


If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. **Were you sent for any of these?**

| Test                                    | Yes | Not sure | No |
|-----------------------------------------|-----|----------|----|
| Blood test(s)                           |     |          |    |
| CT Scan                                 |     |          |    |
| Ultrasound scan                         |     |          |    |
| Barium Enema                            |     |          |    |
| Sigmoidoscopy or colonoscopy            |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                                   |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □         | □        | □          | □         |
| 2. I am tense   | □         | □        | □          | □         |
| 3. I feel upset | □         | □        | □          | □         |
| 4. I am relaxed | □         | □        | □          | □         |
| 5. I feel content | □       | □        | □          | □         |
| 6. I am worried | □         | □        | □          | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Date questionnaire completed:  

If not completed, give reason  

How long is it since the patient was told of his/her diagnosis?  

How long did it take the patient to complete the questionnaire?  

Less than 5 minutes  
Between 5 and 10 minutes  
Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own  
Did the patient ask for any help?  
Yes  No  
If yes, please specify what help was requested  

please specify what help was given  

For the patient selected for the researcher-administered questionnaire  
Did the patient find any of the questions difficult?  
Yes  No  
If yes, please specify which questions and what the difficulty was  

Was the patient made anxious?  
Yes  No  
If yes, please give details  

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other  

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About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

  Yes  No

  Please continue with Question 2

  Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom? Yes ☒ No

Please complete A then B or C below

A When did you first notice this? d d m m y

Estimate: '3 months ago' or 'June'

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

C. Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

C. Put a cross here if you didn't tell your GP or nurse

Yes

No

Please complete A then B or C below

Please go to Question 4

Please complete A then B or C below

Please go to Section 2
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

- Yes
- No

Please complete A then B or C below

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

- Yes
- No

Please complete A then B or C below

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

4. Feeling different ‘in yourself’ from usual

Did you have this?

Yes ☐  Please complete A then B or C below
No ☐  Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn’t tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  OR
B  When did you first tell your GP or nurse?  OR
C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  OR
B  When did you first tell your GP or nurse?  OR
C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. **Were you sent for any of these?**

| Test                                | Yes | Not sure | No  |
|-------------------------------------|-----|----------|-----|
| Blood test(s)                       |     |          |     |
| CT Scan                             |     |          |     |
| Ultrasound scan                     |     |          |     |
| Barium Enema                        |     |          |     |
| Sigmoidoscopy or colonoscopy        |     |          |     |
| (Looking at bowel with internal camera) |     |          |     |
| X-ray                               |     |          |     |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify

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10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes

Please go to Question 12

No

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?
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A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement         | Not at all | Somewhat | Moderately | Very much |
|-------------------|------------|----------|------------|-----------|
| I feel calm       |            |          |            |           |
| I am tense        |            |          |            |           |
| I feel upset      |            |          |            |           |
| I am relaxed      |            |          |            |           |
| I feel content    |            |          |            |           |
| I am worried      |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet  
Researcher initials:  

Date questionnaire completed:  

If not completed, give reason  

How long is it since the patient was told of his/her diagnosis?  

How long did it take the patient to complete the questionnaire?  
Less than 5 minutes  
Between 5 and 10 minutes  
Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own  
Did the patient ask for any help?  
Yes  
No  

If yes,  
please specify what help was requested  

______________________________  

Please specify what help was given  

______________________________  

For the patient selected for the researcher-administered questionnaire  
Did the patient find any of the questions difficult?  
Yes  
No  

If yes,  
please specify which questions and what the difficulty was  

______________________________  

______________________________  

Was the patient made anxious?  
Yes  
No  

If yes,  
please give details  

______________________________  

______________________________  

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other  

______________________________  

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

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Cardiff University
Chief Investigator, Symptoms Study
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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes  

No  

Please complete A then B or C below

Please go to Section 2

A  When did you first notice this?  

OR

B  When did you first tell your GP or nurse?  

OR

C  Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite
   Did you have this?
   Yes  No

   Please complete A then B or C below

   Please go to Question 2

   A When did you first notice this?
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss
   Did you have this?
   Yes  No

   Please complete A then B or C below

   Please go to Question 3

   A When did you first notice this?
   B When did you first tell your GP or nurse?
   OR
   C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  
B When did you first tell your GP or nurse?  
C Put a cross here if you didn't tell your GP or nurse

OR

OR

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  
B When did you first tell your GP or nurse?  
C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

### 7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
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Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

Degree (or equivalent)
Diploma (or equivalent)
'A' level
GCSE / 'O' level
None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
    White British
    White Irish
    Other White background

Mixed
  or
    White & Black Carribean
    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
    Carribean
    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
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Please cross any that are applicable to you

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- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

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Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|                                           | Not at all | Somewhat | Moderately | Very much |
|-------------------------------------------|-----------|----------|------------|-----------|
| 1. I feel calm                             |           |          |            |           |
| 2. I am tense                              |           |          |            |           |
| 3. I feel upset                            |           |          |            |           |
| 4. I am relaxed                            |           |          |            |           |
| 5. I feel content                          |           |          |            |           |
| 6. I am worried                            |           |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time : 

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
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- Between 11 and 15 minutes  
- Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  
- Yes  
- No  

If yes, please specify what help was requested

______________________________________________

Please specify what help was given

______________________________________________

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  
- Yes  
- No  

If yes, please specify which questions and what the difficulty was

______________________________________________

______________________________________________

Was the patient made anxious?  
- Yes  
- No  

If yes, please give details

______________________________________________

______________________________________________

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Looking At Your Symptoms Study
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Yours sincerely

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Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No

Please complete A then B or C below

A When did you first notice this? d d m m y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

- **A** When did you **first notice** this?

- **B** When did you **first tell** your GP or nurse?

- **C** Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

- **A** When did you **first notice** this?

- **B** When did you **first tell** your GP or nurse?

- **C** Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   Yes \(\square\)  \[Please complete A then B or C below\]

   No \(\square\)  \[Please go to Question 2\]

   A When did you **first notice** this?

   \[\square / \square / \square\]  \[OR\]  \[\square / \square / \square\]

   B When did you **first tell** your GP or nurse?

   OR

   C Put a cross here if you didn't **tell** your GP or nurse

2. Unexplained weight loss

   Did you have this?

   Yes \(\square\)  \[Please complete A then B or C below\]

   No \(\square\)  \[Please go to Question 3\]

   A When did you **first notice** this?

   \[\square / \square / \square\]  \[OR\]  \[\square / \square / \square\]

   B When did you **first tell** your GP or nurse?

   OR

   C Put a cross here if you didn't **tell** your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- Yes
- No

Please complete A then B or C below

**Please go to Question 4**

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

Did you have this?

