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Awareness and Beliefs about Cancer (ABC) Study

Public reporting burden for this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-xxxx). Do not return the completed form to this address.

SURVEY

INFORMATION

This study is being conducted by the National Institutes of Health, which is part of the US Department of Health and Human Services.

If you do decide to take part, the survey is estimated to take up to 20 minutes to complete. All information that you give us will be private and your identity will not be passed on to a third party.

Your details will not be passed on to your doctor or other primary care provider. Whether or not you decide to take part, this will not affect your health care in any way.

READ OUT ONLY IF ASKED: Your telephone number has been randomly generated. These numbers are not obtained from any commercially available calling list. Using this process we do not know any details about the household we are calling.

READ OUT ONLY IF ASKED: Ipsos is a member of the Market Research Society and your personal data will be kept private in accordance with the Privacy Act.

VOLUNTARY NATURE OF THE SURVEY

It is up to you to decide whether or not to take part. If you decide to take part you are still free to stop at any time and without giving a reason. If you prefer, you can also skip individual questions on the survey.

ASK ALL

SINGLE CODE

QS4. Now that I have told you about the survey, would you be willing to take part?

1	Yes	CONTINUE
2	No – not available right now AND LOG NAME	MAKE APPOINTMENT TO CALL BACK
3	No – do not want to take part	GO TO QS5

ASK ALL WHO SAY 'NO' AT QS4

MULTICODE

ALLOW "REFUSED"

ENQUIRE GENTLY WITHOUT INSISTING ON AN ANSWER. DO NOT READ OUT

QS5. Please don't feel you have to say, but would you be willing to tell me why you don't want to be interviewed, just to help us get a general idea of why people aren't taking part?

- 1 It would be upsetting / uncomfortable / emotionally difficult to take part
- 2 I don't have time
- 3 Questionnaire is too long
- 4 I don't take part in surveys
- 5 I'm not interested
- 6 I don't know anything about cancer
- 7 Have personal experience of cancer so would be upsetting to take part
- 8 Other

END SURVEY

FOR RESPONDENTS WHO APPEAR DISTRESSED AT ANY POINT OR WHO HAVE CONCERNS OR QUESTIONS ABOUT CANCER – OFFER TO END THE TELEPHONE CALL AND OFFER CONTACT DETAILS AS REQUIRED:

TO SPEAK TO A CANCER INFORMATION SPECIALIST 1-800-422-6237 (TOLL-FREE NUMBER; MON-FRI 8am-8pm EASTERN DAYLIGHT TIME.)

ADD ENDING SCRIPT HERE

Thank you for your time today. Goodbye.

Awareness and Beliefs about Cancer (ABC) measure Interview questionnaire

DEMOGRAPHIC / BACKGROUND INFORMATION 1

I would now like to ask you a couple of questions about yourself, which will help us to analyse the results of the survey.

ASK ALL

WRITE IN

ALLOW "REFUSED"

Q1. What was your age last birthday? RECORD EXACT AGE

IF REFUSED PROBE: Which age group applies to you?

SINGLE CODE. READ OUT

ALLOW "REFUSED"

- 1 50-54
- 2 55-59
- 3 60-64
- 4 65-69
- 5 70-74
- 6 75-79
- 7 80-84
- 8 85-89
- 9 90+

ASK ALL

SINGLE CODE

Q2. INTERVIEWER TO CODE GENDER

- 1 Female
- 2 Male

ASK ALL

SINGLE CODE

ALLOW "REFUSED" OR "DON'T KNOW"

Q3. Have you, or any friends or family members that are close to you, ever been diagnosed with cancer?

IF 'YES', PROBE: May I ask, is that you, someone close to you or both you and someone close to you?

- 1 Yes, respondent (self)
- 2 Yes, someone close
- 3 Yes, both self and someone close
- 4 Yes, but would prefer not to say who
- 5 No

CANCER AWARENESS

This question is about your awareness of, and beliefs about, cancer; it is not assessing your personal risk of cancer. This is not a test, we are interested in your thoughts and beliefs so please answer the questions as honestly as you can.

READ OUT ONLY IF ASKED: I am sorry that I can't answer detailed questions during the interview but we can go back to these at the end if you like. But I won't be able to go back at the end to change any answers.

WARNING SIGNS/SYMPTOMS

ASK ALL

WRITE IN

ALLOW "DON'T KNOW" OR "REFUSED"

Q4. There are many warning signs and symptoms of cancer. Please name as many as you can think of.

READ OUT ONLY IF ASKED: Please think about all different types of cancer.

