Cancer Research UK

Cancer Awareness Measure (CAM)

Toolkit (version 2.1)

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

Toolkit contents

ACKNOWLEDGEMENTS

We would like to acknowledge the valuable contributions made to this guidance document for the Cancer Awareness Measure (CAM) by all those involved in developing the CAM, all the Primary Care Trusts and Cancer Networks who have given us feedback, and in particular by Kathy Elliott at the National Cancer Action Team who provided detailed comments and suggestions for improvement.

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. Please ensure that you lodge the data you gather there (see page 60 for guidance).

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

Cancer Research UK Cancer Awareness Measure (CAM)

Background information and instructions

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

Introduction and purpose of the Cancer Awareness Measure (CAM)

In 2007, the NHS Cancer Reform Strategy[1] 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 developed to help us measure levels of cancer awareness, explore risk factors for poor cancer awareness, and develop and evaluate interventions to promote cancer awareness.

There are many benefits of the CAM:

- Provides a validated set of questions on cancer awareness
- Can be used nationally and regionally
- Can be used to monitor or track how awareness changes over time
- Allows comparisons between different groups of the population
- Identifies information needs
- Monitors the impact of interventions

The CAM comprises 9 questions with a total of 47 items;

- Warning signs (10 items) (Q1 + Q2)
- Seeking help (1 item) (Q3)
- Barriers to seeking help (11 items) (Q4)
    - 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 (Q5 + Q6)
- Cancer and age (1 item) (Q7)
- Most common cancers (6 items) (Q8)
- NHS screening programmes (6 items) (Q9)
    - Knowledge (3 items)
    - Age of first invitation (3 items)

Evaluation and psychometric status

The CAM development paper (Stubbings et al, 2009[2]) indicates that the measure 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

[1] Department of Health (2007). Cancer Reform Strategy. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_081006.

[2] Stubbings S, Robb KA, Waller J, Ramirez A, Austoker J, Macleod U, Hiom S, Wardle J (2009). Development of a measurement tool to assess public awareness of cancer. British Journal of Cancer, 101, Supplement 2, S13-17.

knowledge of common cancers. Item difficulty (Kline, 2000[3]) 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.

Administration

The CAM was designed to be administered as an interview either face-to-face or over the telephone and these delivery methods will yield the best quality data. If it is not possible to use either of these methods we advise using a supervised self-complete method where individuals are asked to complete the measure but under supervised conditions with someone available for guidance. It is possible to use the CAM on the internet, or as a 'self complete' survey that is not supervised (e.g. postal) but this will provide lower quality data.

Face-to-face

Ideally, the CAM should be administered by one trained interviewer in an environment where there will be little distraction.

The internet

Using the CAM on the internet is often a cheaper and more practical option, but there are several things you should consider before using this option. For example, you should be aware that not everybody will have internet access, and in particular those from lower socio-economic groups may not have access. So using the CAM in this way could introduce some inequality and not provide total coverage. It is also worth considering participants familiarity with using the internet. Conducting the survey on-line is also a 'less controlled' environment, for example, it is possible that participants could look up the correct answers while completing the survey or consult with others to help them answer the questions.

If you plan to use an on-line version you should ensure that participants cannot return back to previous questions. For sections where there are lists e.g. symptoms or risk factors, it is best to present these as one item per screen, rather than a long list. You could also consider monitoring the time it takes for participants to complete the survey because this could help pinpoint participants who may have less reliable responses.

If you go ahead with an online version you may want to do a quick pilot to make sure that it is being used appropriately and that you aren't suddenly getting 'odd' responses e.g. if someone can't go back and change their answers, but they didn't understand the response options 'first time' this may result in some errors.

[3] Klein, P (2000). The Handbook of Psychological Testing. Routledge: London.

Telephone

The telephone offers a good alternative to face-to-face interviews. You should ask respondents to ensure that they are not to be distracted by anyone while completing the survey.

Self-complete or postal

If you would like to administer the CAM as 'self-complete' or postal survey you must either remove Q1 and Q5 or Q2 and Q6. Q1 and Q5 are 'unprompted' questions which ask respondents to recall warning signs or risk factors from memory. Q2 and Q6 are 'prompted' questions asking respondents to respond to a prompted list of warning signs and risk factors. If both sets of unprompted and prompted questions are included in the survey respondents could go back and change their answers to Q1 and Q5 as a result of being prompted in Q2 and Q6.

You should consider the aims and objectives of your study and the analyses that you plan to carry out to help you decide which questions to keep in the survey. If you are interested in what people actually 'know' you should keep the unprompted questions. But if you would prefer to assess respondent's ability to 'recognise' signs or risk factors, you should keep the prompted questions. You may also find that the unprompted questions are more difficult to code and use in analyses because they generate a larger variety in responses and so this represents are more difficult option for less experienced researchers.

Recruitment considerations

For information about sampling methods and sample size for your CAM survey please see page 77. Once you have recruited your participants please record the sampling methods using the relevant form (see 'Recruitment Record' on page 28) and submit this to the UK Data Archive together with your data when you have completed your research (for further advice about how to access or upload data in the UK Data Archive see page 60).

Ethical approval

Before you start recruiting your sample, please consider whether you need to obtain ethical approval, this is usually stipulated by the organisation that is funding the research. Regardless of the type of research you are doing it is always appropriate to consider the ethical implications.

Research which falls under the remit of Department of Health approved ethics committees, which abide by governance arrangements for NHS research ethics committees; Department of Health, July 2001, para 3.1, are detailed below:

If the research involves:

- the use of patients and users of the NHS;
- individuals identified as potential research participants because of their status as relatives or carers or patients and users of the NHS;
- access to data, organs or other bodily material of past and present NHS patients;
- the recently dead in NHS premises;
- fetal material and IVF involving NHS patients;
- the use of, or potential access to, NHS premises and facilities;

- NHS staff recruited as research participants by virtue of their professional role, then the ethics of such human research must be referred to the appropriate Department of Health approved ethics committee.

Further details and information on how to apply is available from the Central Office for Research Ethics Committees (COREC): www.corec.org.uk

Informed consent

It is important that you gain consent from the people that you ask to complete a CAM survey. This is especially important when you are asking people for identifiable information such as their postcode. We have developed an example information sheet and consent form that you can use and modify to your own needs (see page 12).

Please see the UK Data Archive website for more information on consent procedures: http://www.data-archive.ac.uk/sharing/confidential.asp

Data protection

Please make sure that your consent and data management procedures are in line with the Data Protection Act (1999).

For more information see: http://www.ico.gov.uk/what_we_cover/data_protection.aspx

Demographics

Please ensure that all participants complete the 'demographics questions' 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.

Coding

Instructions are provided about how to code CAM survey data (see 'Coding Sheet' on page 45). All CAM data will need to be uploaded in to the UK Data Archive using the coding frame that has been provided. For instructions about how to access or upload data see 'Data Archive: Accessing and Depositing data' on page 60.

Ensuring quality

Whether you plan to carry out the survey using volunteers or by commissioning an external agency you should ensure that the research is good quality. The Social Research Association (SRA) and the MRS provide professional standards and guidelines about best practice across all aspects of carrying out research;

SRA: http://www.the-sra.org.uk/guidelines.htm#public

MRS: http://www.mrs.org.uk/standards/mrs_guidelines.htm

Results

The CAM was implemented in a national survey in 2008 with a UK representative population (n=2216). The results are published in full on the Department of Health Website:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108749

CAM survey questions

Q1 – Open (unprompted) warning signs

"There are many warning signs and symptoms of cancer. Please name as many as you can think of" [4]

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

Q2 – Closed (prompted) warning signs

"The following may or may not be warning signs for cancer. We are interested in <u>your</u> opinion. Do you think X is a warning sign for cancer?" [5]

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 – Seeking help

"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?" [6]

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

Q4 – 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. Could you say if any of these might put you off going to the doctor?" [7]

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.

Q5 – Open (unprompted) risk factors

"What things do you think affect a person's chance of getting cancer?" [5]

This is an open question designed to measure how many cancer risk factors a respondent can recall unaided. In face to face interviews this question should always be 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.

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[4] 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

[5] Question developed specifically for the Cancer Awareness Measure

[6] 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

[7] Response options derived from: Breast Cancer Care Breast Awareness Survey (2005)

Q6 – Closed (prompted) risk factors

"These are some of the things that can increase a person's chance of developing cancer. How much do you agree that each of these can increase a person's chance of developing cancer?" [5]

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.

Q7 – Cancer and age

'In the next year, who is most likely to develop cancer?

This question explores the public's knowledge of how age is related to cancer.

Q8 - Most common cancers

"What do you think is the most/second most/third most common cancer in women?" [8]

"What do you think is the most/second most/third common cancer in men?" [8]

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

Q9 - NHS screening programmes

"As far as you are aware, is there an NHS X cancer screening programme?" [5]

"If yes, at what age are women/men first invited for X cancer screening?" [5]

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

[8] 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)

Information sheet & consent form

Information sheet for [name of project]

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

[organisation name] is carrying out a survey to assess awareness of cancer risk factors, and signs and symptoms. The results will be used to develop better and more effective NHS communications and services to help increase the early diagnosis of cancer.

Why have I been invited to take part?

[sampling methods, e.g. 'You have been chosen at random' or ' we are asking everyone aged over 50 to complete this survey in xx area].

Do I have to take part?

It is up to you to decide whether or not to take part, taking part is voluntary. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What would I have to do?

If you decide to take part, the survey will take approximately [xx] minutes to complete.

Confidentiality

All the information that is collected will be anonymous and kept strictly confidential. Your personal data will be held in accordance with the Data Protection Act 1998.

What happens to the information that is collected?

All details that can identify you will be removed before storing the data. All the information collected in this survey (although not your name), will be stored in the UK Data Archive, which is a secure national bank where the results of many surveys are kept.

In the future, researchers will be able to download the information from the UK Data Archive and analyse it in new ways. This will help us to build an understanding of public awareness of cancer so that we can develop ways to improve cancer services. More information about the archive can be found here:
http://www.data-archive.ac.uk/Introduction.asp

Thank you for taking the time to read this information sheet.

