

Together we will beat cancer



**TERMS OF USE FOR THE CANCER RESEARCH UK
CANCER AWARENESS MEASURE**

Please find enclosed/attached the Cancer Research UK Cancer Awareness Measure ("CAM") a validated survey instrument enabling you to gather cancer awareness data and guidance for its use.

As you can appreciate with a tool such as this it is vital that consistency of approach to data capture is maintained.

Please ensure that your use of the CAM complies with our guidance notes.

Please do not alter the CAM or any of the guidance supplied.

Please ensure that the following notice is included on any copies or partial copies that you make of the CAM or any of the guidance supplied, and in any publication based wholly or partly on its use.

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London and Oxford University in 2007-08.

You may use the data collected for your own non-commercial purposes.

We would like to see all CAM data lodged in one place for ease of reference to researchers in the future. To facilitate this we have made arrangements with the UK Data Archive, www.data-archive.ac.uk to provide a repository for this (tbc). Please ensure that you lodge the data you gather there (more details to follow).

If you have any queries please contact naedi@cancer.org.uk

Together we will beat cancer

CANCER RESEARCH UK



Cancer Research UK

Cancer Awareness Measure (CAM)

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

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

The following may or may not be warning signs for cancer. We are interested in your opinion:

| | Yes | No | Don't know |
|--|--------------------------|--------------------------|--------------------------|
| Do you think an unexplained lump or swelling could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think persistent unexplained pain could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think unexplained bleeding could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think a persistent cough or hoarseness could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think a persistent change in bowel or bladder habits could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think persistent difficulty swallowing could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think a change in the appearance of a mole could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think a sore that does not heal could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think unexplained weight loss could be a sign of cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Sometimes people put off going to see the doctor, even when they have a symptom that 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?

| | Yes often | Yes sometimes | No | Don't know |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| I would be too embarrassed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I would be too scared | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I would be worried about wasting the doctor's time | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My doctor would be difficult to talk to | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| It would be difficult to make an appointment with my doctor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I would be too busy to make time to go to the doctor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have too many other things to worry about | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| It would be difficult for me to arrange transport to the doctor's surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I would be worried about what the doctor might find | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I wouldn't feel confident talking about my symptom with the doctor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

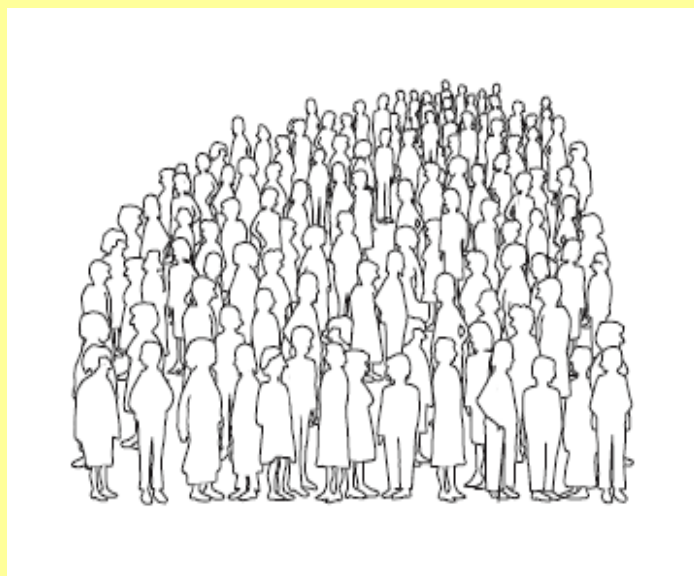
Other (please specify)

What things do you think affect a person's chance of getting cancer?

Medical scientists suggest that these are some of the things that can increase the chance of getting cancer. How much do you agree that each of these can increase the chance of getting cancer?

| | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Smoking any cigarettes at all | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Exposure to another person's cigarette smoke | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Drinking more than 1 unit of alcohol a day | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Eating less than 5 portions of fruit and vegetables a day | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Eating red or processed meat once a day or more | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Being overweight (BMI over 25) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Getting sunburnt more than once as a child | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Being over 70 years old | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having a close relative with cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Infection with HPV (Human Papillomavirus) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Doing less than 30 mins of moderate physical activity 5 times a week | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Here is a picture of 100 people. Out of 100 people, how many do you think will develop cancer at some point in their life?



_____ people out of 100 will develop cancer at some point in their life

What do you think is the **most** common cancer in women?

What do you think is the **second** most common cancer in women?