- Yes
- No

Please complete A then B or C below

**Please go to Question 5**

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

---

**Please try and describe what the feeling was**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ___________________________________________________________
   ___________________________________________________________

A  When did you first notice this?  
   □   /   □   /   □   OR
   ___________________________________________________________

B  When did you first tell your GP or nurse?  
   □   /   □   /   □   OR
   ___________________________________________________________

OR

C  Put a cross here if you didn't tell your GP or nurse
   □

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ___________________________________________________________
   ___________________________________________________________

A  When did you first notice this?  
   □   /   □   /   □   OR
   ___________________________________________________________

B  When did you first tell your GP or nurse?  
   □   /   □   /   □   OR
   ___________________________________________________________

OR

C  Put a cross here if you didn't tell your GP or nurse
   □

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

|                | Yes | Not sure | No |
|----------------|-----|----------|----|
| Blood test(s)  |     |          |    |
| CT Scan        |     |          |    |
| Ultrasound scan|     |          |    |
| Barium Enema   |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | | | |
| X-ray          |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White

-or-

White British
White Irish
Other White background

Mixed

—or-

White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British

-or-

Carribean
African
Other Black background

Asian or Asian British

-or-

Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group

-or-

Chinese
Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| 1. I feel calm     | Not at all | Somewhat | Moderately | Very much |
|--------------------|------------|----------|------------|-----------|
| 2. I am tense      |            |          |            |           |
| 3. I feel upset    |            |          |            |           |
| 4. I am relaxed    |            |          |            |           |
| 5. I feel content  |            |          |            |           |
| 6. I am worried    |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes  
- Between 5 and 10 minutes  
- Between 11 and 15 minutes  
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help?  
Yes  
No

If yes, please specify what help was requested

________________________________________________________________________

please specify what help was given

________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult?  
Yes  
No

If yes, please specify which questions and what the difficulty was

________________________________________________________________________

________________________________________________________________________

Was the patient made anxious?  
Yes  
No

If yes, please give details

________________________________________________________________________

________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

________________________________________________________________________

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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes [X] No

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - **Yes**
   - **No**

   Please complete A then B or C below

   Please go to Question 2

   A When did you **first notice** this?

   \[
   \begin{align*}
   &\text{when}\ /
   \end{align*}
   \]

   OR

   B When did you **first tell** your GP or nurse?

   \[
   \begin{align*}
   &\text{when}\ /
   \end{align*}
   \]

   OR

   C Put a cross here if you **didn't tell** your GP or nurse

   \[
   \begin{align*}
   &\text{ }\ \\
   \end{align*}
   \]

2. **Unexplained weight loss**

   Did you have this?

   - **Yes**
   - **No**

   Please complete A then B or C below

   Please go to Question 3

   A When did you **first notice** this?

   \[
   \begin{align*}
   &\text{when}\ /
   \end{align*}
   \]

   OR

   B When did you **first tell** your GP or nurse?

   \[
   \begin{align*}
   &\text{when}\ /
   \end{align*}
   \]

   OR

   C Put a cross here if you **didn't tell** your GP or nurse

   \[
   \begin{align*}
   &\text{ }\ \\
   \end{align*}
   \]
3. Fatigue or tiredness that is unusual for you

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. Feeling different 'in yourself' from usual

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

OR

C  Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

___________________________________________

___________________________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

___________________________________________

___________________________________________

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

| 7. Were you sent for any of these?                  | Yes | Not sure | No |
|---------------------------------------------------|-----|----------|----|
| Blood test(s)                                     |     |          |    |
| CT Scan                                           |     |          |    |
| Ultrasound scan                                   |     |          |    |
| Barium Enema                                      |     |          |    |
| Sigmoidoscopy or colonoscopy                      |     |          |    |
| (Looking at bowel with internal camera)           |     |          |    |
| X-ray                                             |     |          |    |

**Please go to Question 8**
About you
The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?
   Please cross one box only
   - Employed full-time
   - Employed part-time
   - Self employed full-time
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   - Unemployed (seeking work)
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   - Retired
   - Student
   - Permanently sick/disabled
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   - Looking after family/home
   - Other, please describe

9. What is your highest level of qualification?
   Please cross one box only
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   - Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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Please cross the appropriate statement

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Thank you for completing the questionnaire

Please give it to the research nurse

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Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time:

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
  Less than 5 minutes
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  Between 11 and 15 minutes
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For the patient selected to complete the questionnaire on their own
  Did the patient ask for any help? Yes No
  If yes, please specify what help was requested

  Please specify what help was given

For the patient selected for the researcher-administered questionnaire
  Did the patient find any of the questions difficult? Yes No
  If yes, please specify which questions and what the difficulty was

  Was the patient made anxious? Yes No
  If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Chief Investigator, Symptoms Study
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2. What was the first symptom that made you think something might be wrong?

Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

Yes ☒  Please complete A then B or C below  

No ☐  Please go to Section 2

A When did you first notice this?  

2 3 1 2 0 7 OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?  

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A. When did you **first notice** this?

B. When did you **first tell** your GP or nurse?

C. Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A. When did you **first notice** this?

B. When did you **first tell** your GP or nurse?

C. Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

**Did you have any of the following?**

1. **Decrease in appetite**

   Did you have this?

   **A** When did you *first notice* this?

   **B** When did you *first tell* your GP or nurse?

   **OR**

   **C** Put a cross here if you *didn't tell* your GP or nurse

   Please complete A then B or C below

   ☐ / ☐ / ☐ OR

2. **Unexplained weight loss**

   Did you have this?

   **A** When did you *first notice* this?

   **B** When did you *first tell* your GP or nurse?

   **OR**

   **C** Put a cross here if you *didn't tell* your GP or nurse

   Please complete A then B or C below

   ☐ / ☐ / ☐ OR
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

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A  When did you first notice this?

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If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
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8. Which best describes your employment status?

   Please cross one box only

   Employed full-time
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   Unemployed (seeking work)
   Unemployed (not seeking work)
   Retired
   Student
   Permanently sick/disabled
   Temporarily sick/disabled
   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?

   Please cross one box only

   Degree (or equivalent)
   Diploma (or equivalent)
   'A' level
   GCSE / 'O' level
   None

   Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
or
White British
White Irish
Other White background

Mixed
or
White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British
or
Carribean
African
Other Black background

Asian or Asian British
or
Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group
or
Chinese
Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectatis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm  |           |          |            |           |
| 2. I am tense   |           |          |            |           |
| 3. I feel upset |           |          |            |           |
| 4. I am relaxed |           |          |            |           |
| 5. I feel content |         |          |            |           |
| 6. I am worried |           |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed:  
Date / / Time :  

If not completed, give reason  

How long is it since the patient was told of his/her diagnosis?  