[Insert lead researcher's signature]

Consent form for [name of project]

Please tick the appropriate boxes

I have read and understood the project information sheet dated DD/MM/YYYY.	☐
I have been given the opportunity to ask questions about the project.	☐
I agree to take part in the project. Taking part in the project will include completing a survey/being interviewed [Other forms of participation can be listed].	☐
I understand that my taking part is voluntary; I can withdraw from the study at any time and I will not be asked any questions about why I no longer want to take part.	☐
I understand my personal details such as phone number and address will not be revealed to people outside the project.	☐
I understand that my words may be quoted in publications, reports, web pages, and other research outputs but my name will not be used unless I requested it above.	☐
I agree for the data I provide to be archived at the UK Data Archive.	☐
I understand that other researchers will have access to this data only if they agree to preserve the confidentiality of that data and if they agree to the terms I have specified in this form.	☐
I understand that other researchers may use my words in publications, reports, web pages, and other research outputs according to the terms I have specified in this form.	☐
I agree to assign the copyright I hold in any materials related to this project to [name of researcher].	☐

Name of Participant	Signature	Date
Researcher	Signature	Date

[Contact details for further information: Names, phone, email addresses, etc]

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.

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

2. The following may or may not be warning signs for cancer. We are interested in <u>your</u> opinion:

	Yes	No	Don't know
Do you think an unexplained lump or swelling could be a sign of cancer?	☐	☐	☐
Do you think persistent unexplained pain could be a sign of cancer?	☐	☐	☐
Do you think unexplained bleeding could be a sign of cancer?	☐	☐	☐
Do you think a persistent cough or hoarseness could be a sign of cancer?	☐	☐	☐
Do you think a persistent change in bowel or bladder habits could be a sign of cancer?	☐	☐	☐
Do you think persistent difficulty swallowing could be a sign of cancer?	☐	☐	☐
Do you think a change in the appearance of a mole could be a sign of cancer?	☐	☐	☐
Do you think a sore that does not heal could be a sign of cancer?	☐	☐	☐
Do you think unexplained weight loss could be a sign of cancer?	☐	☐	☐

3. 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?

4. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. 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	☐	☐	☐	☐
I would be too scared	☐	☐	☐	☐
I would be worried about wasting the doctor's time	☐	☐	☐	☐
My doctor would be difficult to talk to	☐	☐	☐	☐
It would be difficult to make an appointment with my doctor	☐	☐	☐	☐
I would be too busy to make time to go to the doctor	☐	☐	☐	☐
I have too many other things to worry about	☐	☐	☐	☐
It would be difficult for me to arrange transport to the doctor's surgery	☐	☐	☐	☐
I would be worried about what the doctor might find	☐	☐	☐	☐
I wouldn't feel confident talking about my symptom with the doctor	☐	☐	☐	☐

Other (please specify)

5. What things do you think affect a person's chance of developing cancer?

6. These are some of the things that can increase a person's chance of developing cancer. How much do you agree that each of these can increase a person's chance of developing cancer?

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

7. In the next year, who is most likely to develop cancer?

Someone in their….

20’s ☐

30’s ☐

40’s ☐

50’s ☐

60’s ☐

70’s ☐

80’s ☐

Cancer is unrelated to age ☐

8a. What do you think is the **most** common cancer in women?
8b. What do you think is the **second** most common cancer in women?
8c. What do you think is the **third** most common cancer in women?

8d. What do you think is the **most** common cancer in men?
8e. What do you think is the **second** most common cancer in men?
8f. What do you think is the **third** most common cancer in men?

	Yes	No	Don't know
9a. As far as you are aware, is there an NHS breast cancer screening programme?	☐	☐	☐
If yes, at what age are women first invited for breast cancer screening? _____			☐
9b. As far as you are aware, is there an NHS cervical cancer screening programme (smear tests)?	☐	☐	☐
If yes, at what age are women first invited for cervical cancer screening? _____			☐
9c. As far as you are aware, is there an NHS bowel cancer screening programme?	☐	☐	☐
If yes, at what age are people first invited for bowel cancer screening? _____			☐

Cancer Research UK Cancer Awareness Measure (CAM)

Demographic Questions

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1. What is your age? ☐☐ Prefer not to say ☐

2. What is your gender?

☐ Male ☐ Female ☐ Prefer not to say

3. Which of these best describes your ethnic group?

White	Mixed	Asian or Asian British	Black or Black British	Chinese/other
☐ White British	☐ White and Black Caribbean	☐ Indian	☐ Black Caribbean	☐ Chinese
☐ White Irish	☐ White and Black African	☐ Pakistani	☐ Black African	☐ Other……
☐ Any other White background	☐ White and Asian	☐ Bangladeshi	☐ Any other Black background	☐ Prefer not to say
	☐ Any other Mixed background	☐ Any other Asian background		

4. What is the main language spoken at home?

☐ English	☐ Sylheti
☐ Urdu	☐ Cantonese
☐ Punjabi	☐ Other……
☐ Gujarati	☐ Prefer not to say

5. What is your marital status?

Single/never married	Married/living with partner	Married separated	Divorced	Widowed	Civil partnership	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

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

- ☐ Degree or higher degree
- ☐ Higher education qualification below degree level
- ☐ A-levels or highers
- ☐ ONC/BTEC
- ☐ Still studying
- ☐ O Level or GCSE equivalent (Grade A - C)
- ☐ O Level or GCSE (Grade D - G)
- ☐ No formal qualifications
- ☐ Other ……
- ☐ Prefer not to say

7. 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)	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

8. What is your postcode? Prefer not to say ☐

9. How many years have you been living in the UK? ☐☐ Prefer not to say ☐

10. Are you currently:

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed
- ☐ Self-employed
- ☐ Full-time homemaker
- ☐ Retired
- ☐ Still studying
- ☐ Disabled or too ill to work
- ☐ Prefer not to say

11. Does your household own a car or van?

No	Yes, one	Yes, more than one	Prefer not to say
☐	☐	☐	☐

12. Have you, your family or close friends had cancer?				
	Yes	No	Don't know	Prefer not to say
You	☐	☐	☐	☐
Partner	☐	☐	☐	☐
Close family member	☐	☐	☐	☐
Other family member	☐	☐	☐	☐
Close friend	☐	☐	☐	☐
Other friend	☐	☐	☐	☐

Optional items:

Are you registered with a GP?			
Yes	No	Don't know	Prefer not to say
☐	☐	☐	☐

If you plan to use the following question we advise piloting it first with the target group to ensure that it is not off-putting.

What is your sexual orientation?					
Bi-sexual	Gay man	Gay woman/lesbian	Heterosexual/ straight	Other	Prefer not to say
☐	☐	☐	☐	☐	☐

Cancer Research UK Cancer Awareness Measure (CAM)

Recruitment Record

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

Introduction

It is important to make your sampling and recruitment methods transparent because it gives people an idea of how representative your sample is and how many factors could have influenced respondent's answers, such as noise levels or confidentiality. This information will influence how the data are analysed and interpreted.

It is also important that you provide us with all the data you receive, so even if people miss out some of the questions, we would like any information they provide.

Purpose and sampling methods

Please outline the purpose of the survey (e.g. to explore awareness of cancer risk factors and signs and symptoms in men aged over 50 years living in x).		
Sampling frame(s) (e.g. electoral registers, postal address file, GP lists, telephone directory, all men over 50 years living in x).		
Target population(s) (e.g. gender, age, geographical area)		
Please describe the methods you used to recruit participants (e.g. flyers, leaflets , posters, newspaper adverts, letter, face-to-face)		
Please describe the method(s) of administration of the CAM (e.g. face-to-face, telephone, internet, other) and complete the number of surveys completed using each method below:		
Face to face	☐	Number of surveys……
Over the telephone	☐	Number of surveys……
Internet	☐	Number of surveys……
Other	☐	Number of surveys……

If the surveys were administered face-to-face:

Please describe the environment(s) in which the surveys were completed (e.g. closed office with one interviewer, communal coffee area, a busy street)
How many other people were present while the interview was being carried out? 0- 1 ☐ More than 1 ☐

If the surveys were administered in a different way:

Please describe how the surveys were distributed (e.g. by post, left on a counter, sent by email)
Please describe the environment(s) in which the surveys were completed (e.g. closed office with one interviewer, communal coffee area, a busy street, at home)

In what language were the interviews carried out?			
☐	English	☐	Sylheti
☐	Urdu	☐	Cantonese
☐	Punjabi	☐	Other……
☐	Gujarati		

Sample characteristics

How many participants were recruited? _____
Did you carry out any power or sample size calculations? (If so, please provide details)
How many people were approached/contacted to complete the CAM? _____

How many people agreed to complete the CAM? _____
How many people refused to complete the CAM? _____
How many participants started to complete the CAM but did not complete it? _____
Over what time period were the interviews carried out? From: _____(dd/mm/yyyy) to: _____(dd/mm/yy)

Cancer Research UK Cancer Awareness Measure (CAM)

Script

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

Introduction

This script is intended for use **during training** of how to administer the CAM. It should not be necessary to use this script once the interviewer is familiar with the questionnaire and these guidelines.

Instructions:

- Before starting the interview record whether the interview was carried out 'face-to-face', over the telephone etc, where the interview took place and what language the interview was carried out (see the 'Recruitment Record' for more information).
- Read out the questions **exactly** as it is written for each question.
- The text that is written in the shaded boxes is what you should read out.
- If a respondent asks for more details or help, please state that for the purposes of the study you cannot give any prompts or explanations (other than those permitted), remind the participant that we are interested in their own thoughts and beliefs and if necessary repeat the question.
- You may discuss queries once the interview is complete, including providing the correct answers where appropriate.
- Do not discuss the correct answers to the CAM if it is being used to evaluate the effectiveness of an intervention aimed to improve knowledge in which the same individuals are being interviewed at different times.
- Do not return to previous questions to amend answers.
- For each question it is possible to record if the respondent refuses or does not wish to answer the question or does not know the answer.
- If the respondent has any questions about symptoms they have had or other questions about cancer, please advise them to speak to their GP.

If you are interviewing people face-to-face it may be useful to use 'prompt cards' for some of the questions (e.g. ethnicity).

The interview

OPTIONAL: These question are being asked on behalf of [organisation] because [insert the reason for your study e.g. we are trying to find out the level of cancer awareness among people living in X] *COMPULSORY: This set of questions is about your awareness of cancer, it is not assessing your personal risk of cancer. The questions should take around 20 minutes to complete. This is not a test, we are interested in your thoughts and beliefs so please answer the questions as honestly as you can. All your answers are confidential. Please be aware that I am unable to answer questions during the interview, but there will be time to address any queries at the end. Please also be aware that I can not go back to a question that has already been asked.*

QUESTION 1 – OPEN WARNING SIGNS

The first set of questions are about warning signs of cancer. There are many warning signs and symptoms of cancer. Please name as many as you can think of
Prompt with 'anything else?' until the respondent can not think of any more signs. If the person says they do not know any, prompt with 'are you sure?' and if necessary 'take a minute to think about it'. Write down all of the warning signs or symptoms that the person mentions exactly as they say it.