What do you think is the **third** most common cancer in women?

What do you think is the **most** common cancer in men?

What do you think is the **second** most common cancer in men?

What do you think is the **third** most common cancer in men?

Yes

No

Don't know

Is there an NHS breast cancer screening programme?

If yes, at what age are women first invited for breast cancer screening? _____

Is there an NHS cervical cancer screening programme (smear tests)?

If yes, at what age are women first invited for cervical cancer screening? _____

Is there an NHS bowel cancer screening programme?

If yes, at what age are people first invited for bowel cancer screening? _____

Please put the following things in order of how much you think they contribute to cancer in the UK:

Lifestyle (e.g. smoking, diet, physical activity)

Chance

Aging

Environmental factors (e.g. pollution, radiation)

Genetic inheritance (e.g. runs in the family)

1. _____ (Most important)

2. _____

3. _____

4. _____

5. _____ (Least important)



Cancer Research UK

Cancer Awareness Measure (CAM)

Demographic Questions

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

We would now like to ask you a few questions about yourself to help to analyse the study. You will not be asked your name and all of your answers are confidential.

1. What is your age?

| | |
|--|--|
| | |
|--|--|

2. What is your gender?

Male

Female

3. Which of these best describes your ethnic group?

| White | Mixed | Asian or Asian British | Black or Black British | Chinese/other |
|---|---|---|---|-------------------------------------|
| <input type="checkbox"/> White British | <input type="checkbox"/> White and Black Caribbean | <input type="checkbox"/> Indian | <input type="checkbox"/> Black Caribbean | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> White Irish | <input type="checkbox"/> White and Black African | <input type="checkbox"/> Pakistani | <input type="checkbox"/> Black African | <input type="checkbox"/> Other..... |
| <input type="checkbox"/> Any other White background | <input type="checkbox"/> White and Asian | <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Any other Black background | |
| | <input type="checkbox"/> Any other Mixed background | <input type="checkbox"/> Any other Asian background | | |

4. What is your marital status?

| | | | | | |
|--------------------------|-----------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Single/never married | Married/living with partner | Married separated from | Divorced | Widowed | Civil partnership |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

5. What is the highest level of education qualification you have obtained?

| | |
|--|---|
| <input type="checkbox"/> Degree or higher degree | <input type="checkbox"/> O Level or GCSE equivalent (Grade A - C) |
| <input type="checkbox"/> Higher education qualification below degree level | <input type="checkbox"/> O Level or GCSE (Grade D - G) |
| <input type="checkbox"/> A-levels or highers | <input type="checkbox"/> No formal qualifications |
| <input type="checkbox"/> ONC/BTEC | <input type="checkbox"/> Other |

6. Please tick the box which best describes your living arrangement:

| | | | | | |
|--------------------------|--------------------------|---|--------------------------|--------------------------|---|
| Own outright | Own mortgage | Rent from Local Authority/Housing Association | Rent privately | Squatting | Other (e.g. living with family/friends) |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7. What is your Postcode?

8. Are you currently:

| | |
|---|--|
| <input type="checkbox"/> Employed full-time | <input type="checkbox"/> Full-time homemaker |
| <input type="checkbox"/> Employed part-time | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Unemployed | <input type="checkbox"/> Student |
| <input type="checkbox"/> Self-employed | <input type="checkbox"/> Disabled or too ill to work |

9. Does your household own a car or van?

| | | |
|--------------------------|--------------------------|--------------------------|
| No | Yes, one | Yes, more than one |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

10. Have you, your family or close friends had cancer? (please tick all that apply)

| | | | | | |
|---------------------|------------------------------|-----------------------------|-----------------------|------------------------------|-----------------------------|
| You | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Close Friend | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Partner | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Other Friend | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Close family member | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Not sure | <input type="checkbox"/> | |
| Other family member | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Do not wish to answer | <input type="checkbox"/> | |

11. How many years have you been living in the UK?

| | |
|--|--|
| | |
|--|--|

12. What is the main language spoken at home?

| | |
|-----------------------------------|-------------------------------------|
| <input type="checkbox"/> English | <input type="checkbox"/> Sylheti |
| <input type="checkbox"/> Urdu | <input type="checkbox"/> Cantonese |
| <input type="checkbox"/> Punjabi | <input type="checkbox"/> Other..... |
| <input type="checkbox"/> Gujarati | |

Cancer Research UK

Cancer Awareness Measure (CAM)

Instruction Sheet

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

CR-UK Cancer Awareness Measure (CAM) - Directions for use

Purpose

In 2007, the NHS Cancer Reform Strategy published by the Department of Health, emphasised the importance of raising awareness of cancer early warning signs and risk factors within the general population. The Cancer Awareness Measure (CAM) has been designed to provide a comprehensive assessment of cancer awareness in the general population.