How long did it take the patient to complete the questionnaire?  
Less than 5 minutes  
Between 5 and 10 minutes  
Between 11 and 15 minutes  
Longer than 15 minutes  

For the patient selected to complete the questionnaire on their own  
Did the patient ask for any help?  
Yes  No  
If yes, please specify what help was requested  

please specify what help was given  

For the patient selected for the researcher-administered questionnaire  
Did the patient find any of the questions difficult?  
Yes  No  
If yes, please specify which questions and what the difficulty was  

Was the patient made anxious?  
Yes  No  
If yes, please give details  

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)  

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes \[ \square \] Please continue with Question 2

   No \[ \square \] Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom? \[ \square \] Yes \[ \square \] No

Please complete A then B or C below

A When did you first notice this? \[ \square \] \[ \square \] / \[ \square \] / \[ \square \] OR

   Estimate \[ \square \] ‘3 months ago’ or ‘June’

B When did you first tell your GP or nurse? \[ \square \] \[ \square \] / \[ \square \] / \[ \square \] OR

   Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

**Did you have any of the following?**

1. **Decrease in appetite**

   Did you have this?

   **Yes**

   Please complete A then B or C below

   **No**

   Please go to Question 2

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   **Yes**

   Please complete A then B or C below

   **No**

   Please go to Question 3

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________
   ____________________________

A When did you first notice this?  
   ___ / ___ / ___ OR

B When did you first tell your GP or nurse?  
   ___ / ___ / ___ OR

OR

C Put a cross here if you didn't tell your GP or nurse  
   ☐

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________
   ____________________________

A When did you first notice this?  
   ___ / ___ / ___ OR

B When did you first tell your GP or nurse?  
   ___ / ___ / ___ OR

OR

C Put a cross here if you didn't tell your GP or nurse  
   ☐

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                          | Yes | Not sure | No |
|-------------------------------|-----|----------|----|
| Blood test(s)                 |     |          |    |
| CT Scan                       |     |          |    |
| Ultrasound scan               |     |          |    |
| Barium Enema                  |     |          |    |
| Sigmoidoscopy or colonoscopy  |     |          |    |
| (Looking at bowel with internal camera) |     |          |    |
| X-ray                         |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

Employed full-time
Employed part-time
Self employed full-time
Self employed part-time
Unemployed (seeking work)
Unemployed (not seeking work)
Retired
Student
Permanently sick/disabled
Temporarily sick/disabled
Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

Degree (or equivalent)
Diploma (or equivalent)
'A' level
GCSE / 'O' level
None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
   or
   White British
   White Irish
   Other White background

Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

Black or Black British
   or
   Carribean
   African
   Other Black background

Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?

Yes
   Please go to Question 12

No
   Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [ ] [ ] / [ ] / [ ]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes [ ]
Between 5 and 10 minutes [ ]
Between 11 and 15 minutes [ ]
Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No

If yes, please specify what help was requested

________________________________________________________________________

please specify what help was given

________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No

If yes, please specify which questions and what the difficulty was

________________________________________________________________________

________________________________________________________________________

Was the patient made anxious? [ ] Yes [ ] No

If yes, please give details

________________________________________________________________________

________________________________________________________________________

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?

Yes ☑️ Please complete A then B or C below

No ☐ Please go to Section 2

A When did you first notice this? d d / m m / y y OR Estimate ‘3 months ago’ or ‘June’

B When did you first tell your GP or nurse?

2 3 / 1 2 / 0 7 OR

C Put a cross here if you didn’t tell your GP or nurse

Please go to Question 3
3. **Change in bowel habit**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you **first notice** this?

B  When did you **first tell** your GP or nurse?

OR

C  Put a cross here if you **didn't tell** your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   Yes  No

   Please complete A then B or C below

   Please go to Question 2

   A  When did you first notice this?

   B  When did you first tell your GP or nurse?

   OR

   C  Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   Yes  No

   Please complete A then B or C below

   Please go to Question 3

   A  When did you first notice this?

   B  When did you first tell your GP or nurse?

   OR

   C  Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

C. Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 4

4. **Feeling different 'in yourself' from usual**

Did you have this?

A. When did you first notice this?

B. When did you first tell your GP or nurse?

C. Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Please go to Question 5

**Please try and describe what the feeling was**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________
   ____________________________________________________________

A  When did you first notice this?
   [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________________________
   ____________________________________________________________

A  When did you first notice this?
   [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?
   [ ] / [ ] / [ ] OR

C  Put a cross here if you didn't tell your GP or nurse
   [ ]

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

| 7. Were you sent for any of these? | Yes | Not sure | No |
|-----------------------------------|-----|----------|----|
| Blood test(s)                     | ☐   | ☐        | ☐  |
| CT Scan                           | ☐   | ☐        | ☐  |
| Ultrasound scan                   | ☐   | ☐        | ☐  |
| Barium Enema                      | ☐   | ☐        | ☐  |
| Sigmoidoscopy or colonoscopy      | ☐   | ☐        | ☐  |
| (Looking at bowel with internal camera) | ☐   | ☐        | ☐  |
| X-ray                             | ☐   | ☐        | ☐  |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
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Mixed
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    White & Black African
    White & Asian
    Other mixed background

Black or Black British
  or
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    African
    Other Black background

Asian or Asian British
  or
    Indian
    Pakistani
    Bangladeshi
    Other Asian background

Chinese or other ethnic group
  or
    Chinese
    Other ethnic group

11. Do you live alone?

Yes

No

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

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Please cross the appropriate statement

- Are you a current smoker?
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Yes
No
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|------------------------|------------|----------|------------|-----------|
| 1. I feel calm          |            |          |            |           |
| 2. I am tense           |            |          |            |           |
| 3. I feel upset         |            |          |            |           |
| 4. I am relaxed         |            |          |            |           |
| 5. I feel content       |            |          |            |           |
| 6. I am worried         |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to
tell us about when you first noticed your symptoms, please do so using
the space below.

If you feel you would like to talk to someone about this questionnaire at a
later stage, please speak to the doctor or nurse who is looking after you,
or be in touch with the research team, whose contact details are on your
patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   - Yes
   - No

   Please continue with Question 2

2. What was the first symptom that made you think something might be wrong?

   Please go to Section 2 on Page 5

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?  

- Yes
  - Please complete A then B or C below
  - OR '3 months ago' or 'June'

- No
  - Please go to Section 2

A  When did you first notice this?  
   d  d  / m  m  / y  y

B  When did you first tell your GP or nurse?  
   2  3  1  2  0  7  
   OR
   Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example, approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

   Did you have this?

   Yes □  Please complete A then B or C below
   No □  Please go to Question 2

   A When did you first notice this?

   [□□□□□□□]

   OR

   B When did you first tell your GP or nurse?

   [□□□□□□□]

   OR

   C Put a cross here if you didn’t tell your GP or nurse

   [□]

2. Unexplained weight loss

   Did you have this?

   Yes □  Please complete A then B or C below
   No □  Please go to Question 3

   A When did you first notice this?

   [□□□□□□□]

   OR

   B When did you first tell your GP or nurse?

   [□□□□□□□]

   OR

   C Put a cross here if you didn’t tell your GP or nurse

   [□]
3. Fatigue or tiredness that is unusual for you

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5.

