

Breast Cancer Awareness Measure (Breast CAM)

Toolkit (version 2)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

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

Please find enclosed/attached the Breast Cancer Awareness Measure (Breast 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 Breast CAM complies with our guidance notes.

Please do not alter the Breast 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 Breast CAM or any of the guidance supplied, and in any publication based wholly or partly on its use.

‘This survey instrument (Breast CAM) was developed by Cancer Research UK, King’s College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.’

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

We would like to see all Breast 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 54 for guidance)

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

Breast Cancer Awareness Measure (Breast CAM)

Background information and instructions

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Introduction and purpose of the Breast Cancer Awareness Measure

In 2007, the NHS Cancer Reform Strategy¹ 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. In addition to the generic version of the CAM, there is a need to develop site specific modules for cancers where early detection is likely to impact survival, as is the case with Breast cancer. This document provides information about the use of the breast specific version of the CAM – the Breast CAM.

The Breast CAM comprises 8 questions with a total of 31 items;

- Warning signs (12 items) (Q1 + Q2)
- Confidence, skills and behaviour (3 items) (Q3)
 - Self-examination behaviour (1 item)
 - Confidence (1 item)
 - Previous help-seeking behaviour (1 item)
- Delay in seeking medical help (1 item) (Q4)
- Breast cancer and age (1 item) (Q5)
- NHS breast cancer screening programme (4 items) (Q6)
 - Knowledge (1 item)
 - Age of first invitation (1 item)
 - Age of last invitation (1 item)
 - Invitation status (1 item)
 - Previous screening participation (1 item)
- Risk factors (10 items) (Q7 + Q8)

Evaluation and psychometric status

The development paper (Linsell et al, 2010²) indicates that the Breast CAM is reliable and valid. Test-retest reliability over 2-week interval was moderate to good for most items with all correlations between 0.42-0.70. In order to ensure construct validity the Breast CAM was completed by 18 cancer experts and 13 non-medical academics. Cancer specialists obtained significantly higher scores than non-medical academics indicating that the Breast CAM is capable of discriminating between those who have high and low levels of breast cancer awareness. In a Randomised Controlled Trial of an intervention to raise cancer awareness and promote symptomatic presentation the intervention significantly increased the proportion of women obtaining the full score for breast cancer awareness one month after the

¹ Department of Health (2007). Cancer Reform Strategy.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_081006.

² Linsell, L, Forbes, L, Burgess, C, Kapari, M, Thurnham, A, Ramirez, A (2010). Validation of a measurement tool to assess awareness of breast cancer. *European Journal of Cancer*, 46, 1374-1381.

intervention. This demonstrates that the Breast CAM is sensitive to increases in cancer awareness.

Administration

The Breast CAM has been designed to measure breast cancer awareness in women. A version to measure men's awareness of breast cancer in women is currently under development. The Breast CAM was designed to be administered as an interview either face-to-face or over the telephone and this delivery method 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 Breast 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 Breast CAM should be administered by one trained interviewer in an environment where there will be little distraction.

The internet

Using the Breast 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 Breast 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.

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 Breast CAM as 'self-complete' or postal survey you must either remove Q1 and Q7 or Q2 and Q8. Q1 and Q7 are 'unprompted' questions which ask respondents to recall warning signs or risk factors from memory. Q2 and Q8 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 Q7 as a result of being prompted in Q2 and Q8.

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 a more difficult option for less experienced researchers.

Recruitment considerations

For information about sampling methods and sample size for your Breast CAM survey please see page 71. Once you have recruited your participants please record the sampling methods using the relevant form (see 'Recruitment Record' on page 25) 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 54).

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 Breast 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 11).

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 Breast CAM survey data (see 'Coding Sheet' on page 41). All Breast 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 'How to access and deposit CAM data' on page 54.

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

Breast CAM questions

Q1 – Open warning signs

“First of all, please would you name as many early warning signs of breast cancer as you can think of”

This is an open question aiming to find out how many early warning signs of breast cancer the woman can think of without specific prompting. In face to face interviews 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. If this survey is completed online, Q1 should be presented on a separate page to Q2 and once the responses from Q1 are submitted respondents should not be able to go back and change or add to existing responses. Please ensure that the respondent does not see Q2 before they have completed Q1.

Q2 – Closed warning signs

“Can you tell me whether you think any of these are warning signs of breast cancer or not?”

These closed questions are designed to measure how many warning signs a woman can recognise when prompted.

Q3 – Confidence, skills and behaviour

“How often do you check your breasts?”

“Are you confident you would notice a change in your breasts?”

“Have you ever been to see a doctor about a change you have noticed in one of your breasts?”

These questions aim to measure confidence, skills and behaviour to detect breast changes and act upon the findings. The first question asks about frequency of breast checking, the second about confidence to detect a breast change and the third asks about reporting a breast change to a doctor.