QUESTION 2 – CLOSED WARNING SIGNS

The following may or may not be warning signs for cancer. We are interested in your opinion.
Do not prompt If the respondent asks for clarification about certain items within this set of questions, please refer to the clarifications written below. Please only read these out if necessary.
Do you think an unexplained lump or swelling could be a sign of cancer? You may answer: 'Yes it could', 'No, it could not', Don't know/not sure'
Repeat the above format for each subsequent question in this group.

Clarifications:

Please only read these out if necessary.

'Persistent' in reference to any of the warning signs refers to 3 weeks or longer
Do you think a persistent change in bowel or bladder habits could be a sign of cancer? [POINT OF CLARIFICATION]: a change in pooing and weeing

QUESTION 3 – SEEKING HELP

The next question is about seeking help
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?
Record the response verbatim

QUESTION 4 – BARRIERS TO SEEKING HELP

The next set of questions is about what barriers may stop you from seeking help *Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor? You may answer: 'Yes often', 'Yes sometimes', 'No', or 'Don't know'*
I would be too embarrassed
Only ask about the barriers that are listed Repeat the above format for each subsequent question in this group.
Is there anything else that you can think of that might put you off going to the doctor?
Write down any other barriers the respondent mentions exactly as they say it.

QUESTION 5 – OPEN RISK FACTORS

The next set of questions is about risk factors for cancer *What things do you think affect a person's chance of developing cancer?*
Prompt with 'anything else?' until the respondent can not think of any more signs. If the person says they do not know any, prompt with 'are you sure?' and if necessary 'take a minute to think about it'. Write down all of the risk factors that the person mentions exactly as they say it.

QUESTION 6 – CLOSED RISK FACTORS

These are some of the things that can increase a person's chance of developing cancer. How much do you agree that each of these can increase a person's chance of developing cancer?
Do NOT prompt
Smoking any cigarettes at all
Strongly disagree
Disagree
Not sure
Agree
Strongly agree
Repeat the above format for each subsequent question in this group.

Clarifications:

Please only read these out if necessary

*Drinking more than 1 unit of alcohol a day [POINT OF CLARIFICATION]: A unit of alcohol is one small measure of spirits, half a pint of lager (3-4% strength) or **half** a small glass (175ml) of wine (12% strength)*
Eating less than 5 portions of fruit and vegetables a day [POINT OF CLARIFICATION]: a portion is equivalent to an apple, orange, banana or similar sized fruit, 2 plums or nectarines or similar sized fruit, a handful of grapes or berries, one tablespoon of raisins, two serving spoons of cooked vegetables, beans or pulses, or a dessert bowl of salad.
Eating red or processed meat once a day or more [POINT OF CLARIFICATION]: processed meat includes bacon, ham, salami, corned beef, sausages
Being overweight [POINT OF CLARIFICATION]: BMI over 25
Having a close relative with cancer [POINT OF CLARIFICATION]: a close relative means parents, children, brothers or sisters
Infection with HPV [POINT OF CLARIFICATION]: Human Papillomavirus
Doing less than 30 minutes of moderate physical activity 5 times a week [POINT OF CLARIFICATION]: moderate physical activity includes anything that leaves you warm and slightly out of breath such as brisk walking, gardening, dancing or housework.

QUESTION 7 – CANCER AND AGE

In the next year, who is most likely to develop cancer? *Someone in their…*
20's
30's
40's
50's
60's
70's
80's
Cancer is unrelated to age

QUESTION 8 – MOST COMMON CANCERS

Do NOT prompt
What is the most common cancer in women?
What is the second most common cancer in women?
What is the third most common cancer in women?
What is the most common cancer in men?
What is the second most common cancer in men?
What is the third most common cancer in men?

QUESTION 9 – NHS SCREENING PROGRAMMES

Do NOT prompt
The next set of questions are about NHS screening programmes *As far as you are aware, is there an NHS breast cancer screening programme? You may answer: 'Yes', 'No', 'Don't know'*
[IF YES] At what age are women first invited for breast cancer screening? *[IF NO] Go to next question/demographic questions*
Repeat for cervical and bowel cancer screening

Demographic questions

We would now like to ask you a few questions about yourself. This will help us to analyse the results of the survey. The data collected will help us to identify specific age or demographic groups of people who are in need of more information about cancer. You will not be asked your name and all of your answers will be kept strictly confidential and anonymous. Your personal data will be held in accordance with the Data Protection Act 1998. Your details will not be passed onto your GP and will not affect your medical care in any way.

Could you tell me your age? ☐☐ Prefer not to say ☐

What is your gender?

☐ Male ☐ Female ☐ Prefer not to say

Which of these best describes your ethnic group?

White	Mixed	Asian or Asian British	Black or Black British	Chinese/other
☐ White British	☐ White and Black Caribbean	☐ Indian	☐ Black Caribbean	☐ Chinese
☐ White Irish	☐ White and Black African	☐ Pakistani	☐ Black African	☐ Other……
☐ Any other White background	☐ White and Asian	☐ Bangladeshi	☐ Any other Black background	☐ Prefer not to say
	☐ Any other Mixed background	☐ Any other Asian background		

What is the main language spoken at home?

☐ English	☐ Sylheti
☐ Urdu	☐ Cantonese
☐ Punjabi	☐ Other……
☐ Gujarati	☐ Prefer not to say

What is your marital status?

Single/never married	Married/living with partner	Married separated	Divorced	Widowed	Civil partnership	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

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

- ☐ Degree or higher degree
- ☐ Higher education qualification below degree level
- ☐ A-levels or highers
- ☐ ONC/BTEC
- ☐ Still studying
- ☐ O Level or GCSE equivalent (Grade A - C)
- ☐ O Level or GCSE (Grade D - G)
- ☐ No formal qualifications
- ☐ Other ……
- ☐ Prefer not to say

Which of these 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)	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

Could you tell me your postcode? ☐☐ Prefer not to say ☐

How many years have you been living in the UK? ☐☐ Prefer not to say ☐

Are you currently:

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed
- ☐ Self-employed
- ☐ Full-time homemaker
- ☐ Retired
- ☐ Still studying
- ☐ Disabled or too ill to work
- ☐ Prefer not to say

Do you or does anyone living with you own a car or van?

No	Yes, one	Yes, more than one	Prefer not to say
☐	☐	☐	☐

Have you, your family or close friends had cancer?				
	Yes	No	Don't know	Prefer not to say
You	☐	☐	☐	☐
Partner	☐	☐	☐	☐
Close family member	☐	☐	☐	☐
Other family member	☐	☐	☐	☐
Close friend	☐	☐	☐	☐
Other friend	☐	☐	☐	☐

Optional items:

Are you registered with a GP?			
Yes	No	Don't know	Prefer not to say
☐	☐	☐	☐

What is your sexual orientation?					
Bi-sexual	Gay man	Gay woman/lesbian	Heterosexual/ straight	Other	Prefer not to say
☐	☐	☐	☐	☐	☐

Thank you for taking time to answer my questions.

Now that the interview is over, would you like to ask any questions? Or do you have any comments?

Cancer Research UK Cancer Awareness Measure (CAM)

Answer Sheet

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

This booklet is intended for use in training only. Respondents should not see this booklet. The following gives the correct answers to the questions asked in the CAM.

Q1. *There are many warning signs and symptoms for cancer. Please name as many as you can think of.*

The correct answers to this question are listed in question 2, although there are other warning signs and symptoms and none of the signs and symptoms listed would necessarily be caused by cancer.

Q2. *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?*

The correct answer for this question is that all of the warning signs and symptoms listed could be (but are not necessarily) warning signs for cancer.

Q3. *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?*

There are no correct answers to this question

Q4. *Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?*

There are no correct answers to this question.

Q5. *What do you think affects a person's chance of developing cancer?*

The correct answers to this question are listed in question 7, although there are other risk factors and none of the risk factors listed would necessarily lead to cancer.

Q6. *These are some of the things that can increase a person's chance of developing cancer. How much do you agree that each of these can increase a person's chance of developing cancer?*

The correct answer for this question is that all of the risk factors listed could (but are not necessarily) increase the chance of developing cancer.

Q7. *In the next year, who is most likely to develop cancer?*

The correct answer is '80's'. The risk of cancer increases with age.

Q8. *What do you think is the most/second/third most common cancer in women?*

The most common cancer in women is breast cancer.

The second most common cancer in women is colorectal (bowel) cancer.

The third most common cancer in women is lung cancer.

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

The most common cancer in men is prostate cancer.

The second most common cancer in men is lung cancer.

The third most common cancer in men is colorectal (bowel) cancer.

Q9*. As far as you are aware, is there an NHS X cancer screening programme?*

There is an NHS cancer screening programme for breast, cervical and colorectal (bowel) cancer.

At what age are people first invited for X cancer screening?

Women are fist invited to breast cancer screening between 47 and 53 years of age.

Women are first invited to cervical cancer screening (in Scotland, Wales and Northern Ireland) at age 20 and in England at age 25.

People are first invited to attend colorectal (bowel) cancer screening between 58 – 62 years of age.

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.

Background and purpose

The coding guidance set out below ensures that data from the CAM is suitable for depositing in the UK Data Archive.

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

For every question it is possible to code data as 'refused' ('98'). Use this code when the respondent actively chooses not to respond. Where appropriate there are also codes for 'don't know' ('99'). 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.

We have not provided guidance about how the CAM should be scored, but we are happy to give advice and can provide syntax files for coding in SPSS.

Contact details: naedi@cancer.org.uk

First of all, please create a participant ID number and describe the method of survey administration.