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  
[ ] [ ] [ ] OR 

B When did you first tell your GP or nurse?  
[ ] [ ] [ ] OR 

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6.

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?  
[ ] [ ] [ ] OR 

B When did you first tell your GP or nurse?  
[ ] [ ] [ ] OR 

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                             | Yes | Not sure | No |
|--------------------------------------------------|-----|----------|----|
| Blood test(s)                                    | ☐   | ☐        | ☐  |
| CT Scan                                          | ☐   | ☐        | ☐  |
| Ultrasound scan                                  | ☐   | ☐        | ☐  |
| Barium Enema                                     | ☐   | ☐        | ☐  |
| Sigmoidoscopy or colonoscopy                     | ☐   | ☐        | ☐  |
| (Looking at bowel with internal camera)          | ☐   | ☐        | ☐  |
| X-ray                                            | ☐   | ☐        | ☐  |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
  Please go to Question 12

No
  Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement              | Not at all | Somewhat | Moderately | Very much |
|------------------------|------------|----------|------------|-----------|
| 1. I feel calm         |            |          |            |           |
| 2. I am tense          |            |          |            |           |
| 3. I feel upset        |            |          |            |           |
| 4. I am relaxed        |            |          |            |           |
| 5. I feel content      |            |          |            |           |
| 6. I am worried        |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: [ ] / [ ] / [ ]

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes [ ]
Between 5 and 10 minutes [ ]
Between 11 and 15 minutes [ ]
Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested

_________________________________________________________________________

please specify what help was given

_________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was

_________________________________________________________________________

_________________________________________________________________________

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details

_________________________________________________________________________

_________________________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

_________________________________________________________________________

_________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

| Decrease in appetite | Yes | Please complete A then B or C below |
|----------------------|-----|------------------------------------|
|                      | No  | Please go to Section 2             |

A  When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A  When did you **first notice this**?

B  When did you **first tell your GP or nurse**?

C  Put a cross here if you **didn't tell** your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you **first notice this**?

B  When did you **first tell your GP or nurse**?

C  Put a cross here if you **didn't tell** your GP or nurse

---

**Please complete A then B or C below**

**Please go to Question 4**

**Please go to Section 2**
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   - **Yes** Please complete A then B or C below
   - **No** Please go to Question 2

   | A | B | C |
   |---|---|---|
   | When did you **first notice** this? | When did you **first tell** your GP or nurse? | Put a cross here if you didn't tell your GP or nurse |
   | | OR | |

2. **Unexplained weight loss**

   Did you have this?

   - **Yes** Please complete A then B or C below
   - **No** Please go to Question 3

   | A | B | C |
   |---|---|---|
   | When did you **first notice** this? | When did you **first tell** your GP or nurse? | Put a cross here if you didn't tell your GP or nurse |
   | | OR | |
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?
B When did you first tell your GP or nurse?
C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________
   __________________________________________
   __________________________________________

A  When did you first notice this?  [ ] [ ] [ ] OR [ ]
B  When did you first tell your GP or nurse?  [ ] [ ] [ ] OR [ ]
C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________
   __________________________________________
   __________________________________________

A  When did you first notice this?  [ ] [ ] [ ] OR [ ]
B  When did you first tell your GP or nurse?  [ ] [ ] [ ] OR [ ]
C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                                        | Yes | Not sure | No |
|-------------------------------------------------------------|-----|----------|----|
| Blood test(s)                                               |     |          |    |
| CT Scan                                                     |     |          |    |
| Ultrasound scan                                             |     |          |    |
| Barium Enema                                                |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                                       |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
or
White British
White Irish
Other White background

Mixed
or
White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British
or
Carribean
African
Other Black background

Asian or Asian British
or
Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group
or
Chinese
Other ethnic group

11. Do you live alone?

Yes
Please go to Question 12

No
Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement            | Not at all | Somewhat | Moderately | Very much |
|----------------------|------------|----------|------------|-----------|
| 1. I feel calm       |            |          |            |           |
| 2. I am tense        |            |          |            |           |
| 3. I feel upset      |            |          |            |           |
| 4. I am relaxed      |            |          |            |           |
| 5. I feel content    |            |          |            |           |
| 6. I am worried      |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed:  
Date  /  /  Time  :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes  
- Between 5 and 10 minutes  
- Between 11 and 15 minutes  
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help?  
- Yes  
- No
  If yes, please specify what help was requested
  ____________________________________________________________
  ____________________________________________________________

please specify what help was given
  ____________________________________________________________
  ____________________________________________________________

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult?  
- Yes  
- No
  If yes, please specify which questions and what the difficulty was
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________

Was the patient made anxious?  
- Yes  
- No
  If yes, please give details
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

Please complete A then B or C below

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?
   
   **A** When did you first notice this?
   
   **B** When did you first tell your GP or nurse?
   
   **OR**
   
   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?
   
   **A** When did you first notice this?
   
   **B** When did you first tell your GP or nurse?
   
   **OR**
   
   **C** Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

Yes [ ] No [ ]

Please complete A then B or C below

Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________________________________________
__________________________________________________________________________________________

A When did you first notice this? 

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse? 

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse


If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________________________________________________________
__________________________________________________________________________________________

A When did you first notice this? 

[ ] / [ ] / [ ] OR

B When did you first tell your GP or nurse? 

[ ] / [ ] / [ ] OR

OR

C Put a cross here if you didn't tell your GP or nurse


If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy              |     |          |    |
| (Looking at bowel with internal camera)   |     |          |    |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
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- Unemployed (seeking work)
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- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

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or

White British
White Irish
Other White background

Mixed

or

White & Black Carribean
White & Black African
White & Asian
Other mixed background

Black or Black British

or

Carribean
African
Other Black background

Asian or Asian British

or

Indian
Pakistani
Bangladeshi
Other Asian background

Chinese or other ethnic group

or

Chinese
Other ethnic group

11. Do you live alone?

Yes

Please go to Question 12

No

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

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- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
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- Previous cancer
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Please cross the appropriate statement

- Are you a current smoker?
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14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

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|                | Not at all | Somewhat | Moderately | Very much |
|----------------|------------|----------|------------|-----------|
| 1. I feel calm |            |          |            |           |
| 2. I am tense  |            |          |            |           |
| 3. I feel upset|            |          |            |           |
| 4. I am relaxed|            |          |            |           |
| 5. I feel content|         |          |            |           |
| 6. I am worried|            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed:  

If not completed, give reason  

How long is it since the patient was told of his/her diagnosis?  

How long did it take the patient to complete the questionnaire?  