Q4. Seeking help for cancer symptoms

“If you found a change in your breast, how soon would you contact your doctor?”

This question aims to find out how long women think they will delay before seeking medical help after discovering a breast change.

Q5 – Breast cancer and age

“In the next year, who is most likely to develop breast cancer?”

This question explores the women’s knowledge of how age is related to breast cancer.

Q6 – NHS Breast Cancer Screening Programme

“As far as you are aware, is there an NHS Breast Screening Programme?”

*“At what age are women **first** invited to the NHS Breast Screening Programme?”*

*“At what age do women receive their **last** invitation to the NHS Breast Screening Programme?”*

“Have you ever been invited for breast screening on the NHS Breast Screening Programme?”

“Have you ever had breast screening on the NHS Breast Screening Programme?”

These questions aim to assess women’s knowledge of the NHS Breast Screening Programme and whether they have had mammograms on the NHS Breast Screening Programme.

Q7. Open risk factors

“What things do you think affect a woman’s chance of developing breast cancer?”

This is an open question designed to measure how many breast cancer risk factors a woman can think of without specific prompting. In face to face interviews Q7 is always printed on a separate sheet to Q8 in order to ensure that respondents answers’ are their own and not taken from the list given for Q8. Please ensure that the respondent does not see Q8 before they have completed Q7.

Q8 – Closed risk factors

“How much do you agree that each of these can increase the chance of developing breast cancer?”

These closed questions are designed to measure how many risk factors a woman can recognise when prompted. The most important risk factor, increasing age, has been included as a separate question, so is not repeated here.

Breast Cancer Awareness Measure (Breast CAM)

Information sheet & consent form

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

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 breast 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?

The data collected from this survey will be archived in the UK Data Archive. The Archive is a repository for social science data. The CAM Archive will help us to build an understanding of public knowledge about cancer so that we can develop ways to improve communications and services that aim to improve cancer outcomes. 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]

Breast Cancer Awareness Measure

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

1. First of all, please would you name as many early warning signs of breast cancer as you can think of:



2. Can you tell me whether you think any of these are warning signs of breast cancer or not?

	Yes	No	Don't know
Do you think a lump or thickening in your breast could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a lump or thickening under your armpit could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think bleeding or discharge from your nipple could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think the pulling in of your nipple could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a change in the position of your nipple could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a rash on or around your nipple could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think redness of your breast skin could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a change in the size of your breast or nipple could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a change in the shape of your breast or nipple could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think pain in one of your breasts or armpit could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think dimpling of the breast skin could be a sign of breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3a. How often do you check your breasts?

Rarely or never	At least once every 6 months	At least once a month	At least once a week
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3b. Are you confident you would notice a change in your breasts?

Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3c. Have you ever been to see a doctor about a change you have noticed in one of your breasts?

Yes	No	Never noticed a change in one of my breasts
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. If you found a change in your breast, how soon would you contact your doctor?

5. In the next year, who is most likely to develop breast cancer?	
A 30 year old woman	<input type="checkbox"/>
A 50 year old woman	<input type="checkbox"/>
A 70 year old woman	<input type="checkbox"/>
A woman of any age	<input type="checkbox"/>

	Yes	No	Don't know
6a. As far as you are aware, is there an NHS breast cancer screening programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, at what age are women first invited for breast cancer screening? _____			<input type="checkbox"/>
If yes, at what age are women last invited for breast cancer screening? _____			<input type="checkbox"/>
6b. Have you ever been invited for breast screening on the NHS Breast Screening Programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6c. Have you ever had breast screening on the NHS Breast Screening Programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. What things do you think affect a woman's chance of developing breast cancer?

8. How much do you agree that each of these can increase the chance of developing breast cancer?"

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Having a past history of breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using HRT (Hormone Replacement Therapy)	<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"/>
Being overweight (BMI over 25)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a close relative with breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having children later on in life or not at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Starting your periods at an early age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a late menopause	<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"/>

Breast Cancer Awareness Measure (Breast CAM)

Demographic Questions

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

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
<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"/> Prefer not to say
	<input type="checkbox"/> Any other Mixed background	<input type="checkbox"/> Any other Asian background		

4. 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	<input type="checkbox"/> 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. 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 |
| <input type="checkbox"/> Still studying | <input type="checkbox"/> 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 |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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:

- | | |
|---|--|
| <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"/> Still studying |
| <input type="checkbox"/> Self-employed | <input type="checkbox"/> Disabled or too ill to work |
| | <input type="checkbox"/> 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Close family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Close friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Optional items:**Are you registered with a GP?**

Yes	No	Don't know	Prefer not to say
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Breast Cancer Awareness Measure (Breast CAM)

Recruitment Record

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

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 women aged over 50 years living in x).

Sampling frame(s) (e.g. electoral registers, postal address file, GP lists, telephone directory, all women 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 Breast 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 Breast CAM?