Participant ID Number **ID**	

Please indicate whether this interview was held face-to-face, over the telephone, via the internet or other. **InterviewMethod** If 'Other' (code 4) create an additional variable **'InterviewMethodOther'** and write the response verbatim.			
Face-to-face **1**	Telephone **2**	Internet **3**	Other **4**

Please indicate where the survey was completed. **InterviewSetting** If 'Other' (code 3) create an additional variable '**InterviewSettingOther**' and write the response verbatim.		
Health service **1**	Home **2**	Other setting **3**

Please indicate which language was used to administer the interview. **InterviewLanguage** If 'Other' (code 7) create an additional variable '**InterviewLanguageOther'** and write the response verbatim.			
English	**1**	Sylheti	**5**
Urdu	**2**	Cantonese	**6**
Punjabi	**3**	Other……	**7**
Gujarati	**4**		

CAM questions

1. OPEN WARNING SIGNS

Create 18 variables labelled from **Symptom 01**, **to Symptom18**. Each symptom must be recorded as a new variable using the coding frame below. For example if the first response is 'weight loss' code **SymptomO1** as '9'. If the second response is 'bleeding' code **Symptom02** as '3' etc

To code a variable that is not on the list code as 'Other' (code 17) create additional variables e.g. **Symptom19**, **Symptom20** etc and write the response the participant has given verbatim.

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**

2. CLOSED WARNING SIGNS

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**

3. SEEKING HELP

Variable name: CancerSignTime
Type in verbatim

4. BARRIERS TO SEEKING HELP

	Scoring			
Question followed by **SPSS/Excel variable name**	**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			

5. OPEN RISK FACTORS

Create 26 variables labelled from **RiskO1** to **RiskO26**. 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 **RiskO1** as '6'. If the second response is 'pollution' code **Risk02** as '22'.

To code a variable that is not on the list code as 'Other' (code 25) create additional variables e.g. **RiskO25**, **RiskO26**, etc and write the response the participant has given verbatim.

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**

6. CLOSED RISK FACTORS

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**

7. CANCER AND AGE

AgeC	
20's	**1**
30's	**2**
40's	**3**
50's	**4**
60's	**5**
70's	**6**
80's	**7**
Cancer is unrelated to age	**8**

8. MOST COMMON CANCERS

The variable names for Q8 are below, the coding frame is on the next page

What do you think is the **most** common cancer in women? **Cancer1F (Cancer1otherF)** What do you think is the **second** most common cancer in women? **Cancer2F (Cancer2otherF)** What do you think is the **third** most common cancer in women? **Cancer3F (Cancer3otherF)**
What do you think is the **most** common cancer in men? **Cancer1M (Cancer1otherM)**
What do you think is the **second** most common cancer in men? **Cancer2M (Cancer2otherM)**
What do you think is the **third** most common cancer in men? **Cancer3M (Cancer3otherM)**

Please use the coding frame below, for example, if the response for the 'most' common cancer in women is 'lung cancer' code **Cancer1F** as '9'**.**

To code an answer that is not our coding list, code as 'Other' (code '19') and then 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**

9. NHS CANCER SCREENING PROGRAMMES

As far as you are aware, is there an NHS breast cancer screening programme? **BreastScreening**	Yes **3**	No **2**	Don't know **1**
If yes, at what age are women first invited for breast cancer screening? _____ Please record the actual age the respondent gives. **BreastAge**	**Age in years**	Refused **988**	Don't know **999**
As far as you are aware, is there an NHS cervical cancer screening programme (smear tests)? **CervicalScreening**	Yes **3**	No **2**	Don't know **1**
If yes, at what age are women first invited for cervical cancer screening? _____ Please record the actual age the respondent gives. **CervicalAge**	**Age in years**	Refused **988**	Don't know **999**
As far as you are aware, is there an NHS bowel cancer screening programme? **BowelScreening**	Yes **3**	No **2**	Don't know **1**
If yes, at what age are people first invited for bowel cancer screening? _____ Please record the actual age the respondent gives. **BowelAge**	**Age in years**	Refused **988**	Don't know **999**

Demographic Questions

1. What is your age?		Prefer not to say
Age		**98**
Record actual age		

2. What is your gender?

Gender

1	Male	**2**	Female	**98**	Prefer not to say

3. Which of these best describes your ethnic group?

EthnicGroup

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

White		**Mixed**		**Asian or Asian British**		**Black or Black British**		**Chinese/other**	
1	White British	**4**	White and Black Caribbean	**8**	Indian	**12**	Black Caribbean	**15**	Chinese
2	White Irish	**5**	White and Black African	**9**	Pakistani	**13**	Black African	**16**	Other……
3	Any other White background	**6**	White and Asian	**10**	Bangladeshi	**14**	Any other Black background	**98**	Prefer not to say
		7	Any other Mixed background	**11**	Any other Asian background				

4. What is the main language spoken at home?

Language

To code a language that is not on the list code as 'Other' (code 7) and write the language verbatim in **'OtherLanguage'**

1	English	**5**	Sylheti
2	Urdu	**6**	Cantonese
3	Punjabi	**7**	Other……
4	Gujarati	**98**	Prefer not to say

5. What is your marital status?

MaritalStatus

Single/never married	Married/living with partner	Married separated	Divorced	Widowed	Civil partnership	Prefer not to say
1	**2**	**3**	**4**	**5**	**6**	**98**

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

HighestEducation

To code an education that is not on the list code as 'Other' (code 9) and write the education verbatim in **'EducationOther'**

1	Degree or higher degree	**6**	O Level or GCSE equivalent (Grade A - C)
2	Higher education qualification below degree level	**7**	O Level or GCSE (Grade D - G)
3	A-levels or highers	**8**	No formal qualifications
4	ONC/BTEC	**9**	Other ……
5	Still studying	**98**	Prefer not to say

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

LivingArrangement

To code an education that is not on the list code as 'Other' (code 6) and write the education verbatim in **'LivingArrangementOther'**

Own outright	Own mortgage	Rent from Local Authority/Housing Association	Rent privately	Squatting	Other (e.g. living with family/friends)	Prefer not to say
1	**2**	**3**	**4**	**5**	**6**	**98**

8. What is your postcode?

Postcode

Record actual postcode

Prefer not to say **98**

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

Years UK

Record actual years

Prefer not to say **98**

10. Are you currently: **Employed**			
1	Employed full-time	**5**	Full-time homemaker
2	Employed part-time	**6**	Retired
3	Unemployed	**7**	Still studying
4	Self-employed	**8**	Disabled or too ill to work
		98	Prefer not to say

11. Does your household own a car or van? **Car**			
No	Yes, one	Yes, more than one	Prefer not to say
1	**2**	**3**	**98**

12. Have you, your family or close friends had cancer?				
	Yes	No	Don't know	Prefer not to say
You **CancerYou**	**1**	**2**	**3**	**98**
Partner **CancerPartner**	**1**	**2**	**3**	**98**
Close family member **CancerCloseFamily**	**1**	**2**	**3**	**98**
Other family member **CancerOtherFamily**	**1**	**2**	**3**	**98**
Close friend **CancerCloseFriend**	**1**	**2**	**3**	**98**
Other friend **CancerOtherFriend**	**1**	**2**	**3**	**98**

Optional items:

Are you registered with a GP? **GP**			
Yes	No	Don't know	Prefer not to say
1	**2**	**3**	**98**

What is your sexual orientation? **SexualOrientation** To code a sexual orientation that is not on the list code as 'Other' (code 5) and write the sexual orientation verbatim in **'SexualOrientationOther'**					
Bi-sexual	Gay man	Gay woman/lesbian	Heterosexual/ straight	Other	Prefer not to say
1	**2**	**3**	**4**	**5**	**98**

Cancer Research UK Cancer Awareness Measure (CAM)

UK Data Archive

How to deposit and access CAM data

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

Background information

The UK Data Archive is hosted by the University of Essex, please contact Susan Cadogan for any queries (see contact details below). We ask anyone who collects data using any of the Cancer Awareness Measures to deposit their data into the archive. This will allow us to build up an evidence base that can be accessed by all.

Contact information:	Susan Cadogan Senior Collections Development and Rights Officer Economic and Social Data Service (ESDS) University of Essex, Colchester, CO4 3SQ, UK
Phone:	+44 1206 872572
Emails:	susan@essex.ac.uk; acquisitions@esds.ac.uk
Web General:	http://www.data-archive.ac.uk
Web Economic and Social Data service:	http://www.esds.ac.uk

How to deposit your data

If you are commissioning your CAM survey please ensure that you specify responsibilities for uploading the data collected using the CAM.

When you are ready to deposit your data, complete the following process:

1. Complete the Data collection deposit form and submit the two XML files created in the process electronically to acquisitions@esds.ac.uk (instructions about how to complete the data deposit form are detailed on the following pages).
   Helpful Hints:
   - *Remember to hit 'save' before switching between the different steps, or the information will not be recorded*
   - *There is a 'help' button at the top of the form which links you to online guidance.*
2. Prepare data and documentation according to best practice guidance on how to manage and share data
   Note. Please include any methodological, technical or end of project reports that will be of use to future researchers as part of the materials being deposited.
3. Submit data files in any of the following ways:
   Note: If data files contain sensitive or personal information, they should be encrypted before submitting.
   - via the University of Essex Dropbox Service, addressing the deposit to email account "acquisitions@essex.ac.uk" and noting study title or depositor surname in the dropbox description
   - by CD/DVD/memory stick
   - via secure electronic transmission - contact acquisitions@esds.ac.uk
4. Print, sign and date the Licence Agreement, keep a copy for your records and send the original to:
   Acquisitions
   UK Data Archive
   University of Essex
   Wivenhoe Park
   Colchester
   CO4 3SQ

Next steps
The acquisitions team will confirm receipt of all materials associated with the data collection. After administrative checks, the data collection will be prepared for release, see processing data at the UK Data Archive for further information.