Less than 5 minutes  ☐
Between 5 and 10 minutes  ☐
Between 11 and 15 minutes  ☐
Longer than 15 minutes  ☐

For the patient selected to complete the questionnaire on their own  

Did the patient ask for any help?  ☐ Yes  ☐ No  

If yes, please specify what help was requested  

please specify what help was given  

For the patient selected for the researcher-administered questionnaire  

Did the patient find any of the questions difficult?  ☐ Yes  ☐ No  

If yes, please specify which questions and what the difficulty was  

Was the patient made anxious?  ☐ Yes  ☐ No  

If yes, please give details  

Where did the patient complete the questionnaire?  

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other  

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
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Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   [ ] Yes
   [ ] No

   Please continue with Question 2

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom?

[ ] Yes

[ ] No

Please complete A then B or C below

A  When did you first notice this?  

   [ ] [ ] [ ] [ ] [ ]

   OR  Estimate

   [ ] '3 months ago' or 'June'

B  When did you first tell your GP or nurse?

   [ ] [ ] [ ] [ ] [ ]

   OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. **Decrease in appetite**

   Did you have this?

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse?

   **OR**

   **C** Put a cross here if you didn't tell your GP or nurse

---

|   | Yes | Please complete A then B or C below | No | Please go to Question 2 |
|---|-----|-------------------------------------|----|-------------------------|
|   |     |                                     |    |                         |
| A |     |                                     |    |                         |
| B |     |                                     |    |                         |
| C |     |                                     |    |                         |

---

|   | Yes | Please complete A then B or C below | No | Please go to Question 3 |
|---|-----|-------------------------------------|----|-------------------------|
|   |     |                                     |    |                         |
| A |     |                                     |    |                         |
| B |     |                                     |    |                         |
| C |     |                                     |    |                         |

---

|   | Yes | Please complete A then B or C below | No | Please go to Question 3 |
|---|-----|-------------------------------------|----|-------------------------|
|   |     |                                     |    |                         |
| A |     |                                     |    |                         |
| B |     |                                     |    |                         |
| C |     |                                     |    |                         |
### 3. Fatigue or tiredness that is unusual for you

| Did you have this? | Yes | No |
|--------------------|-----|----|

**Please complete A then B or C below**

| A When did you first notice this? | / / OR |
|-----------------------------------|--------|

| B When did you first tell your GP or nurse? | / / OR |
|--------------------------------------------|--------|

| OR C Put a cross here if you didn't tell your GP or nurse |
|----------------------------------------------------------|

**Please go to Question 4**

### 4. Feeling different 'in yourself' from usual

| Did you have this? | Yes | No |
|--------------------|-----|----|

**Please complete A then B or C below**

| A When did you first notice this? | / / OR |
|-----------------------------------|--------|

| B When did you first tell your GP or nurse? | / / OR |
|--------------------------------------------|--------|

| OR C Put a cross here if you didn't tell your GP or nurse |
|----------------------------------------------------------|

**Please go to Question 5**

Please try and describe what the feeling was

| _______________________________ |
| _______________________________ |
| _______________________________ |
| _______________________________ |
| _______________________________ |
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  □□□ / □□□ / □□□ OR
   □□□ / □□□ / □□□ OR
B  When did you first tell your GP or nurse?  □□□ / □□□ / □□□ OR
   □□□ / □□□ / □□□ OR
C  Put a cross here if you didn’t tell your GP or nurse  □

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________
   __________________________________________________________

A  When did you first notice this?  □□□ / □□□ / □□□ OR
   □□□ / □□□ / □□□ OR
B  When did you first tell your GP or nurse?  □□□ / □□□ / □□□ OR
   □□□ / □□□ / □□□ OR
C  Put a cross here if you didn’t tell your GP or nurse  □

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. **Were you sent for any of these?**

- Blood test(s)
- CT Scan
- Ultrasound scan
- Barium Enema
- Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera)
- X-ray

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11.

Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectatis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | ☐         | ☐        | ☐          | ☐         |
| 2. I am tense   | ☐         | ☐        | ☐          | ☐         |
| 3. I feel upset | ☐         | ☐        | ☐          | ☐         |
| 4. I am relaxed | ☐         | ☐        | ☐          | ☐         |
| 5. I feel content | ☐       | ☐        | ☐          | ☐         |
| 6. I am worried | ☐         | ☐        | ☐          | ☐         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: ____________________________

If not completed, give reason: ____________________________

How long is it since the patient was told of his/her diagnosis? ____________________________

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes [ ]
- Between 5 and 10 minutes [ ]
- Between 11 and 15 minutes [ ]
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? [ ] Yes [ ] No

If yes, please specify what help was requested

________________________________________________________________________

________________________________________________________________________

please specify what help was given

________________________________________________________________________

________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? [ ] Yes [ ] No

If yes, please specify which questions and what the difficulty was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Was the patient made anxious? [ ] Yes [ ] No

If yes, please give details

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes [ ]  Please continue with Question 2
   No [ ]  Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? [ ] Yes  [ ] No  Please complete A then B or C below

A When did you first notice this? d d / m m / y y

   OR

   Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse?

   2 3 / 1 2 / 0 7

   OR

   Estimate

C Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

4. **Bleeding from back passage**

Did you have this symptom?

A  When did you first notice this?

B  When did you first tell your GP or nurse?

C  Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

| Did you have this? |  | Please complete A then B or C below |
|-------------------|---|------------------------------------|
| Yes               |   |                                     |
| No                |   | Please go to Question 2             |

| A When did you first notice this? |   |  |
|----------------------------------|---|---|
|                                  |   |   |

| B When did you first tell your GP or nurse? OR |
|-----------------------------------------------|
|                                               |

| C Put a cross here if you didn't tell your GP or nurse |
|------------------------------------------------------|
|                                                      |

2. Unexplained weight loss

| Did you have this? |  | Please complete A then B or C below |
|-------------------|---|------------------------------------|
| Yes               |   |                                     |
| No                |   | Please go to Question 3             |

| A When did you first notice this? |   |  |
|----------------------------------|---|---|
|                                  |   |   |

| B When did you first tell your GP or nurse? OR |
|-----------------------------------------------|
|                                               |

| C Put a cross here if you didn't tell your GP or nurse |
|------------------------------------------------------|
|                                                      |
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Yes

No

Please go to Question 4

|   |   |   | OR
|---|---|---|
|   |   |   |

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you **first notice** this?

B When did you **first tell** your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

Yes

No

Please go to Question 5

|   |   |   | OR
|---|---|---|
|   |   |   |

Please try and describe what the feeling was

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy        |     |          |    |
| (Looking at bowel with internal camera) |    |          |    |
| X-ray                               |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
- White British
- White Irish
- Other White background

Mixed
- White & Black Carribean
- White & Black African
- White & Asian
- Other mixed background

Black or Black British
- Carribean
- African
- Other Black background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese or other ethnic group
- Chinese
- Other ethnic group

11. Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
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- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes
No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time : :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? Yes No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? Yes No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

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Yours sincerely

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Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?
   - Yes
   - No
   Please continue with Question 2

2. What was the first symptom that made you think something might be wrong?
   - Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom?

