CARIAD Study number [ ]

The CARIAD Trial: waiting for genetic risk information

QUESTIONNAIRE 1

Thank you for agreeing to complete this questionnaire. We are interested in finding out about how you feel about undergoing cancer genetic risk assessment.

This questionnaire should take about 30 minutes to complete. Please read the instructions for each question carefully. Some of the questions may not seem very relevant to how you are feeling. However, it is very important that you try and answer all of the questions as honestly and as accurately as you can. There are no right or wrong answers.

If you have any questions about filling in the questionnaire or about the study in general, you can call Ceri Phelps on 029 2074 8920.

All the information you give us will be treated in confidence and will only be seen by the researchers working on the study.

Please complete the questionnaire as soon as possible. When you have completed the questionnaire, please check to make sure you have not missed anything out, and that you have signed the consent form on page three, then return it to us in the FREEPOST envelope provided.

Thank you for your help

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The CARIAD Trial

CONSENT FORM

Please be sure to complete the section below as we can only use the information you give us with your signed consent

1. I confirm that I have read and understand the information sheet dated March 2007 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that relevant information from my medical notes and data collected during the study may be accessed by responsible individuals from the NHS and Cardiff University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
4. I agree to take part in the above study.	☐

Name .....

Address .....

.....

.....

Signature .....

Date .....

If you would like a summary of the study results when it is complete, please tick this box. ☐

THIS PAGE WILL BE REMOVED FROM THIS QUESTIONNAIRE AND STORED SEPARATELY: YOUR ANSWERS TO THE FOLLOWING QUESTIONS WILL REMAIN ANONYMOUS.

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A. Your feelings and emotions about cancer genetic risk assessment

Below are a number of words that describe different feelings and emotions. Please indicate to what extent you have felt this way **since your referral**. Please read each item and then tick the appropriate response for each word.

	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
Interested	☐	☐	☐	☐	☐
Distressed	☐	☐	☐	☐	☐
Excited	☐	☐	☐	☐	☐
Upset	☐	☐	☐	☐	☐
Strong	☐	☐	☐	☐	☐
Guilty	☐	☐	☐	☐	☐
Scared	☐	☐	☐	☐	☐
Hostile	☐	☐	☐	☐	☐
Enthusiastic	☐	☐	☐	☐	☐
Proud	☐	☐	☐	☐	☐
Irritable	☐	☐	☐	☐	☐
Alert	☐	☐	☐	☐	☐
Ashamed	☐	☐	☐	☐	☐
Inspired	☐	☐	☐	☐	☐
Nervous	☐	☐	☐	☐	☐
Determined	☐	☐	☐	☐	☐
Attentive	☐	☐	☐	☐	☐
Jittery	☐	☐	☐	☐	☐
Active	☐	☐	☐	☐	☐
Afraid	☐	☐	☐	☐	☐

B. Your thoughts about cancer genetic risk assessment

Below is a list of comments made by people about stressful life events or situations. Please indicate how frequently these statements were true for you **since your referral**. If any item is not relevant to you, please tick the 'not at all' option.

(Tick one box from each row)	Not at all	Rarely	Sometimes	Often
1. I thought about it when I didn't mean to	☐	☐	☐	☐
2. I avoided letting myself get upset when I thought about it or was reminded of it	☐	☐	☐	☐
3. I tried to remove it from my memory	☐	☐	☐	☐
4. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind	☐	☐	☐	☐
5. I had waves of strong feelings about it	☐	☐	☐	☐
6. I had dreams about it	☐	☐	☐	☐
7. I stayed away from reminders of it	☐	☐	☐	☐
8. I felt as if it hadn't happened or wasn't real	☐	☐	☐	☐
9. I tried not to talk about it	☐	☐	☐	☐
10. Pictures about it popped into my mind	☐	☐	☐	☐
11. Other things kept making me think about it	☐	☐	☐	☐
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them	☐	☐	☐	☐
13. I tried not to think about it	☐	☐	☐	☐
14. Any reminder brought back feelings about it	☐	☐	☐	☐
15. My feelings about it were kind of numb	☐	☐	☐	☐

If you have had any specific thoughts about issues relating to your risk assessment since your referral, please write down what you have been thinking about in the space below.