Help
Please contact NAEDI if you have any queries about this process: naedi@cancer.org.uk

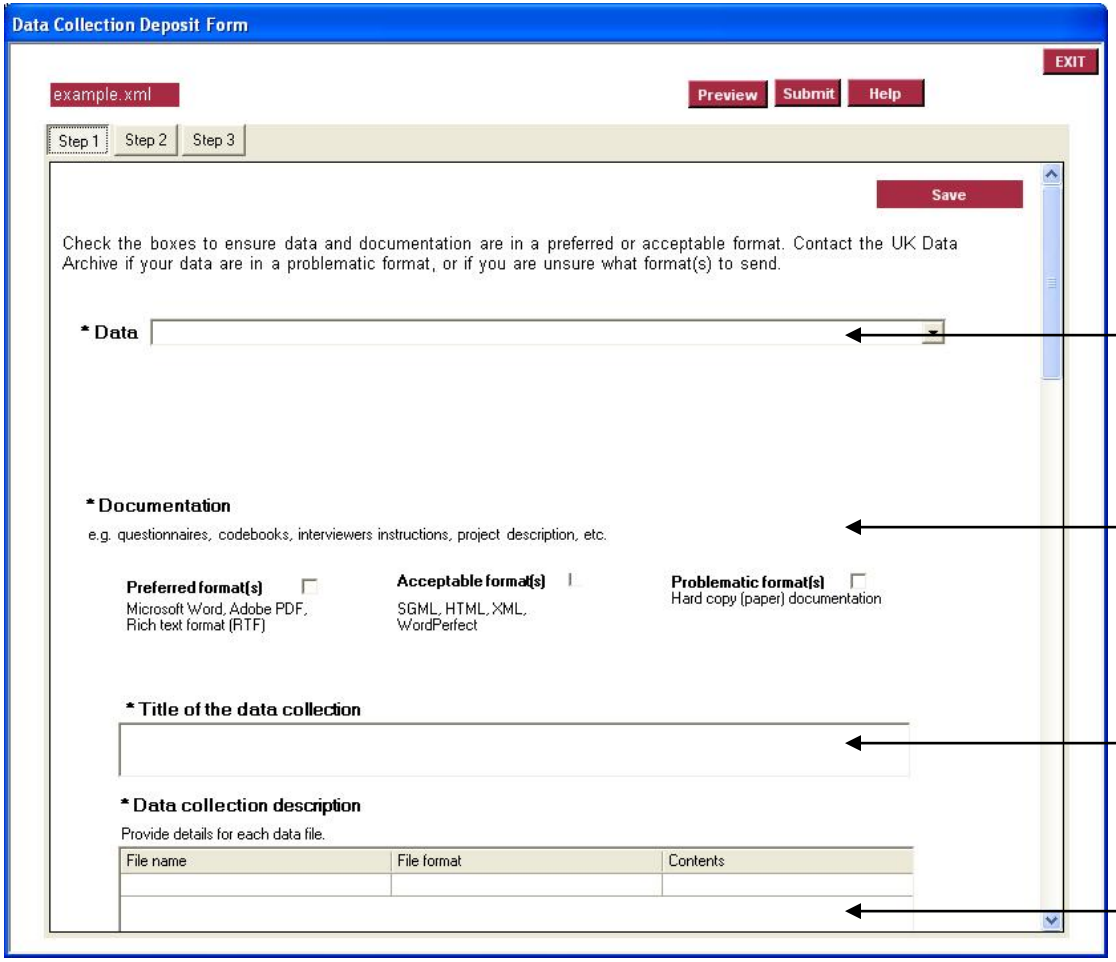
How to access CAM data
Access to the Data Catalogue, including online documentation such as questionnaires, does not require registration. However, to download any CAM data you must register. Go to: http://www.data-archive.ac.uk/sign-up/credentials-application

Once you have registered and have a username and password you can access CAM data. To do so:

1. Go to: http://www.esds.ac.uk/newRegistration/newLogin.asp
2. Login via 'UK Federation'
3. Select 'UK data archive' as your home institution (unless you are an academic in which case select your university)
4. Type in your username and password
5. Click on 'Data Catalogue' and go to 'data catalogue search'
6. Type in 'cancer awareness' and this should bring up all the CAM data that is currently held in the archive
7. Click on 'Download/order'
8. When prompted to provide details on how you will use the data, ensure that you select 'non-commercial' purposes.

Please note that if you would like access to identifiable information in the data, such as postcodes, you will be required to agree to the terms of our 'Special Licence'. The Special Licence asks for details about the person(s) or organisations wishing to access the data and a signed declaration that he/she understands the confidentiality obligations owed to those data including its physical security.

How to deposit your data: Instructions for completing the data deposit form
Step 1



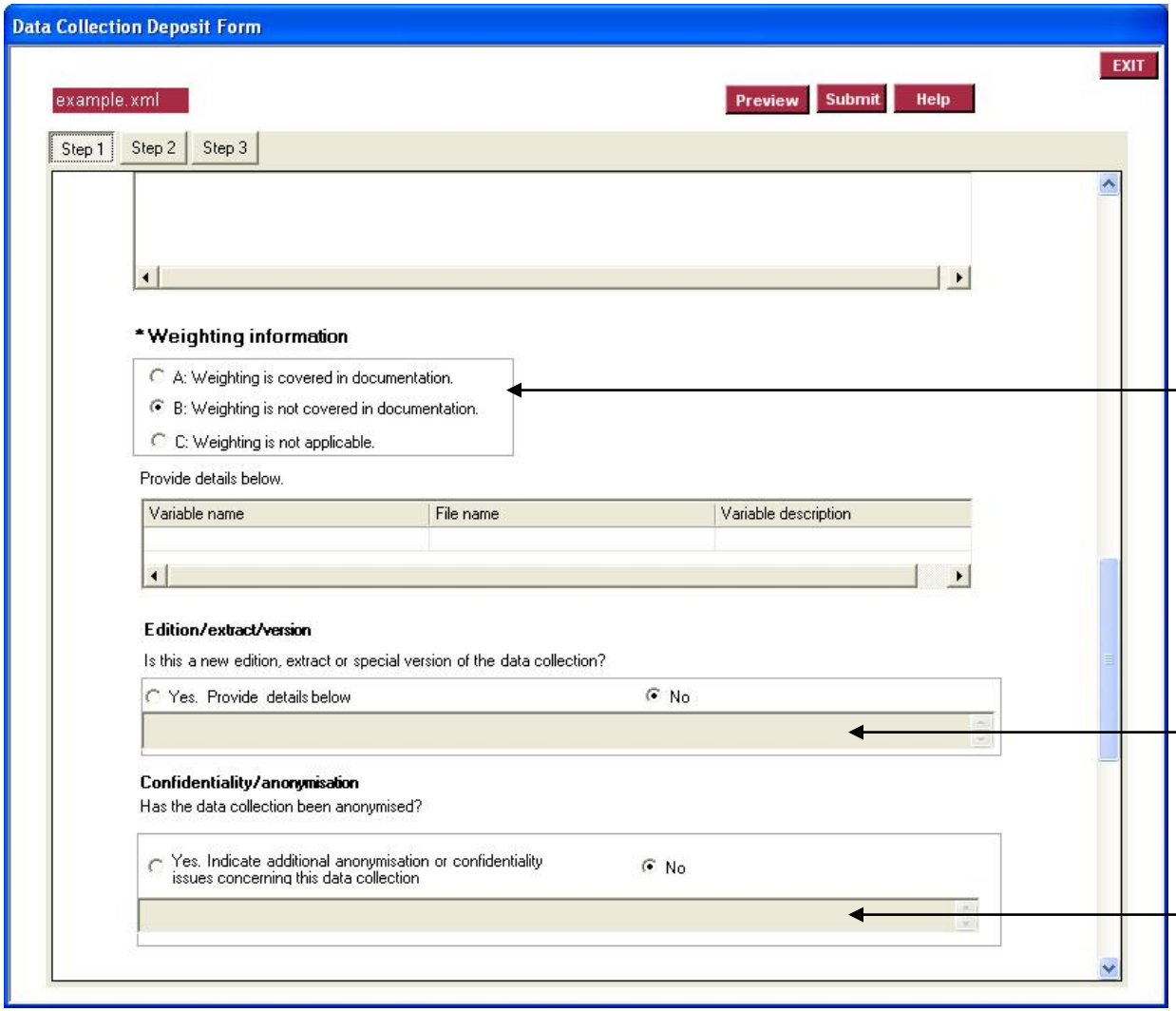
Title should reflect the nature of and subject of the data collection and include a date e.g. General Household Survey, 2001-2002

Provide the format of the supporting documentation such as recruitment record etc.

In the box called 'Title of the data collection' please write in: "Cancer Awareness Measure", followed by the local designation, as appropriate. Alternatively, if Lung CAM was used, write in: 'Lung Cancer Awareness Measure'.

Give the details of the data collected. For each data file attached, list the name of the files, formats and contents.

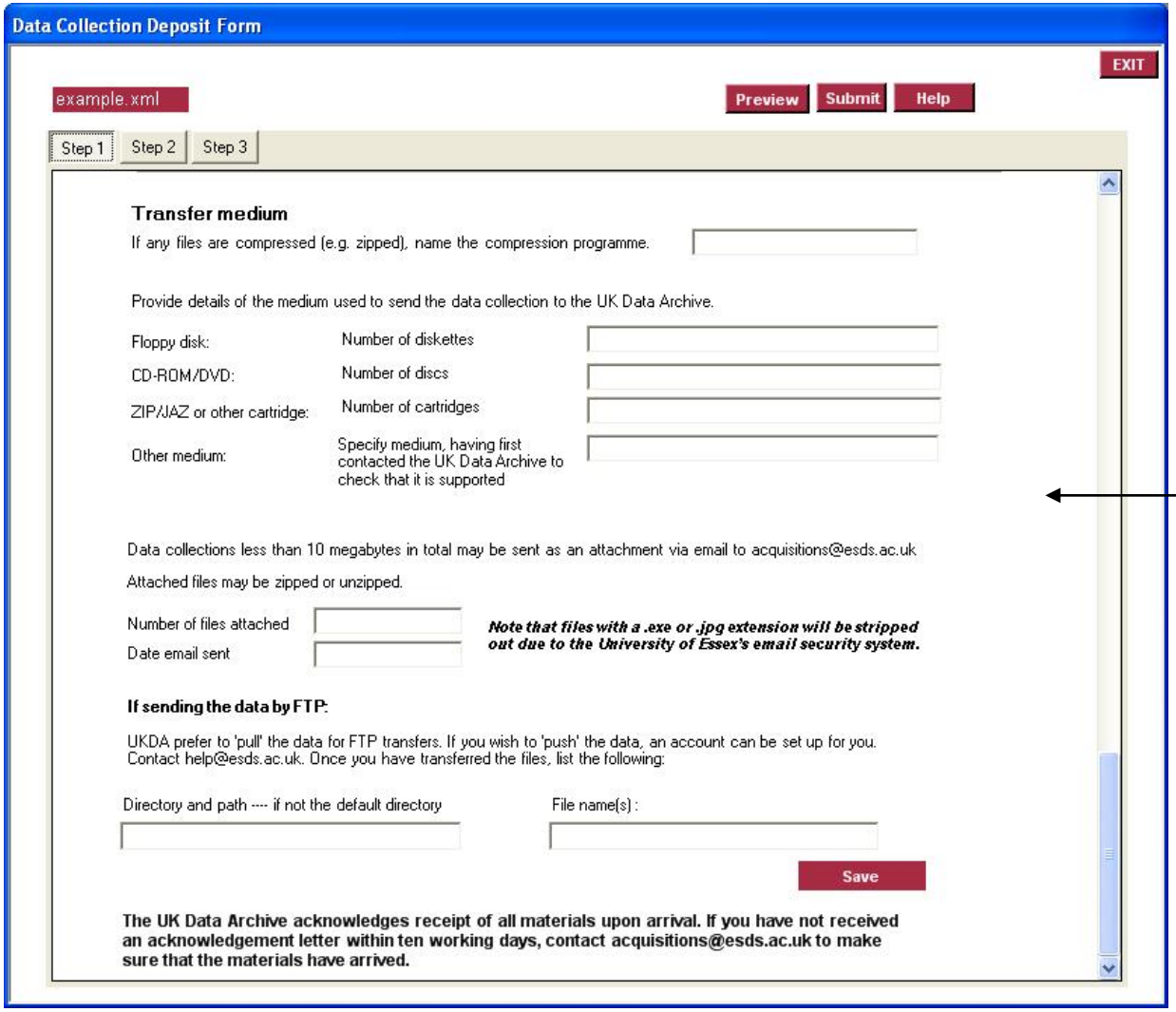
NB. If you have collected postcode data, please indicate this here.