How many people agreed to complete the Breast CAM?

How many people refused to complete the Breast CAM?

How many participants started to complete the Breast CAM but did not complete it?

Over what time period were the interviews carried out?

From: _____(dd/mm/yyyy) to: _____(dd/mm/yy)

Breast Cancer Awareness Measure (Breast CAM)

Script

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Introduction

This script is intended for use **during training** of how to administer the Breast 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 Breast 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 questions 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 breast cancer awareness among people living in X]

COMPULSORY: This set of questions is about your awareness of breast 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 breast cancer - cancer that starts in the breast. Please would you name as many early warning signs of breast cancer 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

<i>Can you tell me whether you think any of these are warning signs of breast cancer or not?</i>
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.
<i>Do you think a lump or thickening in your breast could be a sign of breast cancer?</i>
Repeat the above format for each subsequent question in this group.

Clarifications:

Please only read these out if necessary.

<i>Do you think a change in the position of your nipple could be a sign of breast cancer? [POINT OF CLARIFICATION]: such as pointing up or down or in a different direction to normal</i>
<i>Do you think pulling in of your nipple could be a sign of breast cancer? [POINT OF CLARIFICATION]: where the nipple no longer points outwards but into the breast</i>
<i>Do you think puckering or dimpling of your breast skin could be a sign of breast cancer? [POINT OF CLARIFICATION]: like a dent or orange peel appearance</i>

QUESTION 3 – CONFIDENCE, SKILLS AND BEHAVIOUR

<i>How often do you check your breasts?</i>
<i>Rarely or never</i> <i>At least once every 6 months</i> <i>At least once a month</i> <i>At least once a week</i>
<i>Are you confident you would notice a change in your breasts?</i>
<i>Not at all confident</i> <i>Not very confident</i> <i>Fairly confident</i> <i>Very confident</i>
<i>Have you ever been to see a doctor about a change you have noticed in one of your breasts?</i>
<i>Yes</i> <i>No</i> <i>Not noticed a change in one of my breasts</i>

QUESTION 4 – SEEKING HELP

<i>The next question is about seeking help</i>
<i>If you found a change in your breasts, how soon would you contact your doctor?</i>
Record the response verbatim

QUESTION 5 – BREAST CANCER AND AGE

<i>The next question is about age and breast cancer.</i>
<i>In the next year, who is most likely to develop breast cancer?</i>
<i>A 30 year old woman</i>
<i>A 50 year old woman</i>
<i>A 70 year old woman</i>
<i>A woman of any age</i>

QUESTION 6 – NHS BREAST CANCER SCREENING PROGRAMME

Do NOT prompt
<i>The next set of questions are about the Breast NHS screening programmes</i>
<i>As far as you are aware, is there an NHS breast cancer screening programme? You may answer: 'Yes', 'No', 'Don't know'</i>
<i>[IF YES]</i>
<i>At what age are women first invited for breast cancer screening?</i>
<i>At what age do women receive their last invitation to the NHS Breast Screening Programme?</i>
<i>Have you ever been invited for breast screening on the NHS Breast Screening Programme?</i>
<i>Have you ever had breast screening on the NHS Breast Screening Programme?</i>
<i>[IF NO] Go to next question/demographic questions</i>

QUESTION 7 - OPEN RISK FACTORS

The next set of questions is about risk factors for breast cancer

What things do you think affect a woman's chance of developing breast 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 8 – CLOSED RISK FACTORS

How much do you agree that each of these can increase the chance of developing breast cancer?

Do NOT prompt

Having a close relative with breast cancer

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)*

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

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.

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
<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"/> Prefer not to say
	<input type="checkbox"/> Any other Mixed background	<input type="checkbox"/> 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?

- | | |
|--|---|
| <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 higher | <input type="checkbox"/> No formal qualifications |
| <input type="checkbox"/> ONC/BTEC | <input type="checkbox"/> Other |
| <input type="checkbox"/> Still studying | <input type="checkbox"/> 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 |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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:

- | | |
|---|--|
| <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"/> Still studying |
| <input type="checkbox"/> Self-employed | <input type="checkbox"/> Disabled or too ill to work |
| | <input type="checkbox"/> 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 |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Have you, your family or close friends had cancer?				
	Yes	No	Don't know	Prefer not to say
You	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Close family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Close friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Optional items:

Are you registered with a GP?				
Yes	No	Don't know	Prefer not to say	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What is your sexual orientation?					
Bi-sexual	Gay man	Gay woman/lesbian	Heterosexual/straight	Other	Prefer not to say
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?**

Breast Cancer Awareness Measure (Breast CAM)

Answer sheet

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

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 Breast CAM.

Q1. *First of all, please would you name as many early warning signs of breast cancer 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 breast cancer.

Q2. *Can you tell me whether you think any of these are warning signs of breast cancer or not?*

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 breast cancer.