C. Your coping methods

We are interested in finding out about the various ways in which you may try and cope with undergoing cancer genetic risk assessment. Please indicate **to what extent, if any,** you have worried about the following issues, and if so, what you have **done** or **thought** to deal with these worries.

A. Since your referral, have you had any worries about the following:		**B. For each worry you have had, please select from the options below to indicate the most frequent things you have done or thought to try and deal with it. Please tick all that apply.**								
For each item below, please circle the appropriate number in the adjacent box 0= not at all/not applicable 1 = a little 2 = quite a bit 3= very much so		I did things to take my mind off it	I accepted there was nothing I can do	I searched for more information about it	I focused on the positive aspects	I talked or wrote about how I felt	I sought support from family and/or friends	I thought of positive role models	I made a plan of action and followed it	Other (please describe)
EXAMPLE: implications for family	*0 1 3*			✓	✓				✓	
Not understanding the risk assessment process	0 (2) 3									
Having to wait to find out your risk	0 1 2 3									
Completing the Family History Questionnaire	0 1 2 3									
Asking family members about cancer in the family	0 1 2 3									
How you would cope if found to be at increased risk	0 1 2 3									
How family members would react if found to be at increased risk	0 1 2 3									
Being eligible for genetic testing	0 1 2 3									
Possible decisions about surgery	0 1 2 3									
Being able to get increased screening	0 1 2 3									
The impact on your lifestyle if at increased risk.	0 1 2 3									
The implications for family members if at increased risk	0 1 2 3									
Other (please describe) ……..	0 1 2 3									

D. Your views about your possible risk of cancer

We are now interested in your own personal views about how you think you would feel **if you were found to be at increased risk of cancer.** Please indicate how much you agree or disagree with the following statements by ticking the appropriate box. As people are very different, there are no correct answers. *If you have a current or past personal diagnosis of cancer and do not feel that these questions are relevant to you, please tick here ☐ and go to Section E on the next page.*

Views about being at increased risk of cancer.	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
1. Being at increased risk would be a serious issue for me	☐	☐	☐	☐	☐
2. Being at increased risk would have major consequences on my life	☐	☐	☐	☐	☐
3. Being at increased risk would not have much effect on my life	☐	☐	☐	☐	☐
4. Being at increased risk would strongly affect the way others see me	☐	☐	☐	☐	☐
5. Being at increased risk would have serious financial consequences	☐	☐	☐	☐	☐
6. Being at increased risk would cause difficulties for those who are close to me	☐	☐	☐	☐	☐
7. There is a lot that I could do to control my chances of getting cancer	☐	☐	☐	☐	☐
8. What I do could determine whether or not I developed cancer	☐	☐	☐	☐	☐
9. My chances of developing cancer would depend on me	☐	☐	☐	☐	☐
10. Nothing I do would affect my chances of getting cancer	☐	☐	☐	☐	☐
11. I would have the power to influence my chances of getting cancer	☐	☐	☐	☐	☐
12. My actions would have no affect on my chances of getting cancer	☐	☐	☐	☐	☐
13. The genetic risks of cancer are puzzling to me	☐	☐	☐	☐	☐
14. I have a clear picture or understanding of the genetic risks of cancer	☐	☐	☐	☐	☐
15. I don't understand the genetic risks of cancer	☐	☐	☐	☐	☐
16. There is very little that could be done to control my chances of getting cancer	☐	☐	☐	☐	☐
17. Screening (e.g. mammography, colonoscopy) could help control my chances of getting cancer	☐	☐	☐	☐	☐
18. Surgery could help control my chances of getting cancer	☐	☐	☐	☐	☐
19. There is nothing that could help control my chances of developing cancer.	☐	☐	☐	☐	☐

E. Your views about causes of cancer

We are interested in what you consider to be **the possible causes of cancer**. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that may cause cancer rather than what others, including doctors or family members, may have suggested to you. Below is a list of possible causes of cancer. Please indicate how much you currently agree or disagree that they are possible causes by ticking the appropriate box.