RECORD ALL OF THE WARNING SIGNS OR SYMPTOMS THAT THE PERSON MENTIONS EXACTLY AS THEY SAY IT AND PROMPT UNTIL THE RESPONDENT CANNOT THINK OF ANY MORE SIGNS: Can you think of any others?

1	
2	
3	
4	
5	
6	
7	
8	
9	
10	

ANTICIPATED DELAY IN SEEKING MEDICAL HELP

ASK ALL

SINGLE CODE FOR EACH PART. ROTATE QUESTIONS Q5-Q8a ALLOW "DON'T KNOW" OR "REFUSED"

The next questions are about going to the doctor. I'm going to read you out a list of signs and symptoms. For each one please tell me how long it would take you to go to the doctor from the time you first noticed the symptom.

Q5. A persistent cough?

READ OUT ONLY IF ASKED: By persistent I mean that it has lasted for some time.

Q6. Rectal bleeding, that is bleeding from the back passage or blood in the bowel motions?

ASK WOMEN ONLY

Q7. Any breast changes?

ASK ALL

Q8. Abdominal bloating? By abdominal, I mean your tummy or belly.

Q8a. A change in the appearance of a mole.

IF WOULD NOT GO TO DOCTOR, PROBE ON WHETHER RESPONDENT WOULD GO ANYWHERE ELSE

- 1 Up to 1 week
- 2 Over 1 up to 2 weeks
- 3 Over 2 up to 3 weeks
- 4 Over 3 up to 4 weeks
- 5 More than a month
- 6 I would go as soon as I noticed
- 7 I would not contact my doctor
- 8 I would go to a pharmacist instead of a doctor:
- 9 I would go to a nurse (at my doctor's office) instead of a doctor:
- I would go to a healthcare professional at at a drop-in clinic or clinic in a pharmacy
- I would go to a healthcare professional at a hospital instead of a doctor

I'm now going to list some symptoms that may or may not be warning signs for cancer. For each one, can you tell me whether you think that it could be a warning sign for cancer?

ASK ALL

SINGLE CODE FOR EACH PART. ROTATE QUESTIONS Q9-Q19

ALLOW "REFUSED" AND "DON'T KNOW"

Q9-19. Do you think [INSERT WARNING SIGN] could be a sign of cancer?

READ OUT ONLY IF ASKED: By persistent I mean that it has lasted for 3-6 weeks.

READ OUT ONLY IF ASKED: By unexplained I mean that it is not due to an illness or injury that you already know about.

READ OUT ONLY IF ASKED: By a change in bowel and bladder habits I mean a change in pooing and weeing.

READ OUT ONLY IF ASKED: By night sweats I mean sweats that wake you and make your sheets damp

- Q9. an unexplained lump or swelling
- Q10. a persistent unexplained pain
- Q11. unexplained bleeding
- Q12. a persistent cough or hoarseness
- Q13. a change in bowel or bladder habits
- Q14. a persistent difficulty in swallowing
- Q15. a change in the appearance of a mole
- Q16. a sore that does not heal
- Q17. unexplained night sweats
- Q18. unexplained weight loss
- Q19. unexplained tiredness
 - 1 Yes
 - 2 No

SELF-RATED HEALTH, ACCESS TO A DOCTOR AND SMOKING

I would just like to ask you a couple more questions about yourself.

ASK ALL

SINGLE CODE. READ OUT

ALLOW "DON'T KNOW" OR "REFUSED"

ROTATE RESPONSE OPTIONS FOR 50% OF RESPONDENTS

Q20. In general, would you say your health is...?

- 1 Very good
- 2 Good
- 3 Fair
- 4 Poor
- 5 Very poor

ASK ALL

SINGLE CODE. READ OUT

ALLOW "DON'T KNOW" OR "REFUSED"

ROTATE RESPONSE OPTIONS FOR 50% OF RESPONDENTS

Q21. How easy, or difficult, is it for you to get to see a doctor if you have a symptom that you think might be serious?

- 1 Very difficult
- 2 Somewhat difficult
- 3 Somewhat easy
- 4 Very easy

ASK ALL

SINGLE CODE

ALLOW "DON'T KNOW" OR "REFUSED"

Q22. Do you smoke at all these days, either cigarettes, including hand-rolled ones, pipes or cigars?

- 1 Yes
- 2 No

ASK ALL WHO SAY 'NO' AT Q22

SINGLE CODE

ALLOW "DON'T KNOW" OR "REFUSED"

Q23. Have you ever smoked cigarettes, including hand-rolled ones, pipes or cigars?

- 1 Yes
- 02 No

ACCESS TO CARE: EARLY SYMPTOMATIC PRESENTATION

Sometimes people put off going to see the doctor even when they have a symptom they think might be serious. These are some of the reasons people give for delaying. Could you say if any of these might put you off going to the doctor?