This information is crucial for secondary analysis. Please indicate whether different weights were assigned to the different cases in the analysis file. Weighting is usually used to correct skewness in a sample that is meant to represent a particular population.

Please indicate whether this is a new edition, extract or special version of the data collection.

Please indicate whether data that includes confidential or sensitive data has been anonymised so that individuals, organisations or businesses cannot be identified from the data,. NB. If your data includes postcodes, select 'no'.

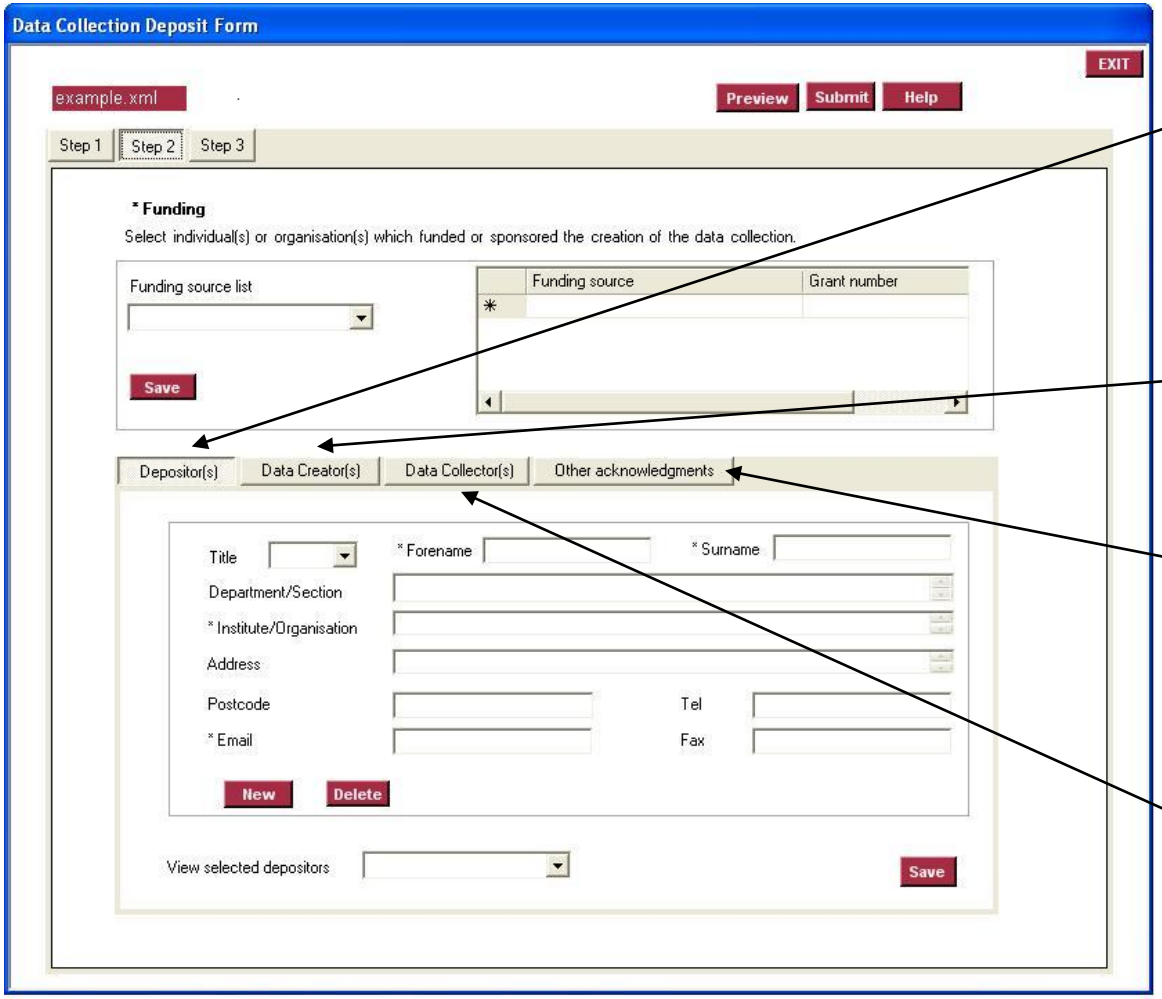


Provide the details of medium/method used to send the data to the UK Data Archive.

NB. **Please do not send by email**. Refer to**:** http://www.esds.ac.uk/aandp/create/ukdadeposit.asp for further information about how to transfer your data.

Step 2

This section of the form asks for information about the funder(s) of the research and contact details of the data creator(s) depositor(s), data collector(s) and any other persons involved in the project.



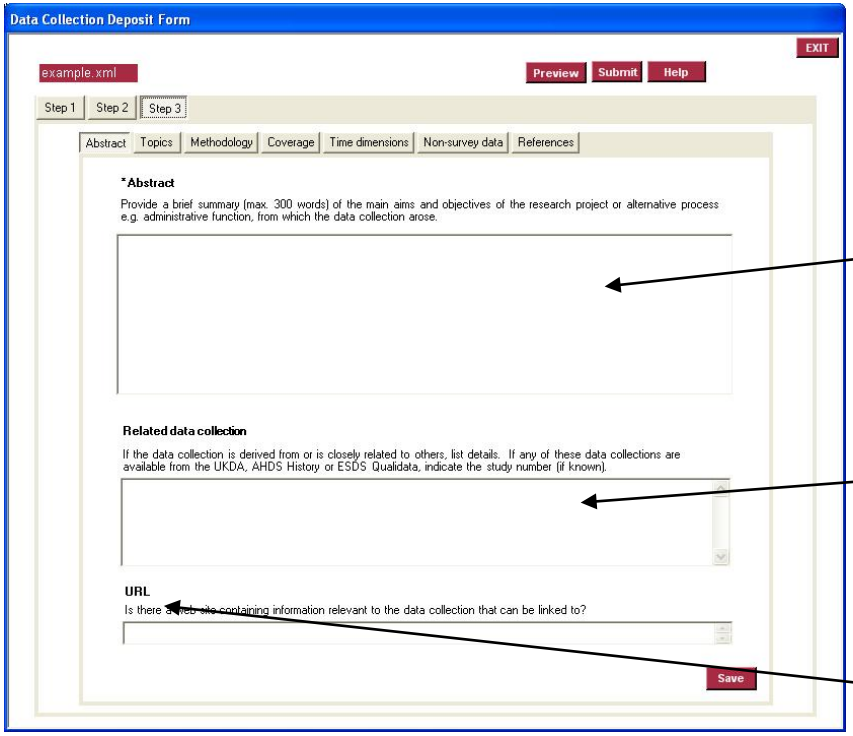
Depositor(s) is (are) person(s) and organisation(s) who deposited the data collection, usually, but not always, the License Agreement signatory.

Data creator(s) - sometimes referred as principal investigator(s) and can be person(s) or organisation(s)

This field should be used for names of individuals or organisations which should be acknowledged as having some input into the data collection.

Data collector(s): person(s) or organisation(s) who collected the data.

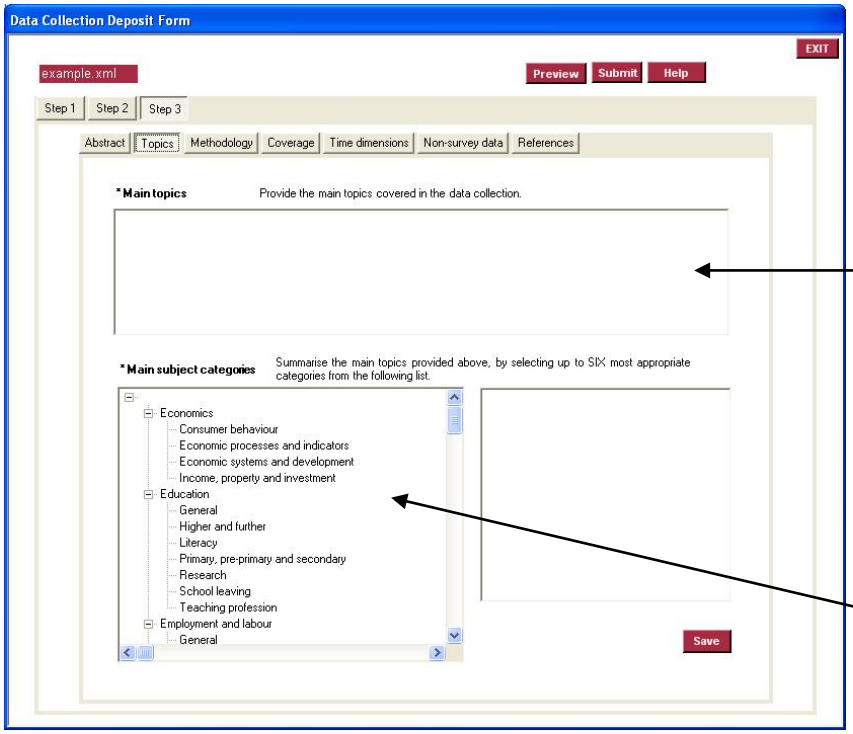
Step 3



The abstract covers the general aims, purpose and background to the data collection (use max. 300 words).