Q3a. *How often do you check your breasts?*

The current Department of Health recommendations on breast checking are as follows:

“It is important to be aware of how your breasts normally look and feel at different times. You will then notice if something is different or if you develop any of the signs and symptoms listed above.

You can become familiar by looking and feeling your breasts from time to time in any way that is best for you.

You can feel your breasts in the bath or shower using a soapy hand or lying down in bed. Using body lotion can help. It is important to feel the whole breast including the armpit.

You can look at your breasts in the mirror. Move your arms (above your head, on your hips or by your sides) so that you can see your breasts from every angle, including the underside.

As older women are at greater risk of breast cancer, it is very important to be aware of any unusual changes after the menopause, when your periods have stopped.

Breasts may change with age and life events, such as pregnancy, breastfeeding, at different times of the month if you still have periods and after the menopause. This is why it is important to know what is normal for you so you will recognise any changes.”

The Department of Health does not provide any firm recommendations on the frequency with which women should check their breasts, because there is no clear evidence that any particular frequency is appropriate.

Q3b. *Are you confident you would notice a change in your breasts?*

This is an attitudinal question with no right or wrong answer.

Q3c. *Have you ever been to see a doctor about a change you have noticed in one of your breasts?*

There is no right or wrong answer to this question.

Q4. *If you found a change in your breast, how soon would you contact your doctor?*

Women, particularly those over the age of 50, should contact their doctor's surgery within a few days of discovering a breast change. We know that the sooner breast cancer is diagnosed, the better the outcome is likely to be. The risk of a breast symptom indicating breast cancer is much higher in an older than a younger woman.

Q5. *In the next year, who is most likely to develop breast cancer?*

The correct answer to this question is 'a 70 year old woman'. The risk of breast cancer increases with increasing age. Most women who get breast cancer are past their menopause (change of life), but around one in five women diagnosed each year are under 50 years old.

Q6a. *As far as you are aware, is there an NHS Breast Screening Programme?*

Q6b. *At what age are women **first** invited to the NHS Breast Screening Programme?*

Q6c. *At what age do women receive their **last** invitation to the NHS Breast Screening Programme?*

Q6d. *Have you ever been invited for breast screening on the NHS Breast Screening Programme?*

Q6e. *Have you ever had breast screening on the NHS Breast Screening Programme?*

Women are currently invited for breast screening between the ages of 50 and 70 and are offered mammograms every three years. From 2009, this age range began to be extended. Women in their late forties and up to the age of 73 are also starting to be invited. It will take a few years for this to happen everywhere in England. NHS breast screening is not usually available for younger women as mammograms are not as effective on younger breasts. Women over 70 can ask for free breast screening every three years, by contacting their local breast screening unit.

Q7. *What things do you think affect a woman's chance of developing breast cancer?*

The correct answers to this question are listed in question 8, although there are other warning signs and symptoms and none of the signs and symptoms listed would necessarily be caused by breast cancer.

Q8. *How much do you agree that each of these can increase the chance of developing breast cancer?*

All of these increase the risk of breast cancer

HRT does increase the risk of getting breast cancer; however, if women only take it for a short time the increased risk is small. The longer you take HRT, the more your breast cancer risk increases. The risk goes back to normal within five years of stopping taking it. If a woman is worried about taking HRT or any of the other risk factors mentioned here, please recommend that she talks her doctor about the benefits and risks in her individual situation.

Breast Cancer Awareness Measure

Coding sheet (for use with SPSS or EXCEL)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Background and purpose

The coding guidance set out below ensures that data from the Breast 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. **Position**). 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 Breast 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
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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		

Breast CAM questions

1. OPEN WARNING SIGNS

Create 13 variables labelled from **Breast_symp01** to **Breast_symp11**. Each symptom named must be recorded using the coding frame below. For example, if the respondent names 'pain in the breast' and 'bleeding from nipple', code **Breast_symp01** as 3 in **Breast_symp02** as 5.

To code a variable that is not on the list code as 'Other' (code 12) create additional variables e.g. **Breast_symp013**, **Breast_symp14**, etc and write the response the participant has given verbatim.