- Yes [X] Please complete A then B or C below
- No

Please go to Section 2

A When did you first notice this? [2 3] [1 2] [0 7] OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? [B]

C Put a cross here if you didn't tell your GP or nurse [C]
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

---

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

---
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes ☐
No ☐

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse

☐

2. Unexplained weight loss

Did you have this?

Yes ☐
No ☐

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse

☐
3.  Fatigue or tiredness that is unusual for you

Did you have this?

Yes  No

Please complete A then B or C below

Please go to Question 4

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4.  Feeling different 'in yourself' from usual

Did you have this?

Yes  No

Please complete A then B or C below

Please go to Question 5

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?

[ ] [ ] [ ] OR

B When did you first tell your GP or nurse?

[ ] [ ] [ ] OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

________________________________________________________________________

________________________________________________________________________

A When did you first notice this?

[ ] [ ] [ ] OR

B When did you first tell your GP or nurse?

[ ] [ ] [ ] OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
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Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

**Please cross the appropriate boxes**

7. **Were you sent for any of these?**

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) |     |          |    |
| X-ray                                     |     |          |    |

**Please go to Question 8**
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

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- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?
   Please cross any that are applicable to you
   - Asthma
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   - Heart disease
   - Anxiety or depression
   - Inflammatory bowel disease
   - Irritable bowel syndrome
   - Peptic ulcer
   - Previous cancer
   - Diabetes
   - Arthritis

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   Please cross the appropriate statement
   - Are you a current smoker?
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   - Yes
   - No
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| Statement               | Not at all | Somewhat | Moderately | Very much |
|-------------------------|------------|----------|------------|-----------|
| 1. I feel calm          |            |          |            |           |
| 2. I am tense           |            |          |            |           |
| 3. I feel upset         |            |          |            |           |
| 4. I am relaxed         |            |          |            |           |
| 5. I feel content       |            |          |            |           |
| 6. I am worried         |            |          |            |           |

Please make sure you have answered all the questions.
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If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: __________/_________/__________  Time: ________:_____

If not completed, give reason: ___________________________________________________________________________________

How long is it since the patient was told of his/her diagnosis? ___________________________________________________________________

How long did it take the patient to complete the questionnaire?  
- Less than 5 minutes [ ]  
- Between 5 and 10 minutes [ ]  
- Between 11 and 15 minutes [ ]  
- Longer than 15 minutes [ ]

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? [ ] Yes [ ] No
If yes, please specify what help was requested
__________________________________________________________________________________________

please specify what help was given
__________________________________________________________________________________________

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? [ ] Yes [ ] No
If yes, please specify which questions and what the difficulty was
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Was the patient made anxious? [ ] Yes [ ] No
If yes, please give details
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Where did the patient complete the questionnaire?  
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)
__________________________________________________________________________________________

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If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

   Yes
   No

   Please continue with Question 2

   Please go to Section 2 on Page 5

2. What was the first symptom that made you think something might be wrong?

   Please go to Question 3

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom?

Yes  [X] Please complete A then B or C below

No

Please go to Section 2

A  When did you first notice this?  2  3  1  2  0  7

   OR

   Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?

   OR

C  Put a cross here if you didn't tell your GP or nurse
3. **Change in bowel habit**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse

4. **Bleeding from back passage**

Did you have this symptom?

A When did you *first notice* this?

B When did you *first tell* your GP or nurse?

C Put a cross here if you *didn't tell* your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
3. Fatigue or tiredness that is unusual for you

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

4. Feeling different 'in yourself' from usual

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________
   ____________________________________________________________

A  When did you first notice this?  [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR

C  Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________________________
   ____________________________________________________________

A  When did you first notice this?  [ ] / [ ] / [ ] OR

B  When did you first tell your GP or nurse?  [ ] / [ ] / [ ] OR

C  Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                | Yes | Not sure | No |
|-------------------------------------|-----|----------|----|
| Blood test(s)                       |     |          |    |
| CT Scan                             |     |          |    |
| Ultrasound scan                     |     |          |    |
| Barium Enema                        |     |          |    |
| Sigmoidoscopy or colonoscopy        |     |          |    |
| (Looking at bowel with internal camera) |   |          |    |
| X-ray                               |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

- White
  - White British
  - White Irish
  - Other White background

- Mixed
  - White & Black Carribean
  - White & Black African
  - White & Asian
  - Other mixed background

- Black or Black British
  - Carribean
  - African
  - Other Black background

- Asian or Asian British
  - Indian
  - Pakistani
  - Bangladeshi
  - Other Asian background

- Chinese or other ethnic group
  - Chinese
  - Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

Asthma
Chronic Obstructive Pulmonary Disease (COPD)
Other lung disease (e.g. fibrosis, bronchiectasis etc)
Heart disease
Anxiety or depression
Inflammatory bowel disease
Irritable bowel syndrome
Peptic ulcer
Previous cancer
Diabetes
Arthritis

13. About smoking

Please cross the appropriate statement

Are you a current smoker?
Are you an ex-smoker?
Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes  No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □ | □ | □ | □ |
| 2. I am tense | □ | □ | □ | □ |
| 3. I feel upset | □ | □ | □ | □ |
| 4. I am relaxed | □ | □ | □ | □ |
| 5. I feel content | □ | □ | □ | □ |
| 6. I am worried | □ | □ | □ | □ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete.
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time : :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes ☐
Between 5 and 10 minutes ☐
Between 11 and 15 minutes ☐
Longer than 15 minutes ☐

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? ☐ Yes ☐ No

If yes, please specify what help was requested

________________________________________________________________________

please specify what help was given

________________________________________________________________________

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? ☐ Yes ☐ No

If yes, please specify which questions and what the difficulty was

________________________________________________________________________

________________________________________________________________________

Was the patient made anxious? ☐ Yes ☐ No

If yes, please give details

________________________________________________________________________

________________________________________________________________________

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

________________________________________________________________________

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No ☐

A When did you first notice this? d d / m m / y y OR Estimate '3 months ago' or 'June'

B When did you first tell your GP or nurse? 2 3 / 1 2 / 0 7 OR Estimate

C Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse

---

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

OR

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes ☐ No ☐

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse

☐

2. Unexplained weight loss

Did you have this?

Yes ☐ No ☐

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

☐ / ☐ / ☐ OR

B When did you first tell your GP or nurse?