If derived from or related to existing data collections, list details.

If there is a website containing information relevant to the data collection, please provide a link.

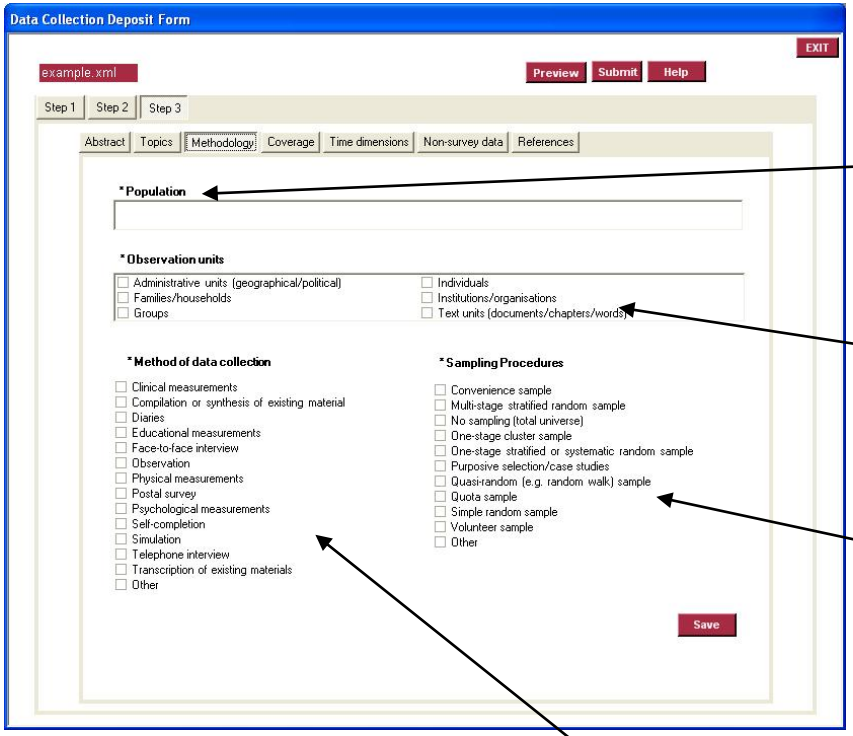


In the box 'Main topics' please list the following:

- cancer awareness
- cancer symptoms
- cancer risk factors
- cancer patient delay
- cancer knowledge

In the box 'Main subject categories' please write the following:

- Specific diseases and medical conditions -Health
- Psychology
- Health services and medical care- Health
- Social attitudes and behaviour - Society and Culture

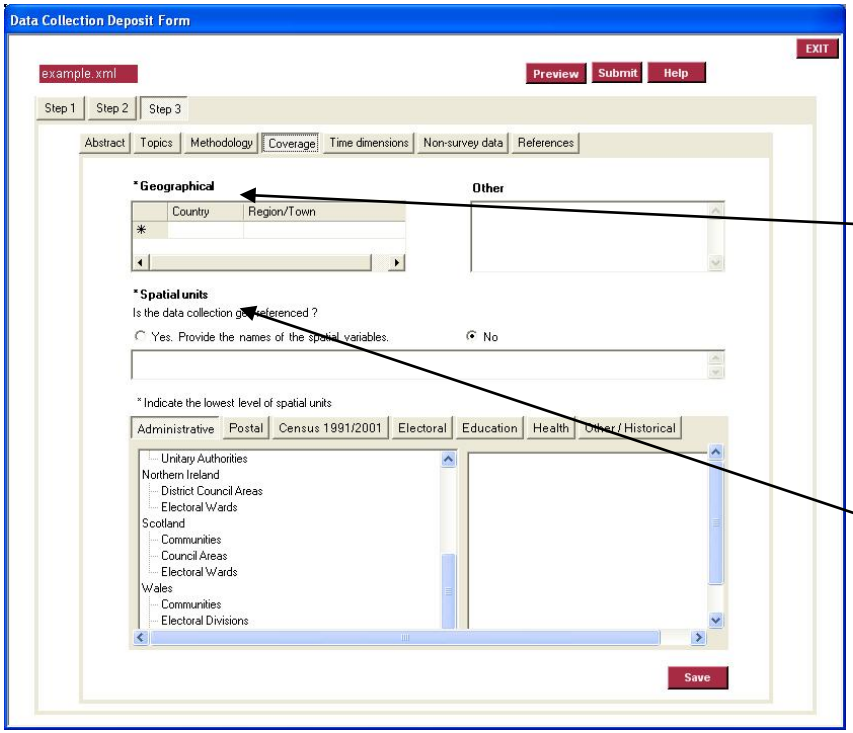


Provide information about the characteristics of the group or units studied e.g. single mothers in Yorkshire.

Categorise the characteristic of the population studied using the options provided.

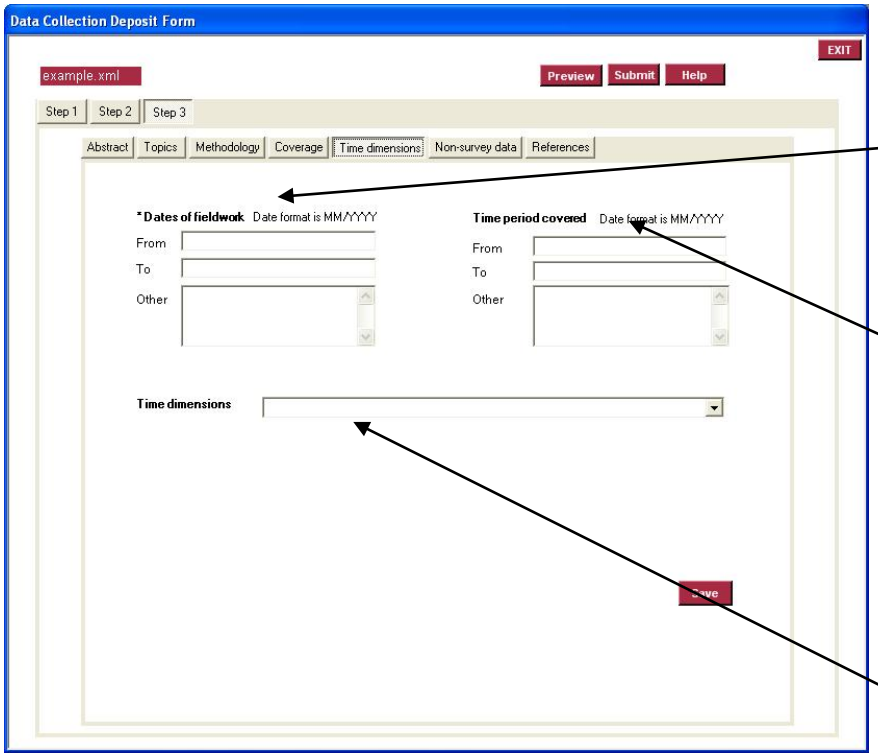
Select an option from the list provided or enter additional information by selecting ‘other’.

From the list, select one or more methods used in the research or select ‘other’ and use free text entry box.



This element can include multiple entries. For some data collections geographical coverage is not categorised by country/region/town e.g. for a computer program or a bibliography. In these cases use the 'other' free text box to provide details.

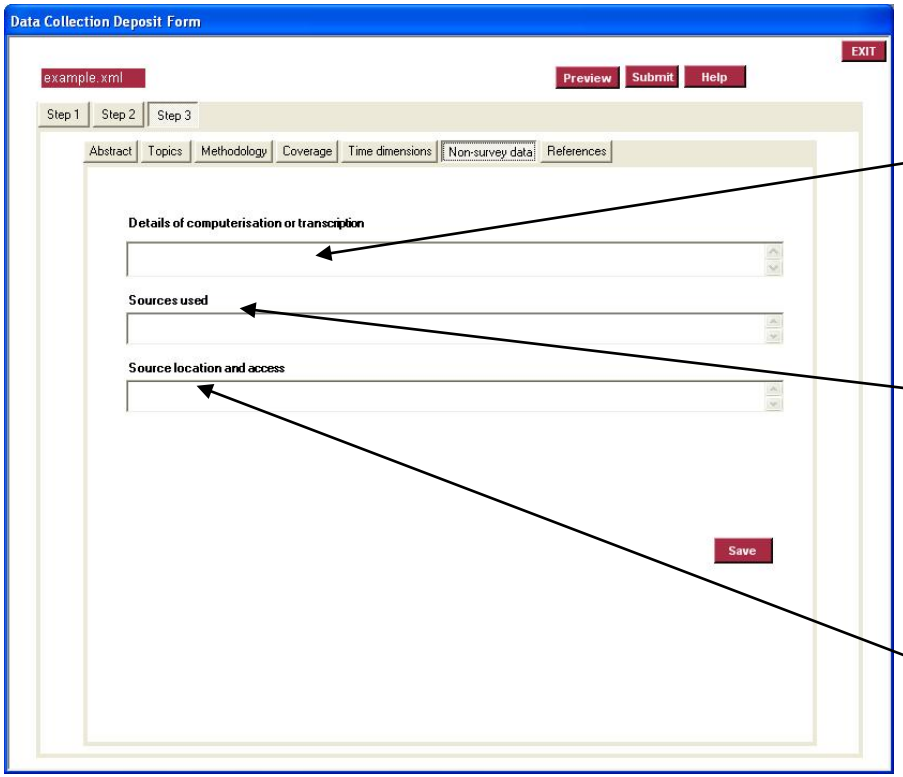
Geo-referenced data consist of measurements or observations taken at specific locations. If the research has been geo-referenced, select 'Yes' and provide the names of the spatial variables, if not select 'No' and proceed to complete the remaining elements of the form.