Possible Causes	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. Stress or worry	☐	☐	☐	☐	☐
2. Hereditary - it runs in my family	☐	☐	☐	☐	☐
3. A germ or virus	☐	☐	☐	☐	☐
4. Diet or eating habits	☐	☐	☐	☐	☐
5. Chance or bad luck	☐	☐	☐	☐	☐
6. Poor medical care in my past	☐	☐	☐	☐	☐
7. Pollution in the environment	☐	☐	☐	☐	☐
8. My own behaviour	☐	☐	☐	☐	☐
9. My mental attitude e.g. thinking about life negatively	☐	☐	☐	☐	☐
10. Family problems or worries	☐	☐	☐	☐	☐
11. Overwork	☐	☐	☐	☐	☐
12. My emotional state e.g. feeling down, lonely, anxious, empty	☐	☐	☐	☐	☐
13. Ageing	☐	☐	☐	☐	☐
14. Alcohol	☐	☐	☐	☐	☐
15. Smoking	☐	☐	☐	☐	☐
16. Accident or injury	☐	☐	☐	☐	☐
17. My personality	☐	☐	☐	☐	☐
18. A faulty immune system	☐	☐	☐	☐	☐

In the table below, please list in rank-order the three most important factors that you believe may cause cancer. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes:

1. .....

2. .....

3. .....

F. How you cope generally

We are interested in finding out **how you generally deal with events in your life**. Using the scale below, please indicate the degree to which you agree with the following statements, according to your own feelings.

	I agree a lot	I agree a little	I neither agree or disagree	I disagree a little	I disagree a lot
In uncertain times I usually expect the best	☐	☐	☐	☐	☐
It's easy for me to relax	☐	☐	☐	☐	☐
If something can go wrong for me, it will	☐	☐	☐	☐	☐
I'm always optimistic about my future	☐	☐	☐	☐	☐
I enjoy my friends a lot	☐	☐	☐	☐	☐
It's important for me to keep busy	☐	☐	☐	☐	☐
I hardly ever expect things to go my way	☐	☐	☐	☐	☐
I don't get upset too easily	☐	☐	☐	☐	☐
I rarely count on good things happening to me	☐	☐	☐	☐	☐
Overall, I expect more good things to happen to me than bad	☐	☐	☐	☐	☐

G. Please use the space below to tell us about anything that you feel we have not covered in this questionnaire.

H. Background details

1. Your age .....

2. At the moment, are you? (please tick one box)

- ☐ Single (never married)
- ☐ Married or living with partner
- ☐ Divorced or separated
- ☐ Widowed

3. What is the highest level of education you have attained? (please tick one box)

- ☐ Left school before age 16 (no formal qualifications)
- ☐ Left school at 16 (GCSE, CSE, O levels or equivalent)
- ☐ Left school at 18 (A levels or equivalent)
- ☐ College certificate or diploma
- ☐ University degree or higher
- ☐ Other (please state below)

.....

4. How many children do you have? .....

5. Prior to your referral, were you AWARE that you may possibly be at increased risk of cancer because of your family history?

- ☐ Yes
- ☐ No

6. Prior to your referral, how WORRIED were you about possibly being at increased risk of cancer because of your family history?

- ☐ Not at all worried
- ☐ A little worried
- ☐ Quite worried
- ☐ Very worried

Thank you for completing this questionnaire. Please check you have completed and signed the consent form on page 3, as we can only use the information you give us with your signed consent.

Date questionnaire completed ...../...../.....

Thank you very much for your help

Please return your questionnaire in the FREEPOST envelope provided.

If you require any further information about this study, please contact:

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