☐ / ☐ / ☐ OR

OR

C Put a cross here if you didn't tell your GP or nurse

☐
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

OR

OR

OR

Please go to Question 4

4. **Feeling different 'in yourself' from usual**

Did you have this?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

OR

OR

OR

Please go to Question 5

**Please try and describe what the feeling was**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. __________________________________________________________

A When did you first notice this? ____________________________________

B When did you first tell your GP or nurse? ___________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. __________________________________________________________

A When did you first notice this? ____________________________________

B When did you first tell your GP or nurse? ___________________________

OR

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

|                                | Yes | Not sure | No |
|--------------------------------|-----|----------|----|
| Blood test(s)                  |     |          |    |
| CT Scan                        |     |          |    |
| Ultrasound scan                |     |          |    |
| Barium Enema                   |     |          |    |
| Sigmoidoscopy or colonoscopy   |     |          |    |
| (Looking at bowel with internal camera) | | | |
| X-ray                          |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

Please cross one box only

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
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- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

Please cross one box only

- Degree (or equivalent)
- Diploma (or equivalent)
- 'A' level
- GCSE / 'O' level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
  or
  White British
  White Irish
  Other White background

Mixed
  or
  White & Black Carribean
  White & Black African
  White & Asian
  Other mixed background

Black or Black British
  or
  Carribean
  African
  Other Black background

Asian or Asian British
  or
  Indian
  Pakistani
  Bangladeshi
  Other Asian background

Chinese or other ethnic group
  or
  Chinese
  Other ethnic group

11. Do you live alone?

Yes

No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectatis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

- Yes
- No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Statement               | Not at all | Somewhat | Moderately | Very much |
|-------------------------|------------|----------|------------|-----------|
| I feel calm             |            |          |            |           |
| I am tense              |            |          |            |           |
| I feel upset            |            |          |            |           |
| I am relaxed            |            |          |            |           |
| I feel content          |            |          |            |           |
| I am worried            |            |          |            |           |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Date questionnaire completed: Date / / Time :

If not completed, give reason:

How long is it since the patient was told of his/her diagnosis:

How long did it take the patient to complete the questionnaire?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own:

Did the patient ask for any help? Yes No

If yes, please specify what help was requested

Please specify what help was given

For the patient selected for the researcher-administered questionnaire:

Did the patient find any of the questions difficult? Yes No

If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No

If yes, please give details

Where did the patient complete the questionnaire?

(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Confidential Questionnaire

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Dear Patient

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I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
Section 1

About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example approximately how long ago, the month or season). You wish to refer to your diary or calendar if you have it with you.

Here is an example question:

**Decrease in appetite**

Did you have this symptom?  

| Yes | Please complete A then B or C below | No | Please go to Section 2 |
|-----|------------------------------------|----|------------------------|

A  When did you first notice this?  

| 2 | 3 | / | 1 | 2 | / | 0 | 7 |

 OR  Estimate '3 months ago' or 'June'

B  When did you first tell your GP or nurse?  

 OR  Estimate

C  Put a cross here if you didn't tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

A When did you first notice this?

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an **exact** date if you can. Otherwise give your best **estimate** (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

**Did you have any of the following?**

1. **Decrease in appetite**

   Did you have this?

   **Yes** | Please complete A then B or C below
   **No** | Please go to Question 2

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse? **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse

2. **Unexplained weight loss**

   Did you have this?

   **Yes** | Please complete A then B or C below
   **No** | Please go to Question 3

   **A** When did you **first notice** this?

   **B** When did you **first tell** your GP or nurse? **OR**

   **C** Put a cross here if you **didn't tell** your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

- Yes
- No

Please go to Question 4

4. **Feeling different 'in yourself' from usual**

Did you have this?

- **A** When did you first notice this?
- **B** When did you first tell your GP or nurse?
- **C** Put a cross here if you didn't tell your GP or nurse

Please complete A then B or C below

- Yes
- No

Please go to Question 5

Please try and describe what the feeling was:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. ____________________________________________________________

A When did you first notice this? [ ] / [ ] / [ ] OR ___________________________
B When did you first tell your GP or nurse? [ ] / [ ] / [ ] OR ___________________________
C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. ____________________________________________________________

A When did you first notice this? [ ] / [ ] / [ ] OR ___________________________
B When did you first tell your GP or nurse? [ ] / [ ] / [ ] OR ___________________________
C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

|                      | Yes | Not sure | No |
|----------------------|-----|----------|----|
| Blood test(s)        |     |          |    |
| CT Scan              |     |          |    |
| Ultrasound scan      |     |          |    |
| Barium Enema         |     |          |    |
| Sigmoidoscopy or colonoscopy  | (Looking at bowel with internal camera) |     |    |
| X-ray                |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

   Please cross one box only

   Employed full-time
   Employed part-time
   Self employed full-time
   Self employed part-time
   Unemployed (seeking work)
   Unemployed (not seeking work)
   Retired
   Student
   Permanently sick/disabled
   Temporarily sick/disabled
   Looking after family/home

   Other, please describe

9. What is your highest level of qualification?

   Please cross one box only

   Degree (or equivalent)
   Diploma (or equivalent)
   'A' level
   GCSE / 'O' level
   None

   Other, please specify
10. How would you describe your ethnicity
   Please cross one box only

   White
   or
   White British
   White Irish
   Other White background

   Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

   Black or Black British
   or
   Carribean
   African
   Other Black background

   Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

   Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?
   Yes
   No
   Please go to Question 12
   Please say who you live with below

   Who do you live with?
   (e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

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- Chronic Obstructive Pulmonary Disease (COPD)
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- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

Yes

No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

|   | Not at all | Somewhat | Moderately | Very much |
|---|------------|----------|------------|-----------|
| 1. I feel calm | □         | □        | □          | □         |
| 2. I am tense  | □         | □        | □          | □         |
| 3. I feel upset| □         | □        | □          | □         |
| 4. I am relaxed| □         | □        | □          | □         |
| 5. I feel content| □       | □        | □          | □         |
| 6. I am worried | □         | □        | □          | □         |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

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Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time : :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?
- Less than 5 minutes
- Between 5 and 10 minutes
- Between 11 and 15 minutes
- Longer than 15 minutes

For the patient selected to complete the questionnaire on their own
Did the patient ask for any help? Yes No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire
Did the patient find any of the questions difficult? Yes No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other)

Thank you. Please now send the questionnaire and patient information sheet and consent form back to Cardiff University in the freepost envelope provided.
Looking At Your Symptoms Study
This Study has been funded by Cancer Research UK
Dear Patient

I am very grateful to you for agreeing to help us with this study.

I hope the information you supply will help us give people a diagnosis earlier.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet.

I can assure you that anything you tell us will be treated in the utmost confidence.

Yours sincerely

[Signature]

Dr Richard Neal
Senior Clinical Lecturer
Cardiff University
Chief Investigator, Symptoms Study
About your symptoms

These questions are about symptoms you noticed before your diagnosis. We are interested in
symptoms which you think are related to your cancer.

Please put a cross in the appropriate box, or write an answer as required.

Looking back...

1. Did you have any symptoms that you feel were due to your cancer before you were diagnosed?

2. What was the first symptom that made you think something might be wrong?

The following questions are about when you first noticed a symptom and when you first
told your GP or nurse about it.