Nipple position	1
Pulling in of nipple	2
Pain breasts/armpit	3
Puckering/dimpling	4
Discharge/bleeding nipple	5
Lump/thickening breast	6
Nipple rash	7
Redness breast skin	8
Lump/thickening armpit	9
Change size breast/nipple	10
Change shape breast/nipple	11
Other	12
Nothing	13
Refused	98
Don't know	99

2. CLOSED WARNING SIGNS

Can you tell me whether you think any of these are warning signs of breast cancer or not?			
	Scoring		
Question followed by corresponding SPSS/Excel Variable Name	Yes	No	Don't know
Do you think a change in the position of your nipple could be a sign of breast cancer? Breast_position	3	2	1
Do you think pulling in of your nipple could be a sign of breast cancer? Breast_pullin	3	2	1
Do you think pain in one of your breasts or armpit could be a sign of breast cancer? Breast_pain	3	2	1
Do you think puckering or dimpling of your breast skin could be a sign of breast cancer? Breast_pucker	3	2	1
Do you think discharge or bleeding from your nipple could be a sign of breast cancer? Breast_disch	3	2	1
Do you think a lump or thickening in your breast could be a sign of breast cancer? Breast_lump	3	2	1
Do you think a nipple rash could be a sign of breast cancer? Breast_rash	3	2	1
Do you think redness of your breast skin could be a sign of breast cancer? Breast_redness	3	2	1
Do you think a lump or thickening under your armpit could be a sign of breast cancer? Breast_armlump	3	2	1
Do you think changes in the size of your breast or nipple could be signs of breast cancer? Breast_size	3	2	1
Do you think changes in the shape of your breast or nipple could be signs of breast cancer? Breast_shape	3	2	1

3. CONFIDENCE, SKILLS AND BEHAVIOUR

How often do you check your breasts?

Breast_check

Rarely or never	At least once every 6 months	At least once a month	At least once a week
4	3	2	1

Are you confident you would notice a change in your breasts?

Breast_confid

Not at all confident	Not very confident	Fairly confident	Very confident
4	3	2	1

Have you ever been to see a doctor about a change you have noticed in one of your breasts?

Breast_doctor

Yes	No	Never noticed a breast change
1	2	3

4. SEEKING HELP

If you found a change in your breast, how soon would you contact your doctor?

Breast_CancerSignTime

Record response verbatim

5. AGE AND BREAST CANCER

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

Breast_AgeC

A 30 year old woman	A 50 year old woman	A 70 year old woman	A woman of any age
4	3	2	1

6. NHS BREAST CANCER SCREENING PROGRAMME

Question followed by corresponding		Yes	No	Don't know	Refused
SPSS/Excel Variable Name					
Is there an NHS Breast Screening Programme? Breast_screening		1	2	99	98
IF YES:	At what age are women first invited to the NHS Breast Screening Programme? Breast_firstage	Age in years		99	98
	At what age do women receive their last invitation to the NHS Breast Screening Programme? Breast_lastage	Age in years		99	98
	Have you ever been invited for breast screening on the NHS Breast Screening Programme? Breast_invite	1	2	98	98
	Have you ever had breast screening on the NHS Breast Screening Programme? Breast_attend	1	2	98	98

7. OPEN RISK FACTORS

Create 21 variable names from **Breast_riskO1** to **Breast_riskO27**

Please create 21 variables labelled 1, 2, 3 etc, up to 21. 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 '4' in **Breast_riskO1**. If the second response is 'stress' code as '19' in **Breast_riskO2** etc.

To code a variable that is not on the list code as 'Other' (code 20) create additional variables e.g. **Breast_riskO22**, **Breast_riskO23**, etc and write the response the participant has given verbatim.

Previous breast cancer	1
Hormone Replacement Therapy (HRT)	2
Drinking alcohol	3
Being overweight	4
Having a close relative with breast cancer	5
Having children later on in life or not at all	6
Starting periods at an early age	7
Having a late menopause	8
Not doing enough exercise/physical activity	9
Older age (unspecified)	10
Having gone through the menopause	11
Being a smoker	12
Diet (unspecified)	13
Drinking alcohol	14
Chance	15
Hormone imbalance	16
Breastfeeding	17
Taking the oral contraceptive pill	18
Stress	19
Other	20
Nothing	21
Refused	98
Don't know	99

8. CLOSED RISK FACTORS

How much do you agree that each of these can increase the chance of developing breast cancer?					
Question followed by corresponding SPSS/Excel Variable Name	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Having a past history of breast cancer Breast_pasthist	1	2	3	4	5
Using HRT (Hormone Replacement Therapy) Breast_hrt	1	2	3	4	5
Drinking more than 1 unit of alcohol a day Breast_alcohol	1	2	3	4	5
Being overweight (BMI over 25) Breast_bmi	1	2	3	4	5
Having a close relative with breast cancer Breast_famhist	1	2	3	4	5
Having children later on in life or not at all Breast_nokids	1	2	3	4	5
Starting your periods at an early age Breast_periods	1	2	3	4	5
Having a late menopause Breast_menopaus	1	2	3	4	5
Doing less than 30 mins of moderate physical activity 5 times a week Breast_exercise	1	2	3	4	5

Demographic Questions

1. What is your age?	<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/>	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 highsers	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?

--	--

Prefer not to say

98

Postcode

Record actual postcode

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

--	--

Prefer not to say

98

Years UK

Record actual years

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 Awareness Measure (CAM) UK Data Archive

How to access and deposit CAM data

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

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 that 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 Acquisitions 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 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.