Evaluation and psychometric status

The DEVELOPMENT PAPER (in prep) indicates that the CAM has satisfactory internal reliability with Cronbach's alpha above 0.7 for all components apart from awareness of NHS screening programmes (Cronbach's alpha 0.62). Test-retest reliability over a 2 week interval was found to be good, with all correlations above 0.7 except for incidence of common cancers. Item difficulty (Kline, 1993) was assessed and the majority of items in the CAM were answered correctly by more than 20% and less than 80% of respondents. Those items that did not were retained on the basis of content validity (e.g. smoking being a risk factor for cancer, a lump being a warning sign for cancer). In order to ensure construct validity the CAM was completed by 12 cancer experts (GP's, oncologists and CR-UK health information specialists) and 21 university academics from a range of non-medical departments. Cancer experts obtained significantly higher scores than non-medical academics, demonstrating that the CAM is capable of discriminating between those who have high and low levels of cancer awareness. There was also an intervention study in which participants randomly received either an intervention leaflet ("Cancer: The Facts") or a control leaflet ("Recycle to save the environment") to read prior to completing the CAM. Participants who received the intervention leaflet consistently obtained higher awareness scores than those who received the control leaflet. This demonstrates that the CAM is sensitive to increases in cancer awareness.

CAM Instructions

Administration

Currently, the measure can be administered face to face, on the internet, or over the telephone, with certain criteria followed. This measure is not suitable for use as a postal survey because people can look up the answers and change responses on the basis of subsequent questions.

Recruitment considerations

Please record how the sample was recruited using the relevant form (see 'Recruitment Record'), for example, note if flyers were given out or put on notice boards, if GP surgeries were approached etc. Please also record the response rate (how many people were asked to complete the CAM and how many of those agreed to complete it). This information is important when interpreting the results as it gives us an idea of how representative the sample is of the general population and hence whether the results can be considered typical of the general population.

When recruiting your sample, consider the following; you want the sample to be as representative of the general population as possible, consequently you want to sample men and women from different backgrounds and of different ages. If you are targeting a particular group in your area e.g. by ethnicity or socio-economic position, you will need to ensure that your sampling method accurately represents this group. However, the respondents need to be able to understand English. Although we have plans to translate the CAM, it is only available in English at present. We would also like to know how many of the people you invite to complete the CAM refuse to participate and if any people start the questionnaire, but

do not finish it. This information is important when analysing and interpreting the data, as again it gives us an idea of how representative the sample is. We would also like you to provide us with all the data you receive, so even if people miss out some of the questions, we would like any information that they provide.

Please describe the area in which the questionnaires were completed by the respondents; for example, was it in a closed office with just the interviewer and the respondent, or was it in a communal coffee area? Was the questionnaire completed face-to-face or over the telephone? This information is important when interpreting the results as it gives us an idea of how many factors could have been influencing the respondent's answers, such as noise levels or confidentiality.

Before you start recruiting your sample, please consider whether and how you will need to obtain informed consent.

Demographics

Please ensure that all participants complete the 'demographics questions' sheet at the end of the interview. This information is needed to ensure that comparisons of different groups, such as different age groups can be made.

Scoring

Instructions are provided to score each item, along with instructions on how to input the data from the respondents into SPSS or EXCEL (see 'Coding Sheet'). All CAM data will need to be submitted to the UK Data Archive using the coding frame that has been provided.

Interpretation

The CAM comprises 11 questions with a total of 57 items;

- Warning signs (10 items) (Q1 + Q2)
- Delay in seeking medical help (10 items) (Q3 + Q4)
- Barriers to seeking medical help (11 items) (Q5)
 - Emotional – embarrassed, scared, worried about what the doctor might find, confidence discussing symptom (4 items)
 - Practical – too busy, too many worries, transport (3 items)
 - Service – wasting time, difficulty making appointment, difficulty talking to doctor (3 items)
 - Other – verbatim (1 item)
- Risk factors 12 items (Q6 + Q7)
- Incidence (1 item) (Q8)
- Common cancers (6 items) (Q9)
- NHS screening programme (6 items) (Q10)
 - Knowledge (3 items)
 - Age of first invitation (3 items)
- Risk factor ranking (1 item) (Q11)

CAM Questions

Please note it is important that the wording of the questions and answers are not changed.