Please give an exact date if you can. Otherwise give your best estimate. (For example
approximately how long ago, the month or season). You wish to refer to your diary or
calendar if you have it with you.

Here is an example question:

Decrease in appetite

Did you have this symptom? Yes ☒ No

Please complete A then B or C below

Please go to Section 2

A When did you first notice this? d m / y

OR Estimate

‘3 months ago’ or ‘June’

B When did you first tell your GP or nurse?

2 3 / 1 2 / 0 7

OR Estimate

C Put a cross here if you didn’t tell your GP or nurse
3. Change in bowel habit

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse

4. Bleeding from back passage

Did you have this symptom?

**A** When did you first notice this?

**B** When did you first tell your GP or nurse?

**C** Put a cross here if you didn't tell your GP or nurse
Section 2

Please give an exact date if you can. Otherwise give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Did you have any of the following?

1. Decrease in appetite

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 2

A When did you first notice this?

/ / OR

B When did you first tell your GP or nurse?

/ / OR

OR

C Put a cross here if you didn't tell your GP or nurse

2. Unexplained weight loss

Did you have this?

Yes
No

Please complete A then B or C below

Please go to Question 3

A When did you first notice this?

/ / OR

B When did you first tell your GP or nurse?

/ / OR

OR

C Put a cross here if you didn't tell your GP or nurse
3. **Fatigue or tiredness that is unusual for you**

   Did you have this?

   A  When did you first notice this?

   B  When did you first tell your GP or nurse?

   OR

   C  Put a cross here if you didn't tell your GP or nurse

4. **Feeling different 'in yourself' from usual**

   Did you have this?

   A  When did you first notice this?

   B  When did you first tell your GP or nurse?

   OR

   C  Put a cross here if you didn't tell your GP or nurse

Please try and describe what the feeling was

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

Yes  Please complete A then B or C below

No   Please go to Question 4

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

Yes  Please complete A then B or C below

No   Please go to Question 5

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

Please go to Question 4

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________
If you had any further symptoms which you feel are relevant to your cancer diagnosis, please list them below. If not, please go to Question 7.

Please describe the symptom here and complete A then B or C below

5. 

Please describe the symptom here and complete A then B or C below

A When did you first notice this? 

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

If you had another symptom you feel is relevant, please write it below, otherwise go to Question 7.

Please describe the symptom here and complete A then B or C below

6. 

A When did you first notice this? 

B When did you first tell your GP or nurse?

C Put a cross here if you didn't tell your GP or nurse

If you had further symptoms you would like to tell us about, there is space at the end of the Questionnaire for you to write them.
Did your GP send you for any tests?

Thinking back to the time immediately before you diagnosis, did your GP send you for any of the following tests?

Please cross the appropriate boxes

7. Were you sent for any of these?

| Test                                      | Yes | Not sure | No |
|-------------------------------------------|-----|----------|----|
| Blood test(s)                             |     |          |    |
| CT Scan                                   |     |          |    |
| Ultrasound scan                           |     |          |    |
| Barium Enema                              |     |          |    |
| Sigmoidoscopy or colonoscopy (Looking at bowel with internal camera) | | | |
| X-ray                                     |     |          |    |

Please go to Question 8
About you

The next questions relate to general information about you. It would help us to know more about the background of the people completing the questionnaire.

8. Which best describes your employment status?

*Please cross one box only*

- Employed full-time
- Employed part-time
- Self employed full-time
- Self employed part-time
- Unemployed (seeking work)
- Unemployed (not seeking work)
- Retired
- Student
- Permanently sick/disabled
- Temporarily sick/disabled
- Looking after family/home

Other, please describe

9. What is your highest level of qualification?

*Please cross one box only*

- Degree (or equivalent)
- Diploma (or equivalent)
- ‘A’ level
- GCSE / ‘O’ level
- None

Other, please specify
10. How would you describe your ethnicity

Please cross one box only

White
   or
   White British
   White Irish
   Other White background

Mixed
   or
   White & Black Carribean
   White & Black African
   White & Asian
   Other mixed background

Black or Black British
   or
   Carribean
   African
   Other Black background

Asian or Asian British
   or
   Indian
   Pakistani
   Bangladeshi
   Other Asian background

Chinese or other ethnic group
   or
   Chinese
   Other ethnic group

11. Do you live alone?

Yes
No

Please go to Question 12

Please say who you live with below

Who do you live with?
(e.g. wife, husband, partner, family member)
12. Are you suffering from, or have you suffered from, any of the following in the past 2 years?

Please cross any that are applicable to you

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (e.g. fibrosis, bronchiectasis etc)
- Heart disease
- Anxiety or depression
- Inflammatory bowel disease
- Irritable bowel syndrome
- Peptic ulcer
- Previous cancer
- Diabetes
- Arthritis

13. About smoking

Please cross the appropriate statement

- Are you a current smoker?
- Are you an ex-smoker?
- Are you a non-smoker (never smoked)?

14. Do you think you were more at risk of getting cancer because of your family history?

[ ] Yes
[ ] No
15. The following questions are about how completing the questionnaire made you feel.

A number of statements which people have used to describe themselves are given below. Read each statement and then cross the most appropriate box to indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feeling best.

| Not at all | Somewhat | Moderately | Very much |
|------------|----------|------------|-----------|
| 1. I feel calm | ☐ | ☐ | ☐ | ☐ |
| 2. I am tense | ☐ | ☐ | ☐ | ☐ |
| 3. I feel upset | ☐ | ☐ | ☐ | ☐ |
| 4. I am relaxed | ☐ | ☐ | ☐ | ☐ |
| 5. I feel content | ☐ | ☐ | ☐ | ☐ |
| 6. I am worried | ☐ | ☐ | ☐ | ☐ |

Please make sure you have answered all the questions.
If you have any other comments or there is anything else you would like to tell us about when you first noticed your symptoms, please do so using the space below.

If you feel you would like to talk to someone about this questionnaire at a later stage, please speak to the doctor or nurse who is looking after you, or be in touch with the research team, whose contact details are on your patient information sheet

Thank you for completing the questionnaire

Please give it to the research nurse

The next page is for the Researcher to complete
Researcher - Post-completion Sheet

Date questionnaire completed: Date / / Time :

If not completed, give reason

How long is it since the patient was told of his/her diagnosis?

How long did it take the patient to complete the questionnaire?

Less than 5 minutes
Between 5 and 10 minutes
Between 11 and 15 minutes
Longer than 15 minutes

For the patient selected to complete the questionnaire on their own

Did the patient ask for any help? Yes No
If yes, please specify what help was requested

please specify what help was given

For the patient selected for the researcher-administered questionnaire

Did the patient find any of the questions difficult? Yes No
If yes, please specify which questions and what the difficulty was

Was the patient made anxious? Yes No
If yes, please give details

Where did the patient complete the questionnaire?
(Please specify whether this was in a separate room alone, in a corner of the clinic, the ward or other

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