For each one that I read out, please respond either 'Yes, often', 'Yes, sometimes', or 'No'.

ASK ALL

SINGLE CODE FOR EACH PART. ROTATE QUESTIONS Q24-Q27 IF RESPONDENT REQUESTS, READ OUT RESPONSES AGAIN ALLOW "DON'T KNOW" OR "REFUSED"

- Q24. I would be too embarrassed.
- Q25. I would be worried about wasting the doctor's time.
- Q26. I would be worried about what the doctor might find.
- Q27. I am too busy to make time to go to the doctor.
- Q27a. I would be worried about the cost.
- Q27b. I would be worried the doctor would not take my symptom seriously.
 - 1 Yes, often
 - 2 Yes, sometimes
 - 3 No

GENERAL CANCER BELIEFS AND BELIEFS ABOUT EARLY SYMPTOMATIC PRESENTATION AND EARLY DIAGNOSIS OF CANCER

I'm now going to read you some statements that are sometimes made about cancer.

For each of the statements can you tell me how much you agree or disagree with each item?

ASK ALL

SINGLE CODE FOR EACH PART. ROTATE QUESTIONS Q28-Q32 ALLOW "DON'T KNOW" OR "REFUSED"

IF RESPONDENT SAYS AGREE / DISAGREE: Is that strongly or tend to agree / disagree?

- Q28. These days, many people with cancer can expect to continue with normal activities and responsibilities.
- Q29. Most cancer treatment is worse than the cancer itself.
- Q30. I would NOT want to know if I have cancer.
- Q31. Cancer can often be cured.
- Q32. Going to the doctor as quickly as possible after noticing a symptom of cancer could increase the chances of surviving.
 - 1 Strongly disagree
 - 2 Tend to disagree
 - 3 Tend to agree
 - 4 Strongly agree

ASK ALL

SINGLE CODE

ALLOW "DON'T KNOW" OR "REFUSED"

Q33. Some people think that a diagnosis of cancer is a death sentence. To what extent do you agree or disagree that a diagnosis of cancer is a death sentence?

IF RESPONDENT SAYS AGREE / DISAGREE: Is that strongly or tend to agree / disagree?

- 1 Strongly disagree
- 2 Tend to disagree
- 3 Tend to agree
- 4 Strongly agree

ASK ALL

WRITE IN NUMBER (FROM 0-10) FOR EACH PART. ROTATE QUESTIONS Q34-Q37 ALLOW "DON'T KNOW" OR "REFUSED"

I would now like you to think about people with different types of cancer and how long they may live after finding out they have cancer.

Q34. Out of 10 people diagnosed with colon cancer, how many do you think would be alive 5 years later?

Q35. Out of 10 people diagnosed with breast cancer, how many do you think would be alive 5 years later?

Q36. Out of 10 people diagnosed with ovarian cancer, how many do you think would be alive 5 years later?

Q37. Out of 10 people diagnosed with lung cancer, how many do you think would be alive 5 years later?

1 Record number of people here

RISK

And I would now like you to think about the population in general.

ASK ALL

SINGLE CODE. READ OUT

ALLOW "DON'T KNOW" OR "REFUSED"

Q38. Over the next year, which of these groups of people do you think is most likely to be diagnosed with cancer?

- 1 30 year olds
- 2 50 year olds
- 3 70 year olds
- 4 People of any age are equally likely to be diagnosed with cancer

Module 1 Cancer Screening beliefs and behaviour

CANCER SCREENING BEHAVIOUR

The next section is about cancer screening programs that invite everyone in a particular age group to have tests to check whether they may have colon or breast cancer.

Firstly I am interested in whether you have attended screening.

ASK ALL FEMALES

SINGLE CODE.

ALLOW "DON'T KNOW", "REFUSED" OR "NOT APPLICABLE"

QM1. Have you had a breast cancer screening test, mammogram, in the past 5 years?

- 1 Yes
- 2 No

ASK ALL

SINGLE CODE.

ALLOW "DON'T KNOW", "REFUSED" OR "NOT APPLICABLE"

QM2. Have you had a colon cancer screening test in the past 5 years?

- 1 Yes
- 2 No

BELIEFS ABOUT CANCER SCREENING

ASK ALL FEMALES

SINGLE CODE FOR EACH PART. ROTATE QUESTIONS QM3-QM5 ALLOW "DON'T KNOW" OR "REFUSED"

The next items are about breast cancer screening, mammograms. Can you tell me how much you agree or disagree with each item?

IF RESPONDENT SAYS AGREE / DISAGREE: Is that strongly or tend to agree / disagree

QM3. I would be so worried about what might be found at breast cancer screening that I would prefer not to have it

QM4 Breast cancer screening is only necessary if I have symptoms

QM5 Breast cancer screening could reduce my chance of dying from breast cancer.