This relates to the date(s) the data were collected. The format of the From: and To: elements is MM/YYYY e.g. 02 1999 denotes February 1999

This relates to the time period covered by the data, if different from the dates of fieldwork. The format of the From: and To: elements is MM/YYYY e.g. 02 1999 denotes February 1999

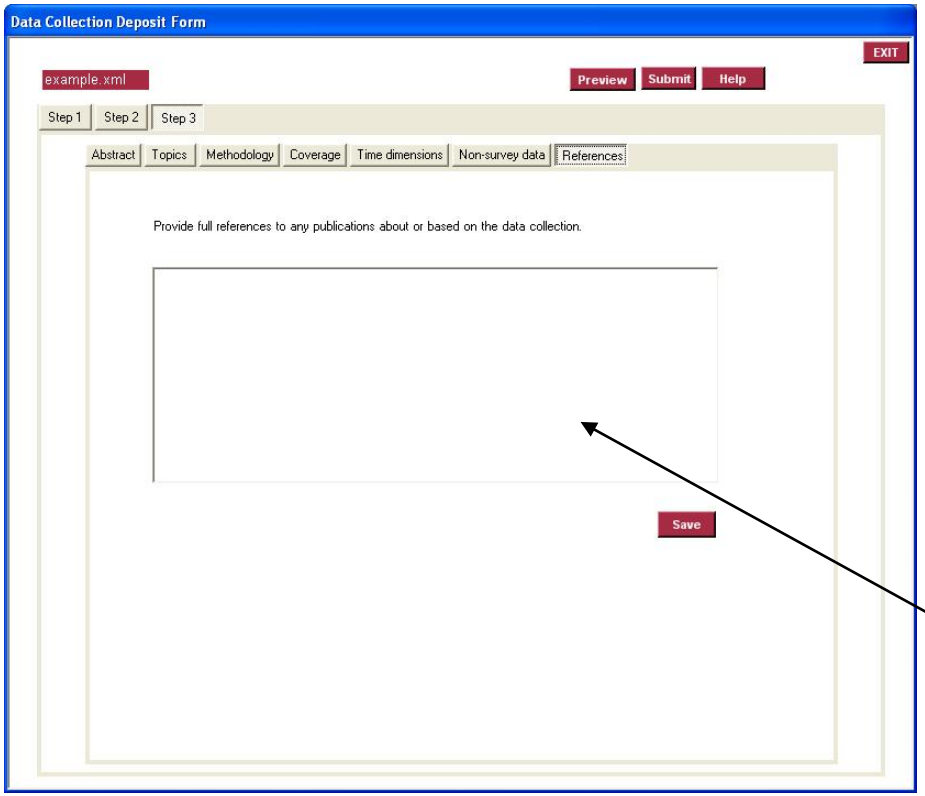
Select an option from the drop down list.



If the data collection was derived in whole or in part from other published or unpublished sources, indicate the methodology used for digitising the original source materials and whether the data represent a complete or partial transcription/copy.

If the data were derived in whole or in part from other published or unpublished, printed or electronic sources, give references to the original material e.g. Enumerators' books; probate records; court materials; newspapers; parliamentary records.

Give details of where the sources described in 'sources used' are held, how they are documented and how they can be accessed.



In the box called 'References' please include the following:

- Stubbings S, Robb KA, Waller J, Ramirez A, Austoker J, Macleod U, Hiom S, Wardle J (2009). Development of a measurement tool to assess public awareness of cancer. British Journal of Cancer, 101, S13–S17
- Robb KA, Stubbings S, Ramirez A, Austoker J, Macleod U, Waller J, Hiom S, Wardle J (2009) Public awareness of cancer in Britain. British Journal of Cancer (in press)
- Waller J, Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Hiom S, Jane Wardle J (2009) Awareness of cancer symptoms and anticipated help-seeking among ethnic minority groups in England British Journal of Cancer, 101, S24-S30

Please also add any references for publications that have resulted directly from your own data.

Together we will beat cancer

CANCER RESEARCH UK

Cancer Research UK Cancer Awareness Measure (CAM)

Flexibility in using the CAM

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

Introduction

It is important to promote the use of the CAM and make it as accessible and easy to use as possible. The CAM includes nine questions and twelve demographic questions and takes between 15-20 minutes to complete. Many researchers will need to shorten the CAM, prioritising some of the questions over others and may want to ask additional questions of their own. This brief guide outlines how this can be possible while retaining the validity and reliability of the CAM questions.

CAM modules

It is possible to separate the questions in the CAM into distinct 'modules' that can be used on their own, in conjunction with other items from the CAM or elsewhere. However it is extremely important that all the items in the modules are retained, removing items could result in reduced reliability or validity of the measure. The modules are listed below.

Module 1. Q1 - Open warning signs (1 item)

Module 2. Q2 - Closed warning signs (9 items)

Module 3. Q3 – Seeking help (1 item)

Module 4. Q4 - Barriers to seeking help (11 items)

- Emotional – embarrassed, scared, worried about what the doctor might find, confidence discussing symptom (4 items)
- Practical – too busy, to many worries, transport (3 items)
- Service – wasting time, difficulty making appointment, difficulty talking to doctor (3 items)
- Other – verbatim (1 item)

Module 5. Q5 - Open risk factors (1 item)

Module 6. Q6 - Closed risk factors (11 items)

Module 7. Q7 - Cancer and age (1 item)

Module 8. Q8 – Most common cancers (6 items)

Module 9. Q9 - NHS screening programme (6 items)

- Knowledge (3 items)
- Age of first invitation (3 items)

Ordering of CAM questions

It is possible to change the order of the CAM modules, for example, you can ask about knowledge of NHS screening programmes first and warning signs last. There is one exception to this; closed or prompted questions such as 'The following may or may not be warning signs for cancer. We are interested in <u>your</u> opinion', should always be asked <u>after</u> open or unprompted questions such as 'There are many warning signs and symptoms of cancer. Please name as many as you can think of'. This is because the closed/prompted questions essentially provide the answers to the open/unprompted questions.

Taking this into account, it is possible to ask the CAM modules in any order you like. It is also possible to change the ordering of items within modules. You may wish to counterbalance or rotate the order to see if this has any affect on people's responses.

You can also to ask additional questions alongside the CAM questions. For example, if you're using the CAM to assess the impact of an intervention you will want to ask some more specific questions about the intervention itself. In doing so, you should consider how these questions could affect the respondent's response to the CAM. For example, you should avoid asking questions that could increase the participant's knowledge about cancer.

Demographic questions

It is also possible to include fewer demographic questions. We have outlined the essential demographic items below and these questions must be included in the survey. All other items are optional and you are welcome to add any additional questions if you have more specific needs.

Essential demographic items:

- Age
- Gender
- Ethnicity
- Experience of cancer
- At least one indicator of deprivation[9], e.g. education, employment, living arrangement, car/van ownership, postcode

[9] We advise using an individual level of deprivation such as education or employment AND an area-level indicator of deprivation such as postcode.

Cancer Research UK Cancer Awareness Measure (CAM)

Sampling

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

Introduction

Your sampling method and your sample size determine the 'generalisability' of your results, in other words, the extent to which you can claim that your findings are an accurate reflection of the population of interest. If you have access to public health expertise, we suggest you involve them in developing your sampling strategy. There are a number of methods of sampling that you may consider:

Simple random sampling – where each individual has an equal chance of being selected. This is the best way of generating a representative sample (as long as you achieve a good response from potential participants you approach). To do random sampling you must have a list (sampling frame) of all the potential study participants of interest, e.g. a GP list, the electoral register, or a list of church members, you can then randomly sample participants from this list.

A commonly used sampling frame is the 'Postal Address File', which actually lists addresses rather than individuals. Addresses are randomly drawn from the list and then one person from the household is selected to take part in the survey. A tool called a 'Kish grid' is commonly used to select the individual. Strictly speaking, this technique does not randomly sample individuals because the probability of being selected is influenced by the number of people living at an address. Nevertheless, this method is used in many national surveys, e.g. the Health Survey for England, and is a good way of selecting representative samples.

Stratified sampling – where you randomly select individuals to take part from subgroups (e.g electoral wards or census super output areas, people attending particular schools or registered with particular GP practices) of your sampling frame. These subgroups may be selected systematically (e.g. to represent areas with a range of deprivation levels) or randomly. This method is efficient because data collection can be limited to a smaller number of areas than in simple random sampling. Stratified sampling is a reliable method of generating representative samples (as long as you achieve a good response from potential participants you approach) and is commonly used in national surveys, for example, the Health Survey for England.

Random digit dialling – used for telephone surveys. This is a form of random sampling and can be simple or stratified by area code. Telephone directories can be used as a sampling frame from which to draw participants, but many people in the UK elect not to have their number listed in the directory, and increasing use of mobile phones means that this method is less likely to generate a representative sample.

Quota sampling – where you decide in advance how many people of different age or sex groups you would like to have in your sample and continue to sample by any method until you fill the "quota" for those groups. You may also define the quotas by other characteristics such as socioeconomic status or ethnicity. A quota sample is a convenience sample and is less likely to be truly representative of your population than a sample generated by random sampling methods.

Points to consider when deciding on sampling methods and sample size:

- Funding.
- The target group of interest (e.g. all men over 50 years living in x).
- Method of data collection: face-to-face, telephone, internet or postal?
- Aims and objectives – do you want to simply measure cancer awareness or to evaluate the impact of an awareness raising initiative?
- Generalisability of the sample – do you want to be able to generalise your results to a wider population? If so, which population?
- Which comparisons you wish to make e.g. between sexes, ethnic or socioeconomic groups?
- The likely response to the questionnaire, i.e. the number of people who complete the survey out of the number you approached (e.g. 50% for a postal survey).
- A strategy for maximising response (e.g. repeat visits, postal reminders)
- Level of 'unusable' questionnaires (e.g. those that are returned but not valid or incomplete).
- The margin of error - for example, if you selected a margin of 5% and 40% of respondents said they thought a lump could be a sign of cancer then you would expect (if you'd asked everyone in your sampling frame) that the correct answer would fall between 35-45% (40±5).
- Statistical level of confidence - usually set at 95%. This means that you have 95% chance of the response being true and 5% chance the response is due to chance/not representative.

Cancer Research UK Cancer Awareness Measure (CAM)

Glossary

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

Glossary

Barrier for seeking help – Any reason given for not seeking help for a suspected warning sign or symptom.

Cancer screening – Testing large groups of apparently healthy people for early signs of certain types of cancer. Screening for a specific cancer can only be carried out when there are good enough tests available and studies have shown that screening will do more good than harm.

Cancer screening programme – Invites certain sections of the population to screening at regular intervals over a period of years.

Closed question – A query that requires the respondent to answer using given options.

Interviewer – The person giving the questionnaire to respondents.

Open question – A query that allows the respondent to answer freely.

Risk factor for cancer – Something about us or our lives that increases our chances of developing cancer.

Respondents – The people giving the answers to the CAM.

Seeking help – Visiting a doctor in regards to a suspected warning sign or symptom.

Symptom of cancer – A feeling of illness, or physical or mental change, caused by cancer.

Warning sign of cancer – A feeling of illness, or physical or mental change, that may or may not be caused by cancer.