Q1 – Open warning signs

“There are many warning signs and symptoms of cancer. Please name as many as you can think of”¹

This is an open question designed to measure how many cancer warning signs a respondent can recall unaided. In face to face interviews this Q1 is always printed on a separate page to Q2 to ensure that respondents’ answers are their own and not taken from the list for Q2. Please ensure that the respondent does not see Q2 before they have completed Q1.

Q2 – Closed warning signs

“The following may or may not be warning signs for cancer. We are interested in your opinion. Do you think X is a warning sign for cancer?”²

These closed questions are designed to measure how many warning signs a respondent can recognise when prompted. The 9 warning signs have been widely publicised in previous awareness campaigns, and were taken from the Cancer Research UK website in 2007.

Q3 - Help-seeking

“If you noticed X how soon would you contact your doctor to make an appointment to discuss it?”³

This set of questions can be used to measure when an individual would seek help for each of the 9 cancer warning signs listed.

Q4 - Seeking help for cancer symptoms

“If you had a symptom that you thought might be a sign of cancer how soon would you contact your doctor to make an appointment to discuss it?”²

This question can be used to assess when an individual would seek help for a symptom that they thought could be a sign of cancer.

Q5 – Barriers to seeking help

“Sometimes people put off going to see the doctor, even when they have a symptom that 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?”⁴

The purpose of these closed questions is to examine the potential barriers to help seeking. The barriers can be grouped as emotional barriers, practical barriers and service barriers.

Q6 – Open risk factors

“What things do you think affect a person’s chance of getting cancer?”²

This is an open question designed to measure how many cancer risk factors a respondent can recall unaided. In face to face interviews Q6 is always printed on a separate sheet to Q7 in order to ensure that respondents’ answers are their own and not taken from the list given for Q7. Please ensure that the respondent does not see Q7 before they have completed Q6.

Q7 – Closed risk factors

“Medical scientists suggest that these are some of the things that can increase the chance of getting cancer. How much do you agree that each of these can increase the chance of getting cancer?”²

These closed questions are designed to measure a respondent’s level of agreement with the 11 risk factors. As with the warning signs the risk factors have been widely publicised in previous awareness campaigns, and have been taken from the Cancer Research UK website.

Q8 - Incidence

“Here is a picture of 100 people. Out of 100 people, how many do you think will develop cancer at some point in their life?”²

This is an open question assessing whether people are aware of the life time risk of cancer. We have found the picture to be a useful aid when answering this question.

For interviews conducted over the telephone please omit *“Here is a picture of 100 people”* and replace with *“Please imagine 100 people”*.

Q9 - Most common cancers

“What do you think is the most/second most/third most common cancer in women?”⁵

“What do you think is the most/second most/third common cancer in men?”⁵

The purpose of these open questions is to explore whether respondents are aware of the most common cancers in men and women.

Q10 - NHS screening programmes

“Is there an NHS X cancer screening programme?”²

“If yes, at what age are women/men first invited for X cancer screening?”²

This set of questions assesses awareness of NHS screening programmes, and the age at which people are first invited for screening.

Q11 - Contribution to cancer

“Please put the following things in order of how much you think they contribute to cancer in the UK”²

This question was included in the awareness measure as we thought it would be useful to explore how controllable respondents believed developing cancer to be (i.e. do people think lifestyle is the main contributor, or do they believe it is it largely due to chance/genetics).

¹ Question is a modified version of the original: McCaffery, K., Wardle, J. & Waller, J. (2003). Knowledge, attitudes, and behavioural intentions in relation to the early detection of colorectal cancer in the United Kingdom. *Preventive Medicine, 36*, 525-535

² Question developed specifically for the Cancer Awareness Measure

³ Question is a modified version of the original: Jackson, A., Wilkinson C. & Pill, R. (1999). Moles and melanomas - who's at risk, who knows, and who cares? A strategy to inform those at high risk. *British Journal of General Practice, 49*, 199-203

⁴ Response options derived from: Breast Cancer Care Breast Awareness Survey (2005)

⁵ Question is a modified version of the original: Adlard, A. W. & Hume, J. W. (2003). Cancer knowledge of the general public in the United Kingdom: survey in a primary care setting and review of the literature. *Clinical Oncology, 15*, 174-180



Cancer Research UK

Cancer Awareness Measure (CAM)

Coding sheet (for use with SPSS or EXCEL)

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

Below is a format for recording the data of the CAM so that it is suitable for depositing in the data archive. We are currently making arrangements to deposit the data at the UK Data Archive and will provide instructions on how to do this at a later date.