1. Go to: <http://www.data-archive.ac.uk>
2. Go to 'How to register' and follow the appropriate steps

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

1. Go to: <http://www.data-archive.ac.uk>
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. Use the 'Data Catalogue' to search for 'cancer awareness'. This should bring up all the CAM data that is currently held in the archive
6. Click on 'Download/order'
7. 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

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

To deposit your data into the archive you will need to complete three basic tasks:

1. Complete a set of deposit forms
2. Provide the data with supporting documentation
3. Complete the licence agreements

These tasks 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.

Next steps

Once you have sent your data to the UKDA, they should acknowledge receipt of your data via email. They will then review your submission and create a 'report' based on the documents you have provided. You should check this report as it will be held alongside your data in the archive. You should make any changes to the report and then confirm that you are happy with a final version. Your data will then be transferred to the archive and available on the web to other interested researchers.

Help

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

Step 1

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Save

Check the boxes to ensure data and documentation are in a preferred or acceptable format. Contact the UK Data Archive if your data are in a problematic format, or if you are unsure what format(s) to send.

* Data

* Documentation
e.g. questionnaires, codebooks, interviewers instructions, project description, etc.

Preferred format(s)
 Microsoft Word, Adobe PDF,
 Rich text format (RTF)

Acceptable format(s)
 SGML, HTML, XML,
 WordPerfect

Problematic format(s)
 Hard copy (paper) documentation

* Title of the data collection

* Data collection description
Provide details for each data file.

File name	File format	Contents

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: "Breast Cancer Awareness Measure", followed by the local designation, as appropriate.

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.

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

***Weighting information**

A: Weighting is covered in documentation.
 B: Weighting is not covered in documentation.
 C: Weighting is not applicable.

Provide details below.

Variable name	File name	Variable description

Edition/extract/version

Is this a new edition, extract or special version of the data collection?

Yes. Provide details below No

Confidentiality/anonymisation

Has the data collection been anonymised?

Yes. Indicate additional anonymisation or confidentiality issues concerning this data collection No

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'.

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Transfer medium

If any files are compressed (e.g. zipped), name the compression programme:

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

Floppy disk:	Number of diskettes	<input type="text"/>
CD-ROM/DVD:	Number of discs	<input type="text"/>
ZIP/JAZ or other cartridge:	Number of cartridges	<input type="text"/>
Other medium:	Specify medium, having first contacted the UK Data Archive to check that it is supported	<input type="text"/>

Data collections less than 10 megabytes in total may be sent as an attachment via email to acquisitions@esds.ac.uk.
Attached files may be zipped or unzipped.

Number of files attached *Note that files with a .exe or .jpg extension will be stripped out due to the University of Essex's email security system.*
Date email sent

If sending the data by FTP:

UKDA prefer to 'pull' the data for FTP transfers. If you wish to 'push' the data, an account can be set up for you. Contact help@esds.ac.uk. Once you have transferred the files, list the following:

Directory and path ---- if not the default directory File name(s) :

Save

The UK Data Archive acknowledges receipt of all materials upon arrival. If you have not received an acknowledgement letter within ten working days, contact acquisitions@esds.ac.uk to make sure that the materials have arrived.

Provide the details of medium used to send the data to the UK Data Archive (by email, by FTP, CD/DVD etc.)

NB. If your data includes postcodes please do not send by email but use an FTP transfer, or send an encrypted CD-ROM/DVD or memory stick. More information about data formats, data transfer and encryption is available here: <http://www.data-archive.ac.uk/sharing/acceptable.asp>

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.

The screenshot shows the 'Data Collection Deposit Form' interface. At the top, there's a blue header with the title. Below it, a navigation bar shows 'Step 1', 'Step 2' (selected), and 'Step 3'. The main content area is divided into sections. The 'Funding' section has a dropdown for 'Funding source list' and a table with columns 'Funding source' and 'Grant number'. Below the table is a 'Save' button. The 'Data Collector(s)' tab is selected, showing a form with fields for 'Title', '* Forename', '* Surname', 'Department/Section', '* Institute/Organisation', 'Address', 'Postcode', '* Email', 'Tel', and 'Fax'. There are 'New' and 'Delete' buttons at the bottom of this section. At the very bottom, there's a 'View selected depositors' dropdown and a 'Save' button. The top right corner has 'Preview', 'Submit', 'Help', and 'EXIT' buttons. A file name 'example.xml' is visible in the top left.

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

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data References

***Abstract**
Provide a brief summary (max. 300 words) of the main aims and objectives of the research project or alternative process e.g. administrative function, from which the data collection arose.

Related data collection
If the data collection is derived from or is closely related to others, list details. If any of these data collections are available from the UKDA, AHDS History or ESDS Qualidata, indicate the study number (if known).

URL
Is there a web site containing information relevant to the data collection that can be linked to?

Save

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.