- 1 Strongly disagree
- 2 Tend to disagree
- 3 Tend to agree
- 4 Strongly agree

Now I'm going to ask you some items about colon cancer screening.

For each of the statements can you tell me how much you agree or disagree with each item?

ASK ALL

SINGLE CODE FOR EACH PART. ROTATE QUESTIONS QM6-QM8 ALLOW "DON'T KNOW" OR "REFUSED"

IF RESPONDENT SAYS AGREE / DISAGREE: Is that strongly or tend to agree / disagree?

QM6. I would be so worried about what might be found at colon cancer screening, that I would prefer not to do it.

QM7 Colon cancer screening is only necessary if I have symptoms

QM8 Colon cancer screening could reduce my chances of dying from colon cancer.

- 1 Strongly disagree
- 2 Tend to disagree
- 3 Tend to agree
- 4 Strongly agree

DEMOGRAPHIC / BACKGROUND INFORMATION 2

I would now like to ask you a few more questions about yourself, to help us analyze the results of the survey.

ASK ALL

MULTICODE. READ OUT

ALLOW "REFUSED / PREFER NOT TO SAY"

Q39US. Are you Hispanic, Latino/a, or Spanish Origin?

- 1 No, not of Hispanic, Latino/a, or Spanish origin
- 2 Yes, Mexican, Mexican American, Chicano/a
- 3 Yes, Puerto Rican
- 4 Yes, Cuban
- 5 Yes, Another Hispanic, Latino/a or Spanish origin

ASK ALL

MULTICODE. READ OUT

ALLOW "REFUSED / PREFER NOT TO SAY"

Q39aUS. What is your race?

- 1 White
- 2 Black or African American
- 3 American Indian or Alaska Native
- 4 Asian Indian
- 5 Chinese
- 6 Filipino
- 7 Japanese
- 8 Korean
- 9 Vietnamese
- 10 Other Asian
- 11 Native Hawaiian
- 12 Guamanian or Chamorro
- 13 Samoan
- 14 Other Pacific Islander

ASK ALL

SINGLE CODE. READ OUT

ALLOW "REFUSED"

Q40. How well do you speak English?

- 1 Very well
- 2 Well
- 3 Not well
- 4 Not at all

ASK ALL

SINGLE CODE. READ OUT

ALLOW "REFUSED / PREFER NOT TO SAY"

Q41. What is the highest level of education you have achieved?

1 CODES TO BE CONFIRMED

ASK ALL WHO SAY 'OTHER' AT Q41

WRITE IN

ALLOW "REFUSED"

Q41o. Could you please tell me what this other education level is?

ASK ALL

SINGLE CODE. READ OUT

ALLOW "REFUSED" OR "DON'T KNOW"

Q42. Which of these best describes your current marital status?

- 1 Married or in a civil partnership
- 2 Living with my partner
- 3 Single, that is never married and not living with a partner
- 4 Divorced or separated and not living with another partner
- 5 Widowed and not living with another partner

ASK ALL

SINGLE CODE

ALLOW "REFUSED" OR "DON'T KNOW"

Q43a. Are you deaf or do you have serious difficulty hearing?

- 1 Yes
- 2 No

ASK ALL

SINGLE CODE

ALLOW "REFUSED" OR "DON'T KNOW"

Q43b. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

- 1 Yes
- 2 No

ASK ALL

SINGLE CODE

ALLOW "REFUSED" OR "DON'T KNOW"

Q43c. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

- 1 Yes
- 2 No

ASK ALL

SINGLE CODE

ALLOW "REFUSED" OR "DON'T KNOW"

Q43d. Do you have serious difficulty walking or climbing stairs?

- 1 Yes
- 2 No

ASK ALL

SINGLE CODE

ALLOW "REFUSED" OR "DON'T KNOW"

Q43e. Do you have difficulty dressing or bathing?

- 1 Yes
- 2 No

ASK ALL

SINGLE CODE

ALLOW "REFUSED" OR "DON'T KNOW"

Q43f. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

- 1 Yes
- 2 No

FOR RESPONDENTS WHO WOULD LIKE FURTHER INFORMATION ABOUT THE SURVEY

Please contact the research team using the following details:

Colin Gardiner – xxx-xxx-xxxx or Laura Davies – xxx-xxx-xxxx

THANK RESPONDENT AND CLOSE

Thank you on behalf of Ipsos.

If you have any queries regarding the survey or our company, I can give you the telephone number of the company.

PROVIDE AS NECESSARY

Company number - xxx-xxx-xxx

Job number - 12-054721-01