You can see that as well as numbers for coding the data, we are also providing a set of correct 'variable names' (e.g. **LumpC**). Please use these 'variable names' when recording your data.

For every question it is possible to code data as 'refused'. Use this code when the participant actively chooses not to respond. Where appropriate there is a code for 'don't know', please see relevant questions below. For all other missing data just leave a blank.

Please store the data in either EXCEL or SPSS for transfer to the archive. There is a template EXCEL and SPSS data file available, if you require it.

If you have any queries, please contact Dr Alice Simon:
alice.simon@ucl.ac.uk

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

Variable names: SymptomO1 to SymptomO18

- **Please create 18 variables labelled 1, 2, 3' etc up to 18. Each symptom must be recorded as a new variable using the coding frame below. For example if the first response is 'weight loss' code as '9' in SymptomO1. If the second response is 'bleeding' code as '3' in SymptomO2 etc**
- **To code a variable that is not on the list code as 'Other' (code 17) and write the variable verbatim in: SymptomO17 or SymptomO18. This can be done for 2 'other' variables.**

| Warning sign | Code |
|--------------------------------|-------------|
| Lump/swelling | 1 |
| Pain | 2 |
| Bleeding | 3 |
| Cough/hoarseness | 4 |
| Change in bowel/bladder habits | 5 |
| Difficulty swallowing | 6 |
| Change in appearance of a mole | 7 |
| Sore that does not heal | 8 |
| Weight loss | 9 |
| Tiredness/fatigue | 10 |
| Nausea/sickness | 11 |
| Generally unwell | 12 |
| Bruising | 13 |
| Loss of appetite | 14 |
| Blurred vision | 15 |
| Feeling weak | 16 |
| Other | 17 |
| Nothing | 18 |
| Refusal | 98 |
| Don't know | 99 |

The following may or may not be warning signs for cancer. We are interested in your opinion:

| Question followed by corresponding SPSS/Excel Variable Name | Scoring | | |
|---|---------|----|------------|
| | Yes | No | Don't know |
| Do you think an unexplained lump or swelling could be a sign of cancer? LumpC | 3 | 2 | 1 |
| Do you think persistent unexplained pain could be a sign of cancer? PainC | 3 | 2 | 1 |
| Do you think unexplained bleeding could be a sign of cancer? BleedingC | 3 | 2 | 1 |
| Do you think a persistent cough or hoarseness could be a sign of cancer? CoughC | 3 | 2 | 1 |
| Do you think a persistent change in bowel or bladder habits could be a sign of cancer? BowelC | 3 | 2 | 1 |
| Do you think persistent difficulty swallowing could be a sign of cancer? SwallowingC | 3 | 2 | 1 |
| Do you think a change in the appearance of a mole could be a sign of cancer? MoleC | 3 | 2 | 1 |
| Do you think a sore that does not heal could be a sign of cancer? SoreC | 3 | 2 | 1 |
| Do you think unexplained weight loss could be a sign of cancer? WeightC | 3 | 2 | 1 |

If you noticed an unexplained lump or swelling how soon would you contact your doctor to make an appointment to discuss it? **Variable name: LumpTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you had unexplained pain how soon would you contact your doctor to make an appointment to discuss it? **Variable name: PainTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you had unexplained bleeding how soon would you contact your doctor to make an appointment to discuss it? **Variable name: BleedingTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you had a cough or hoarseness how soon would you contact your doctor to make an appointment to discuss it? **Variable name: CoughTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you noticed a change in bowel or bladder habits how soon would you contact your doctor to make an appointment to discuss it? **Variable name: BowelTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you had difficulty swallowing how soon would you contact your doctor to make an appointment to discuss it? **Variable name: SwallowingTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you noticed a change in the appearance of a mole how soon would you contact your doctor to make an appointment to discuss it? **Variable name: MoleTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you had a sore that did not heal how soon would you contact your doctor to make an appointment to discuss it? **Variable name: SoreTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you had unexplained weight loss how soon would you contact your doctor to make an appointment to discuss it? **Variable name: WeightTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

If you had a symptom that you thought might be a sign of cancer how soon would you contact your doctor to make an appointment to discuss it? **Variable name: CancerSignTime**

| 1-3 days | 4-6 days | 1 week | 2 weeks | 1 month | 6 weeks | 3 months | 6 months | 12 months | Never |
|----------|----------|--------|---------|---------|---------|----------|----------|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