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data References

***Main topics** Provide the main topics covered in the data collection.

***Main subject categories** Summarize the main topics provided above, by selecting up to SIX most appropriate categories from the following list.

- [-] Economics
 - Consumer behaviour
 - Economic processes and indicators
 - Economic systems and development
 - Income, property and investment
- [-] Education
 - General
 - Higher and further
 - Literacy
 - Primary, pre-primary and secondary
 - Research
 - School leaving
 - Teaching profession
- [-] Employment and labour
 - General

Save

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

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract Topics **Methodology** Coverage Time dimensions Non-survey data References

***Population**

***Observation units**

Administrative units (geographical/political)
 Individuals
 Families/households
 Institutions/organisations
 Groups
 Text units (documents/chapters/words)

***Method of data collection**

Clinical measurements
 Compilation or synthesis of existing material
 Diaries
 Educational measurements
 Face-to-face interview
 Observation
 Physical measurements
 Postal survey
 Psychological measurements
 Self-completion
 Simulation
 Telephone interview
 Transcription of existing materials
 Other

***Sampling Procedures**

Convenience sample
 Multi-stage stratified random sample
 No sampling (total universe)
 One-stage cluster sample
 One-stage stratified or systematic random sample
 Purposive selection/case studies
 Quasi-random (e.g. random walk) sample
 Quota sample
 Simple random sample
 Volunteer sample
 Other

Save

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.

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data References

***Geographical** ← **Other**

Country	Region/Town
*	

***Spatial units**

Is the data collection geo-referenced?

Yes. Provide the names of the spatial variables. No

Indicate the lowest level of spatial units

Administrative Postal Census 1991/2001 Electoral Education Health Other/Historical

- Unitary Authorities
- Northern Ireland
 - District Council Areas
 - Electoral Wards
- Scotland
 - Communities
 - Council Areas
 - Electoral Wards
- Wales
 - Communities
 - Electoral Divisions

Save

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.

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data References

***Dates of fieldwork** Date format is MM/YYYY

From:

To:

Other:

Time period covered Date format is MM/YYYY

From:

To:

Other:

Time dimensions:

None

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.

Data Collection Deposit Form

example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data References

Details of computerisation or transcription

Sources used

Source location and access

Save

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.

Data Collection Deposit Form

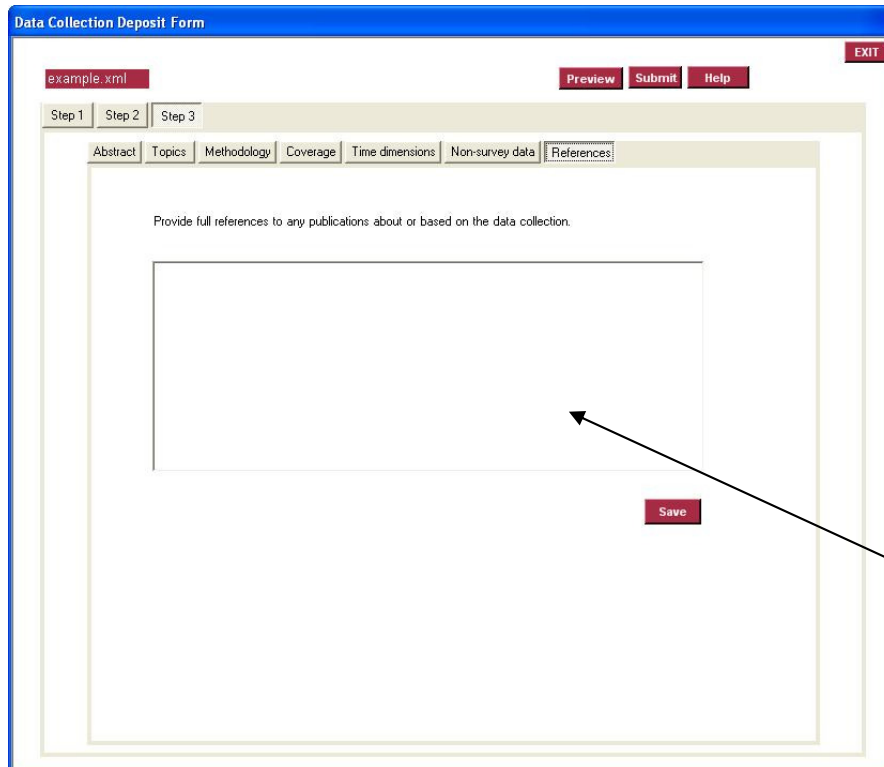
example.xml Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data **References**

Provide full references to any publications about or based on the data collection.

Save



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.

Breast Cancer Awareness Measure (CAM)

Flexibility in using the Breast CAM

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Introduction

It is important to promote the use of the Breast CAM and make it as accessible and easy to use as possible. The Breast CAM includes eight questions and twelve demographic questions and takes between 15-20 minutes to complete. Many researchers will need to shorten the Breast 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 Breast CAM questions.