Sometimes people put off going to see the doctor, even when they have a symptom that 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?

| Question followed by SPSS/Excel variable name | Scoring | | | |
|---|------------------|---------------|----|------------|
| | Yes often | Yes sometimes | No | Don't know |
| I would be too embarrassed Embarrassed | 4 | 3 | 2 | 1 |
| I would be too scared Scared | 4 | 3 | 2 | 1 |
| I would be worried about wasting the doctor's time WorryTime | 4 | 3 | 2 | 1 |
| My doctor would be difficult to talk to DifficultTalk | 4 | 3 | 2 | 1 |
| It would be difficult to make an appointment with my doctor Appointment | 4 | 3 | 2 | 1 |
| I would be too busy to make time to go to the doctor Busy | 4 | 3 | 2 | 1 |
| I have too many other things to worry about WorryMany | 4 | 3 | 2 | 1 |
| It would be difficult for me to arrange transport to the doctor's surgery Transport | 4 | 3 | 2 | 1 |
| I would be worried about what the doctor might find WorryFind | 4 | 3 | 2 | 1 |
| I wouldn't feel confident talking about my symptom with the doctor Confident | 4 | 3 | 2 | 1 |
| Other (please specify) Other | Type in verbatim | | | |

What things do you think affect a person's chance of getting cancer?

Variable names: RiskO1 to RiskO26

Please create 26 variables labelled 1, 2, 3 etc, up to 26. Each risk factor must be recorded as a new variable using the coding frame below. For example if the first response is 'being overweight' code as '6' in RiskO1. If the second response is 'pollution' code as '22' in RiskO2 etc.

To code a variable that is not on the list code as 'Other' (code 25) and write the variable verbatim in: RiskO25 or RiskO26. This can be done for 2 'other' variables.

| Risk Factor | Code |
|--|------|
| Smoking | 1 |
| Exposure to another person's cigarette smoke (passive smoking) | 2 |
| Drinking alcohol | 3 |
| Not eating enough fruit and vegetables | 4 |
| Eating red or processed meat | 5 |
| Being overweight | 6 |
| Getting sunburnt/exposure to the sun | 7 |
| Older age | 8 |
| Family history/having a close relative with cancer/Hereditary | 9 |
| Infection with HPV (human papillomavirus) | 10 |
| Not doing enough exercise/physical activity | 11 |
| Diet (unspecified) | 12 |
| A high fat diet | 13 |
| A low fibre diet | 14 |
| Food additives | 15 |
| Being underweight | 16 |
| Genes/genetics | 17 |
| Infection with viruses (Unspecified/Other) | 18 |
| Having many sexual partners | 19 |
| Taking HRT/the (contraceptive) pill | 20 |
| Living near power lines | 21 |
| Pollution | 22 |
| Radiation | 23 |
| Stress | 24 |
| Other | 25 |
| Nothing | 26 |
| Refusal | 98 |
| Don't know | 99 |

Medical scientists suggest that these are some of the things that can increase the chance of getting cancer. How much do you agree that each of these can increase the chance of getting cancer?

| Question followed by SPSS/Excel variable name | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|--|-------------------|----------|----------|-------|----------------|
| Smoking any cigarettes at all SmokingC | 1 | 2 | 3 | 4 | 5 |
| Exposure to another person's cigarette smoke PassiveC | 1 | 2 | 3 | 4 | 5 |
| Drinking more than 1 unit of alcohol a day AlcoholC | 1 | 2 | 3 | 4 | 5 |
| Eating less than 5 portions of fruit and vegetables a day FruitC | 1 | 2 | 3 | 4 | 5 |
| Eating red or processed meat once a day or more MeatC | 1 | 2 | 3 | 4 | 5 |
| Being overweight (BMI over 25) OverweightC | 1 | 2 | 3 | 4 | 5 |
| Getting sunburnt more than once as a child SunburnC | 1 | 2 | 3 | 4 | 5 |
| Being over 70 years old OlderC | 1 | 2 | 3 | 4 | 5 |
| Having a close relative with cancer FamilyC | 1 | 2 | 3 | 4 | 5 |
| Infection with HPV (Human Papillomavirus) HPVC | 1 | 2 | 3 | 4 | 5 |
| Doing less than 30 mins of moderate physical activity 5 times a week ExerciseC | 1 | 2 | 3 | 4 | 5 |

Here is a picture of 100 people. Out of 100 people, how many do you think will develop cancer at some point in their life?



___ ___ ___ people out of 100 will develop cancer at some point in their life

Record the actual number (0-100) that the respondent gave as the answer in the variable name: **Incidence**

Below are the variable names used in Q9, please turn to the next page for the appropriate coding frame that accompanies these variable names.

What do you think is the **most** common cancer in women?

Variable name: Cancer1F

NB To code a variable that is not on the list, code as 'Other' (code '19') and then write the variable verbatim in: 'Cancer1otherF' or in the appropriate 'other' variable field. Further explanation on next page.

(Cancer1otherF)

What do you think is the **second** most common cancer in women?

Variable name: Cancer2F

(Cancer2otherF)

What do you think is the **third** most common cancer in women?

Variable name Cancer3F

(Cancer3otherF)

What do you think is the **most** common cancer in men?

Variable name: Cancer1M

(Cancer1otherM)

What do you think is the **second** most common cancer in men?

Variable name: Cancer2M

(Cancer2otherM)

What do you think is the **third** most common cancer in men?

Variable name: Cancer3M

(Cancer3otherM)

CODING FRAME ON NEXT PAGE

Data archive: Please use the coding frame for men and women below for transfer to the data archive. Example: If the response for the ‘most’ common cancer in women is ‘lung cancer’ place code ‘9’ under variable name **Cancer1F**.

Code a response that is not on the list code as ‘Other’ (code ‘25’) and write the variable verbatim in: Cancer1otherF or in the appropriate ‘other’ variable field.

| Cancer type | Code |
|--|-------------|
| Bladder | 1 |
| Bowel/colorectal/rectal | 2 |
| Brain | 3 |
| Breast | 4 |
| Cervical/cervix | 5 |
| Kidney | 6 |
| Leukaemia | 7 |
| Liver | 8 |
| Lung | 9 |
| Lymphoma | 10 |
| Melanoma | 11 |
| Mesothelioma (protective lining of the lung, stomach, heart) | 12 |
| Multiple myeloma | 13 |
| Non-Hodgkin's lymphoma | 14 |
| Oesophagus/gullet/food pipe | 15 |
| Oral/mouth/oropharynx/lips/tongue | 16 |
| Ovarian | 17 |
| Pancreatic | 18 |
| Prostate | 19 |
| Skin | 20 |
| Stomach | 21 |
| Testicular | 22 |
| Throat | 23 |
| Uterus/endometrial/womb | 24 |
| Other | 25 |
| Refusal | 98 |
| Don't know | 99 |

| | | | |
|---|--------------|---------|------------|
| <p>Is there an NHS breast cancer screening programme?</p> <p>Variable name: BreastScreening</p> | Yes | No | Don't know |
| | 3 | 2 | 1 |
| <p>If yes, at what age are women first invited for breast cancer screening? _____</p> <p>For the age component of this question, please record the actual age the respondent gave as the answer in the variable name.</p> <p>Variable name: BreastAge</p> | Age in years | Refused | Don't know |
| | | 988 | 999 |
| <p>Is there an NHS cervical cancer screening programme (smear tests)?</p> <p>Variable name: CervicalScreening</p> | Yes | No | Don't know |
| | 3 | 2 | 1 |
| <p>If yes, at what age are women first invited for cervical cancer screening? _____</p> <p>For the age component of this question, please record the actual age the respondent gave as the answer in the variable name</p> <p>Variable name: CervicalAge</p> | Age in years | Refused | Don't know |
| | | 988 | 999 |
| <p>Is there an NHS bowel cancer screening programme?</p> <p>Variable name: BowelScreening</p> | Yes | No | Don't know |
| | 3 | 2 | 1 |
| <p>If yes, at what age are people first invited for bowel cancer screening? _____</p> <p>For the age component of this question, please record the actual age the respondent gave as the answer in the variable name</p> <p>Variable name: BowelAge</p> | Age in years | Refused | Don't know |
| | | 988 | 999 |

Please put the following things in order of how much you think they contribute to cancer in the UK:

Lifestyle (e.g. smoking, diet, physical activity)

Chance

Aging

Environmental factors (e.g. pollution, radiation)

Genetic inheritance (e.g. runs in the family)

1. _____ (Most important)

2. _____

3. _____

4. _____

5. _____ (Least important)