CAM modules

It is possible to separate the questions in the Breast CAM into distinct 'modules' that can be used on their own, in conjunction with other items from the Breast 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 - Warning signs (1 item)

Module 2. Q2 – Closed warning signs (11 items)

Module 3. Q3 - Confidence, skills and behaviour (3 items)

Module 4. Q4 - Delay in seeking medical help (1 item)

Module 5. Q5 - Breast cancer and age (1 item)

Module 6. Q6 - NHS breast cancer screening programme (4 items)

Module 7. Q7 – Open risk factors (1 item)

Module 8. Q8 – Closed risk factors (9 items)

Ordering of CAM questions

It is possible to change the order of the Breast CAM modules, for example, you can ask about confidence in detecting Breast cancer symptoms 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 Breast cancer. We are interested in your opinion', should always be asked after open or unprompted questions such as 'There are many warning signs and symptoms of Breast 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 Breast 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 Breast CAM questions. For example, if you're using the Breast 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 Breast CAM. For example, you should avoid asking questions that could increase the participant's knowledge about cancer.

Additional modules from the CAM

Additional modules from the generic CAM can be added to the Breast CAM. For example, Module 4 on barriers to help-seeking, or Module 9 on NHS Cancer Screening Programmes.

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 deprivation³, e.g. education, employment, living arrangement, car/van ownership, postcode

³ We advise using an individual level of deprivation such as education or employment AND an area-level indicator of deprivation such as postcode.

Breast Cancer Awareness Measure (CAM)

Sampling

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

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 want to obtain a 'baseline' level of cancer awareness in a particular region or locality, your sample should be representative of that population. Consequently you would need to sample men and women from different backgrounds and of different ages. Alternatively, you might want to assess knowledge in a specific group of people, for example, a particular ethnic group⁴ or socio-economic group. In this case, your sample should be representative of this specific group.

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

- Funding.
- Sampling frames/target group (e.g. all men over 50 years living in x).
- Feasibility of data collection - how will you reach your target group? Face-to-face interviews somewhere private or interviews carried out via telephone are best, but the CAM has been used on the internet or as a postal survey.
- Research aims and objectives – do you want to obtain a baseline of 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?
- How many comparisons do you wish to make e.g. how many ethnic groups, how many SES groups do you want to compare?
- How many variables are you measuring? - are you just using the CAM, or are you adding questions to it?
- 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 your results being true and 5% chance your results will be due to chance/not representative.
- Response rates – it is best to assume 50-60% response at best.
- Level of 'unusable' questionnaires (e.g. those that are returned but not valid or incomplete).

Obtaining a baseline of awareness of cancer in your region/locality

The gold standard approach to getting a good baseline of awareness would be to get a 'population representative' sample using random sampling. Random sampling means that each person in your sampling frame (e.g. the UK population) has an equal chance of being asked to take part. To be able to do this you will need to access the details of the sampling frame in order to randomly select from them, a list of all the people that live in the area, their contact details and other demographic information. For example the Office for National Statistics use the Royal Mail's Postcode Address File (PAF) of 'small users': <http://www.royalmail.com/portal/rm/content1?mediaId=56000706&catId=400085>

⁴ Please note that the CAM is only available in English at present.

The ONS methods are described here: <http://www.ons.gov.uk/about/who-we-are/our-services/omnibus-survey/index.html>

If random sampling is not feasible the next best option would be to randomly sample locations across your locality or target areas and then carry out quota sampling within each location.

Other options include selecting areas or wards which result in a range of social economic deprivation according to area-based indicators like the Index of Multiple Deprivation (available on the National Statistics website) and then quota sampling within those areas to ensure you have a proportional number of males/females, ethnic groups etc.

Assessing the impact of an awareness-raising initiative

If you are using the Breast CAM as a way of assessing the impact of an initiative designed to increase Breast cancer awareness you will want to ensure that the people who complete the Breast CAM have been exposed to that initiative, or at least have had an opportunity to be exposed to it. In this case your sample should be representative of those targeted by the awareness raising initiative. For example, if the project you would like to assess aimed to increase awareness of cancer in a specific locality then your gold standard approach would be randomly sample from within that locality.

Some useful definitions

Random sampling

- Simple - random selection from census.
- Stratified - random selection from within subgroups such as male/female etc
- Cluster - random selection from clusters e.g. geographical areas
- Multistage - stratified random sampling from within clusters

Non-random sampling

- Convenience sampling (e.g. on street using footfall)
- Purposive sampling e.g. women aged between 40-60years
- Quota sampling - certain quotas required from specified subgroups. This can be proportional/non-proportional
- Snowball sampling – following up recruitment leads from participants already taking part

Cancer Awareness Measure (CAM)

Glossary

CAM glossary of terms

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.