Data archive: Please use the following coding frame for transfer to the data archive –

| Contributing factor | Corresponding variable name in EXCEL/SPSS data file | Code | | | | |
|--------------------------|---|------|--------|-------|--------|-------|
| | | Most | Second | Third | Fourth | Least |
| 11i. Lifestyle | Lifestyle | 1 | 2 | 3 | 4 | 5 |
| 11ii. Chance | Chance | 1 | 2 | 3 | 4 | 5 |
| 11iii. Aging | Aging | 1 | 2 | 3 | 4 | 5 |
| 11iv. Environment | Environment | 1 | 2 | 3 | 4 | 5 |
| 11v. Genetic inheritance | Genetic | 1 | 2 | 3 | 4 | 5 |

Demographic Questions – Coding

1. What is your age?

Variable name: Age

2. What is your gender?

Variable name: Gender

Male

Female

1

2

3. Which of these best describes your ethnic group?

Variable name: EthnicGroup

To code an ethnic group that is not on the list code as 'Other' (code 16) and write the variable verbatim in: OtherEthnic

| White | | Mixed | | Asian or Asian British | | Black or Black British | | Chinese/other | |
|----------------------------|---|----------------------------|---|----------------------------|----|----------------------------|----|---------------|----|
| White British | 1 | White and Black Caribbean | 4 | Indian | 8 | Black Caribbean | 12 | Chinese | 15 |
| White Irish | 2 | White and Black African | 5 | Pakistani | 9 | Black African | 13 | Other..... | 16 |
| Any other White background | 3 | White and Asian | 6 | Bangladeshi | 10 | Any other Black background | 14 | | |
| | | Any other Mixed background | 7 | Any other Asian background | 11 | | | | |

4. What is your marital status?

Variable name: MaritalStatus

Single/never married

Married/living with partner

Married separated from spouse

Divorced

Widowed

Civil partnership

1

2

3

4

5

6

5. What is the highest level of education qualification you have obtained?

Variable name: HighestEducation

To code an ethnic group that is not on the list code as 'Other' (code 7) and write the variable verbatim in: OtherEducation

- | | | | |
|---|---|---|--|
| 1 | Degree or higher degree | 5 | O Level or GCSE equivalent (Grade A - C) |
| 2 | Higher education qualification below degree level | 6 | O Level or GCSE (Grade D - G) |
| 3 | A-levels or higher | 7 | Other |
| 4 | ONC/BTEC | 8 | No formal qualifications |

6. Please tick the box which best describes your living arrangement:

| | | | | | |
|--------------|--------------|---|----------------|-----------|---|
| Own outright | Own mortgage | Rent from Local Authority/Housing Association | Rent privately | Squatting | Other (e.g. living with family/friends) |
| 1 | 2 | 3 | 4 | 5 | 6 |

7. What is your Postcode?

Variable name: Postcode

Please record the respondents postcode by writing it in the variable field labelled Postcode

8. Are you currently:

Variable name: Employed

- | | | | |
|---|--------------------|---|-----------------------------|
| 1 | Employed full-time | 5 | Full-time homemaker |
| 2 | Employed part-time | 6 | Retired |
| 3 | Unemployed | 7 | Student |
| 4 | Self-employed | 8 | Disabled or too ill to work |

9. Does your household own a car or van?

Variable name: Car

- | | | |
|----|----------|--------------------|
| No | Yes, one | Yes, more than one |
| 1 | 2 | 3 |

10. Have you, your family or close friends had cancer? (please tick all that apply)

| | | | | | | | | | |
|---|-----|---|----|---|---|-----|---|----|---|
| You CancerYou | Yes | 1 | No | 2 | Close Friend CancerCloseFriend | Yes | 1 | No | 2 |
| Partner CancerPartner | Yes | 1 | No | 2 | Other Friend CancerOtherFriend | Yes | 1 | No | 2 |
| Close family member CancerCloseFamily | Yes | 1 | No | 2 | Not sure CancerNotSure | 99 | | | |
| Other family member CancerOtherFamily | Yes | 1 | No | 2 | Do not wish to answer CancerRefusal | 98 | | | |

11. How many years have you been living in the UK?

Variable name: YearsUK

12. What is the main language spoken at home?

Variable name: Language

To code an ethnic group that is not on the list code as 'Other' (code 7) and write the variable verbatim in: OtherLanguage

| | | | |
|---|----------|---|------------|
| 1 | English | 5 | Sylheti |
| 2 | Urdu | 6 | Cantonese |
| 3 | Punjabi | 7 | Other..... |
| 4 | Gujarati | | |